

The London School of Economics and Political Science

**Mediated transparency:**

Truth, truthfulness, and rightness in digital healthcare discourse

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## ABSTRACT

This thesis addresses the challenges of producing digitally mediated healthcare information, a high-stakes arena which is conceptualised as a complex discourse and its diverse producers as interlocutors within this discourse. The study is located theoretically in the tradition of universal or formal pragmatics, the foundation of Habermas's theory of communicative action. Building on this theoretical core a conceptual framework is developed that integrates insight from several other traditions, including communication studies. The notion of communicative transparency is aligned with the idealised goal of a rich informational context supporting a range of perspectives in movement towards a balanced and consensual understanding by lay and expert actors of healthcare in our world. The central research question is: *Can digital mediation increase the transparency of healthcare communication?*

The empirical focus rests on two organisations involved in the creation of digital information products. Key mediators of meaning in digital healthcare information are identified as the diverse types of expertise of its producers, the materiality of digital artefacts, and the communicative mechanisms, processes and practices that often lead to departures from the normative idealised standard of transparency. The methodology is a comparative case analysis based on field research employing principally interviews to build a rich corpus, analysed using a recursive in-depth thematic coding procedure to reveal the ways in which digitally mediated healthcare meanings are shaped and shared.

The study demonstrates how communicative transparency emerges from shared frames of reference and common models of communication. It is concluded that digital mediation can indeed increase the transparency of healthcare information by supporting the deepening of Habermasian rational discourse, providing that validity claims to truth, truthfulness, and rightness can be raised and resolved at all stages in the discourse among all interlocutors, whatever their role and status.

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## GLOSSARY

CMS	Content Management System
Cochrane Collaboration	an international not-for-profit association of researchers who systematically review clinical research evidence in order to inform evidence-based practice in healthcare
Embase	A proprietary database of clinical research abstracts
EPR	Electronic Patient Record
Excel / MS Excel	Microsoft's popular spreadsheet application
GP	General Practitioner, the term for a generalist physician in the UK
HTML	Hypertext Markup Language
ICD-9	The International Classification of Diseases, version 9
InDesign	Adobe's page layout application
MEDLINE	A bibliographic database of biomedical research owned by the US National Library of Medicines
MeSH	Medical Subject Headings; a controlled vocabulary for medicine
NICE / NIHCE	The UK's National Institute for Health and Care Excellence (formerly the National Institute for Clinical Excellence)
PDF	Portable Document Format. A proprietary digital encoding format owned by Adobe
PICO	A framework for categorising the relevance of clinical research: Population, Intervention, Comparison, Outcome

Read codes	A clinical terminology system, popular in the UK
RCT	Randomised Controlled Trial
SNOMED / SNOMED-CT	A clinical reference terminology
SR	Systematic Review
Word / MS Word	Microsoft's popular word processing application
WYSIWIG	What You See Is What You Get; a user-friendly approach to editing code
XML	eXtensible Markup Language
XSLT	A technology for manipulating XML code

# CHAPTER ONE

## Introduction:

### The digital mediation of the healthcare discourse

#### Introduction

This study looks at the relationship between what we mean, what we say, and what is understood from what we say, within the particular context of digitally mediated healthcare information. With 80% of (American) internet users searching for health topics online (Fox 2011), this is an arena which is now as ubiquitous as it is impactful, and in which the stakes are among the very highest, touching on matters of health and sickness, life and death. In this introductory chapter, I present my own approach to the examination of the complex relationships that arise in this area between information, information technologies, and the way that these are understood by the diverse actors who come into contact with them. My central research question is: *Can digital mediation increase the transparency of healthcare communication?* Throughout the study I treat digitally mediated healthcare information as a complex *discourse*. Discourse is a key term in the study, and refers to the conversational, or, in the case of mediated discourse, conversation-like, exchange of meanings between conversational participants, or *interlocutors*. This use of the term *discourse* is inspired by the linguistic tradition of pragmatics, and is explored further in Chapter 2, Section 2.1 of this thesis, *A pragmatic basis for the analysis of communication*. As a discourse in this sense, digitally mediated healthcare information is understood to carry multiple meanings and therefore implications and consequences for those whose lives are mediated by this information. This chapter considers why the primary interest in this study is in the digital mediation of healthcare meanings (section 1.1), identifies the research opportunity that is taken up in this study (section 1.2), and, in the final section, outlines the remainder of the thesis.



## 1.1 The digital mediation of healthcare meanings

The arrival of digital technologies such as the internet has changed the way we access and share information, and in no arena has this been more evident than in healthcare.

Kreps and Neuhauser (2010: 329) point to

“a communication **revolution** brewing in the modern health care system fueled by the growth of powerful new health information technologies (HITs) that hold tremendous promise for enhancing the delivery of health care and the promotion of health.” (my emphasis)

They temper this optimistic view by warning of the “daunting responsibility” that accompanies that promise. Communication which has the potential to do good, equally has the potential to do harm, and in the interests of promoting the former, and mitigating the risk of the latter, it is necessary first to identify the factors implicated in the potential causing of harm, and those more likely to do good.

Even without the added complication of mediating digital technologies, healthcare communication raises complex questions of power, control, autonomy, and authority (Parsons 1951: 428-479, Foucault 1973, Mishler 1984). The promise of digital mediation is that, by making information more readily available, and inviting a broader range of voices into the discourse, the traditional hierarchies and power imbalances of medicine might be broken down, and a more democratised healthcare discourse might result.

There is widespread acknowledgement in the healthcare information literature that the digital mediation of healthcare has changed the dynamic of the clinical relationship, as in this example:

The presence of computers in the examination room has already transformed the traditional patient - doctor relationship from dyadic to triadic. It is now an interaction between the patient, the doctor and the computer  
(Reis, Visser, and Frankel 2013)

In this study, I suggest that healthcare relationships in the age of digitally-mediated communication are more complex than this simple triadic view. By unpacking the “black box” of the computer as a communicative agent to reveal the underlying agency of concealed human actors, the study examines a wide range of expert roles that are closely involved in the creation and sharing of healthcare meanings. In the course of this examination, I treat the holders of these roles as participants in a digitally mediated *healthcare discourse*.

The concept of discourse adopted in this study is narrowly defined, and broadly applied. It is based on the universal or formal pragmatics developed by Habermas, and employed as the foundation of his theory of communicative action (Habermas 1984), which presents an idealised, normative framework for discursively negotiated mutual understanding. In this study, the theoretical framework is applied to examine the creation and dissemination of digital media artefacts such as websites on healthcare topics, so that the activity of creating and circulating digital healthcare information is conceived of in its entirety as a complex, broad, holistic, but ultimately *single* healthcare discourse.

The conceptual framework developed in Chapter 2 of the thesis enables close examination of issues of truth, of sincerity, or truthfulness, and of appropriateness, or rightness, issues that are crucially important in the sharing of healthcare meanings, and yet which are often taken for granted in explorations of digital mediation within the field of healthcare. Adopting a Habermasian discourse framework brings issues of meaning and truth into the centre of my analysis, supporting the development of a normative framework against which instances of digital mediation in healthcare can be assessed.

There are many ways in which digital mediation can be studied in relation to healthcare. One might focus on clinical outcomes, measuring the effect on wellbeing of administering information for medicinal effect, or on the potentially huge economic gains and losses that arise in this area, or on the structure and governance of the institutions involved in the circulation of such information. These approaches have contributed rich insights, but there is less research that examines digital mediation in healthcare

principally from the perspective of meaning creation, focusing on the truth, truthfulness, and appropriateness of these meanings from the vantage points of different actors. It is especially important to understand different actors' perspectives on meaning because these perspectives lead to actions with very real consequences, in terms of both economics and human suffering.

It is precisely the great impact that the mediated communication of healthcare information can have that makes an in-depth understanding of the ways meanings may be preserved or compromised so crucial. There is a temptation, when dazzled either by the claimed gargantuan benefits (e.g. *eHealth is Worth it*, Stroetmann et al. 2006) or by the claimed cataclysmic harms (e.g. *Bad Health Informatics Can Kill*<sup>1</sup>) which the digital mediation of healthcare communication might give rise to, to forego detailed analysis (Black et al. 2011). I argue, however, that one key to maximising potential benefits, while minimising potential harms, lies in a robust analysis of meanings and practices to provide a better understanding of the mechanisms and processes of communicative action. To those who may question whether a detailed analysis of the conveyance of meaning and its implications for human wellbeing really matters in the field of healthcare information, I respond with a quote from the poet WS Graham, who in his poem "What is the language using us for?" poses the following question-and-answer, in verse (Graham 1979: 191):

"What are Communication's

Mistakes in the magic medium doing  
To us? It matters only in  
So far as we want to be telling

Each other alive about each other  
Alive"

The modes by which digital mediation is implemented have an impact on what can be said, on who can say it, and on how and by whom it can be accessed; on our ability to tell

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<sup>1</sup> *Bad Health Informatics Can Kill*: <http://iig.umat.ac/efmi/badinformatics.htm> (accessed 17 June 2014)

“Each other alive about each other / Alive”. The word “alive” is key to the significance of this quotation. It is important that our systems of digital mediation allow us to converse widely and freely about issues of human importance, rather than constraining us to pre-determined pathways. There is a risk that consideration of technological constraints might stray towards the fallacy of technical determinism. In this study social features of the modes of implementation in the digital mediation of healthcare communication do not fade from view and technical constraints are explicitly related to their social contexts. It is the scale of the impact on human wellbeing which makes healthcare such a priority area for analysis, but because many developments in healthcare are predicated on the ideal of unambiguous communication between peers it is particularly important to analyse the modes of digital mediation in the arena of healthcare from a discourse perspective, using an analytical strategy that can reveal, as far as possible, insight into the extent to which healthcare actors are saying what they mean to say, and in understanding what is meant; in telling “Each other alive about each other / Alive”.

## **1.2 The research opportunity**

As an editor and producer of digital information products, my own professional work has placed me in a position to observe first-hand the social and technical complexity of digital content creation. In the course of that work, I became intrigued by the interactions I observed between communication amongst information producers and communication with users of information products. This interest, which I elaborate in section 7.3 of Chapter 7, led me to the empirical object of interdisciplinary communication and collaboration involved in digital healthcare content that I examine in this study.

There is a wealth of research on technology in healthcare focusing on measurable improvements in clinical outcomes (see e.g. Black et al. 2011 for an overview). In parallel, a richly descriptive ethnographic strand of research focuses on social aspects in digital healthcare (see Greenhalgh and Swinglehurst 2011 for an introduction and overview). In another strand of research, a broadly critical sociological framework is brought to the analysis of health technology more generally (e.g. Webster 2007,

Timmermans and Berg 2003b), while a further critical strand of enquiry is rooted in the literature on the social construction of science and technology to examine ontological questions of power (e.g. Lehoux 2006, Oudshoorn 2008). While informed by these traditions, this study stands apart from them in its use of a Habermasian-framed analysis of actual discourses used by the diverse participants in the construction of a digitally mediated healthcare environment to support a context-transcendent normative framework for the analysis of digitally mediated healthcare information. I engage with the detail of the mechanisms and process by which digitally mediated healthcare meanings are shared generally, rather than dwelling on the detail of a specific situated instance. By applying an approach inspired by linguistics and the philosophy of language to the analysis of the digital mediation of healthcare meanings, I aim to achieve a measure of context-transcendence, in the interest of identifying normative principles for digital mediation. My intention is that the identification of such principles might shine a light on small, but specific, actions that those concerned with digital mediation in the healthcare field can take to ensure that benefits are maximised, harms minimised, and the democratising promise of digitally mediated communication and information is achieved as far as is practically possible in our imperfect world.

The participants in the healthcare discourse examined in this study form a perhaps surprisingly diverse group. In face-to-face healthcare communication, the healthcare discourse plays out in largely private encounters among actors with well-defined healthcare roles, with clinicians, patients, and carers acting more or less in accordance with their pre-conceived position within the healthcare encounter. There is of course a tradition in research on healthcare communication of examining points of difference between lay and expert perspectives (e.g. Prior 2003). Mediation by published information artefact, whether digital or not, brings the healthcare discourse out of the clinical context and into a broader public domain, and in so doing, changes the dynamic of the healthcare relationship. What distinguishes digital mediation, in this respect, is its reach and the number and diversity of actors, including editors, graphic designers, and

systems designers, as well as clinicians and patients, required to enact a communicative relationship.

This study starts from the presumption that the lay/expert dichotomy is an inadequate conceptualisation of the division of expertise in digitally mediated healthcare communication settings, due to the diversity of expertises necessary for the creation and dissemination of digital media artefacts on the topic of healthcare. In this study, I examine interactions between these diverse expertises, which include the healthcare expertises of clinician and patient, as well as information process expertises such as editorial and information management, and systems expertises such as systems development and implementation. Thus, the healthcare interlocutors presented in this study include patients, clinicians, authors, editors, graphic designers, information specialists, systems developers, and information technologists, each of whom is seen as participating fully in the discourse.

This study is guided by the normative principle that the digitally mediated healthcare discourse ideally should seek to create a rich informational context to support a balanced, growing, and consensual understanding of the place and meaning of sickness and healthcare in our world. It is motivated by a belief that the contributions of all of those engaged in this discourse should be recognised, both reflexively by those who contribute and more widely. In adopting this position, I acknowledge the importance of promoting democratisation and broad participation in the healthcare discourse and support the responsible use of digital technologies to promote the discussion of healthcare issues openly and inclusively. Ultimately, this study is undertaken in the hope that healthcare communication can support wellbeing, and is therefore aimed at moving towards the definition of normative principles for the digital mediation of such communication. The highly idealised nature of the normative discourse standards that I propose makes this a rather challenging, and hence problematic aspiration, which I therefore ground practically in empirical work concerned with the nuances of the way healthcare actors, especially those who might not consider themselves as such, interact with healthcare meanings in the course of their work. The study is designed not only to analyse the status quo, but also

to elicit insights that might lead to improvement. In the light of this goal, the core research question was formulated as “Can digital mediation increase the transparency of healthcare communication?” with an inclination towards the future potential of digitally mediated communication. To answer this overarching question, the focus was further refined to ask: “What particular challenges to communicative transparency arise from the digital mediation of healthcare meanings?”

The empirical study draws on data collected in two organisations, one a healthcare charity, one a medical publisher, both engaged in the creation and dissemination of healthcare information, and both at the time the research was undertaken on the brink of technological change. The interviews on which the study was based took place in the period 2006-2008, at a time when the internet was already revolutionising healthcare information, but when the smartphones and apps which are ubiquitous in 2013 were still a distant prospect. Then, as now, healthcare information providers peered into a murky future, trying to negotiate a shifting landscape of software and devices in order to share healthcare meanings with patients and clinicians. The study examines editors and technical developers working together to make sense of each other’s unfamiliar environments and concerns, and to meld systems and content into a mediated communication environment through which digitally-encoded healthcare meanings can be created and shared.

The details both of technology and of healthcare meanings clearly change over time, and change quickly, but the value of identifying and adhering to the principles of transparent communication in order to communicate sensitive and important meanings in a shifting technological landscape, arguably remains paramount as far as this can be achieved.

### **1.3 Outline of chapters**

In Chapter 2, I introduce the linguistic discipline of pragmatics as the central theoretical basis for this study. In particular, I introduce Habermas’s socially informed, idealised concept of formal or universal pragmatics, and relate this to the key notion of communicative transparency. I discuss the pragmatics perspective in relation to the

classic, face-to-face healthcare encounter which is nominated as the communicative baseline for the digitally mediated healthcare discourse examined in this study, highlighting the way validity claims to truth, truthfulness, and rightness are understood to be made in such encounters. I then note the implications for communication of the layering of mediating factors such as expectations of care, levels of clinical and patient expertise, power imbalances inherent in clinical encounters, and the further mediating factor of the standardisation of clinical practice. The social, technological, and media contexts of healthcare communication are introduced, before examining the potential of mediated information to alter the dynamics of healthcare, potentially enabling a more democratic, socially transparent healthcare discourse. I also consider the pragmatic implications of the mediation of discourse and introduce the idea that all participants in a mediated relationship can be considered as interlocutors in a mediated discourse. I then consider some alternative framings of the concept of transparency in communication, and explain the concept of interlocutor models of communication which are helpful in understanding what it might mean to share meaning. Dimensions of materiality in relation to digital media are also considered. To integrate some of these aspects into my analysis, I draw inspiration from work in the fields of information systems, and especially from research on the processes of standardisation. Finally, I develop my conceptual framework which serves as a guide for my identification of challenges to the achievement of transparency in the digital mediation of healthcare meanings. Towards the end of this chapter I identify the empirical research questions that are investigated in response to the core research question, defined above as *Can digital mediation increase the transparency of healthcare communication?*

In Chapter 3, I set out the methodology, including the research design for the study and the methods that are used. I explain how I operationalised the core concepts in the conceptual framework introduced in Chapter 2 so as to answer the empirical research questions. I explain the rationale, criteria, and process leading to my recruitment of two case study organisations, my subsequent identification and selection of informants within those organisations, and how my selection was informed by the expertise profiles of



potential participants. I present a reflective narrative account of the process of data collection, via interviews, and transcription and coding. I then describe the process of thematic analysis that was applied to the coded interview data.

In Chapter 4, I begin my close empirical analysis by examining the range of expertises brought to bear on the digital mediation of healthcare meanings. These expertises include healthcare expertise, both clinical and experiential, as well as content expertise and systems expertise, and they manifest along a continuum from inexpert to expert, via the transitional process of becoming expert. The thematic analysis is structured around the different types of expertise and presented in a tabulated matrix form, so that the perspectives of each of the participating expertise groups can be cross-referenced against the expertise groups they are discussing and presented in a collated form to support comparative analysis. This structured approach to the empirical data supports an increasingly rich understanding of both the expertise groups under discussion, and the informant expertise groups that discuss them. The thematic analysis begins by examining the dimensions of healthcare expertise, both professional and patient, presented by informants in the study, moving on to consider dimensions of content expertise in roles such as author, editor, graphic designer, and information specialist, and, finally, dimensions of systems expertise in roles such as systems developer and information technologist.

Chapter 5 presents the second and final part of the thematic analysis, and examines the presentation by informants of digital healthcare information products against the analytical dimensions of intent, action, and materiality. As in Chapter 4, the thematic analysis is presented in a tabulated matrix form to support cross referencing of themes organised according to the expertise group of informants. This cross cutting approach supports the development of a comparative understanding of the perspectives held by members of different expertise groups. The analysis initially highlights perceived intent in healthcare information products, via an examination of informant perspectives on two empirical questions, “What is the information product for?” and “Who is the information product for?” Next, perceptions of action, organised around the questions “What do users

do with the product?” and “What does the information product do?” are considered. The final, and largest section of the chapter focuses on informant perspectives on the materiality of digital healthcare information artefacts, framed by the question “What are information products made of?” The answers are grouped and analysed in terms of *common components*, *generic components* at both high and low levels, and *domain-specific components*.

In Chapter 6, I consider the implications of the empirical analysis in the preceding two chapters in the light of the conceptual framework for the study. I begin with a consideration of the relationship between healthcare communication for a specific interlocutor, and healthcare communication for a generalised mass interlocutor, and the role played by standardisation in the mediation of this relationship. I consider *standards of practice*, *material standards*, and standards that encompass both practice and materiality, which I term *blended standards*. I then consider the role of interlocutor models of discourse in sharing meanings. In the third section of the chapter, expertise is considered as a mediator in healthcare communication, and digitally mediated healthcare discourse is presented as a *layered discourse*, progressively mediated by healthcare expertise, content expertise, and systems expertise. Throughout this section I build up a diagrammatic picture of this complex discourse, exploring the interactions between different types of expertise that are brought to bear in digitally mediated healthcare information. In the fourth section, the different models of information and communication that appear to be expressed in the empirical corpus are examined, covering various models of intent, action, and materiality in information artefacts. Finally, I consider the challenges to the ideal of transparency that have been found to arise in the digital mediation of healthcare meanings.

Chapter 7 forms the conclusion to the thesis. Here, I return to the theoretical discussion in Chapter 2, providing a synthesis of the insights derived from a consideration of the way the empirical findings inform the conceptual framework developed at the outset of this study. I consider the extent to which the empirical insights are consistent with my theoretical approach, especially with respect to the applicability of the concepts of

discourse, interlocutor, speech acts (locutionary, illocutionary, and perlocutionary), and context. The implications of the normative aspects of my framework are discussed in relation to Habermas's notion of systematically distorted communication, and I relate this to the implications for the concept of transparency which is at the heart of this thesis. The main points in my conceptual framework are reviewed as a means of structuring this discussion. In section 7.2, my empirical findings are discussed in the light of the research questions identified in Chapter 2. In section 7.3 I reflect on the strengths and weaknesses of the study, before suggesting where the original contribution of this study lies, and making suggestions in section 7.4 for further research. Section 7.5 concludes the thesis with a restatement of the key finding.

## CHAPTER TWO

### Theorising the digitally mediated healthcare discourse

#### Introduction

In the previous chapter, my intention to investigate digitally mediated healthcare information as a complex but single discourse was explained. In adopting this research approach my intention is to present a theorisation of mediated communication that is centred on the mechanisms and processes through which intersubjective meaning is created and shared, as a step towards answering the core research question in this study: *Can digital mediation increase the transparency of healthcare communication?*

In this chapter, I consider insights from a range of theoretical approaches that I employ towards this goal. Firstly, I present concepts from pragmatic approaches to the analysis of communication that I mobilise as the core theoretical basis of this study and to provide a model for understanding the mediated sharing of healthcare meanings based on Habermas's theory of communicative action (Habermas, 1984). This perspective is then considered in relation to healthcare, to define a "communicative baseline" for the study. I also introduce perspectives on the standardisation of healthcare as embodied by Evidence Based Medicine (EBM), a concept and practice that will be shown to serve as one of the mediators of individual experiences in healthcare for both patients and clinicians.

Since the concept of context is central to a pragmatic understanding of communication, I then consider the varied contexts through which healthcare information circulates, including social, technological, and media contexts. This leads to an exploration of the potential of mediated healthcare information to change the pragmatic dynamics of healthcare communication. This dimension provides a basis for making the case for increased transparency in the healthcare discourse and for examining the roles of standardised practice and specialist expertise in mediating that transparency. I then examine the pragmatics of mediated information more generally, considering perspectives on the ways in which aspects of mediation can be related to meaning, and I present my perspective on the particular dimensions of materiality that are manifested in

digital media. Finally, I discuss the conceptual framework for the study, and set out four sets of empirical questions that are derived from this framework.

## **2.1 A pragmatic basis for the analysis of communication**

The simplest forms of discourse are those which take place face-to-face, in real time, between *interlocutors* who share similar social perspectives. Mey (2005: 25) defines interlocutors as “conversational partners”, and conversation, according to Levinson (1983: 284) “is clearly the prototypical kind of language usage.” Prototypical though face-to-face conversation might be, even here the relationship between what is meant, what is said, and what is understood, is not straightforward. Much of the creation and sharing of meaning relies on context, assumptions, and perspectives existing beyond the simple exchange of encoded signs. Such subtleties are easily overlooked in communication that is intended to serve a particular goal, such as the promotion of healthcare, or in the introduction of new communication technologies, when the sheer practical challenges may limit the view of communication to a simple transfer model that presents messages as being encoded into text by their senders and then transparently decoded by their recipients (e.g. Shannon and Weaver 1949). Such models, though perhaps useful in the planning of practical projects, cannot, of course, fully account for the complexities of communication at the discourse level.

In contrast to such practical simplification, the linguistic and philosophical field of pragmatics (Brown and Yule, 1983; Levinson, 1983; Mey, 2001; Cummings, 2005) sets out a framework for analysis of communication and, in particular, the ways in which meanings are shared between people that pays attention to interactions between interlocutors and context. The term *interlocutor* underlines the ways in which participants in conversation connect with each other, intersubjectively, in order to share meanings, via *locutionary* acts, or “speech acts” defined by Mey (2005: 95) as “verbal actions happening in the world”.

It is the emphasis placed on interlocutors and on context that distinguishes pragmatic approaches from semantic approaches, which focus on a mapping from sign to meaning

(Saussure, 1959, Lacan, 1977). As a mode of communications analysis, pragmatics is concerned with the relationship between communication and the surrounding world. The foundations of its analysis are concepts such as reference, which is concerned with the direction of attention both within and beyond discourses, and inference, which looks at the ways in which meanings are created not from what is said, but from what is assumed. Pragmatics relies on the idea of underlying principles and assumptions, shared within cultures, which enable interlocutors to make sense of one another's contributions, despite the fallibility of language as an encoding mechanism. These principles and assumptions include Grice's "Co-operative Principle":

"Make your conversational contribution such as is required, at the stage at which it occurs, by the accepted purpose or direction of the talk exchange in which you are engaged" (Grice, 1989: 26)

and Sperber and Wilson's "Principle of Relevance":

"Every act of ostensive communication communicates a presumption of its own optimal relevance" (Sperber and Wilson, 1995: 158)

The content of these principles and maxims demonstrates the centrality, in the pragmatic analysis of discourse, of: (i) the interlocutor's understanding of the nature of discourse; (ii) of the interlocutor's understanding of the context of that discourse, and (iii) of the interlocutor's understanding of the perspective of their co-interlocutor.

Another key aspect of pragmatic analyses of discourse is the concept of communication as action, played out via "speech acts", as first identified by Austin in his strikingly entitled "How to do things with words", (1962) and further developed by Searle (1969). Austin identified three main types of speech act: (i) locution, the simple act of making an utterance; (ii) illocution, the intention to communicate something via an utterance (iii) perlocution, which applies to the real world effects, beyond the simple understanding of the intended meaning, brought about by the utterance.

Habermas's work in "formal pragmatics" (Habermas 1999, Cooke, 1994) explicitly extends the work of Austin and Searle into a broader theory of rational communicative action. Habermas divides communication into communicative action, oriented towards mutual understanding, and strategic action, in which category he places any communication with goals beyond that of mutual understanding. Habermas's programme of formal pragmatics is explicitly normative and emancipatory, concerned with promoting communication which enables interlocutors to understand one another *intersubjectively* without domination or distortion: "Communicative rationality contains the idea of undamaged subjectivity and intersubjectivity – so that individuals can reach understanding with one another" (Cooke, 1994: 44). In addition to intersubjectivity, the concept of *intent* is central to this account: "We can explain the concept of reaching understanding only if we specify what it means to use sentences with a communicative intent" (Habermas, 1984: 287).

In Habermas's account, strategic action is secondary to, and parasitic on, communicative action, as without the assumed truth basis of consensus-oriented communication, no communication could occur at all. Habermas delineates this truth basis of communication via the concept of validity claims, which encapsulates the idea that every speech act makes a claim to its own validity across three dimensions. The three types of validity claims identified by Habermas are: (i) the claim to propositional truth, related to the objective world; (ii) the claim to expressive truthfulness, related to the subjective world; (iii) the claim to normative rightness, related to the social world. Communicative action depends upon the proposition that all validity claims can potentially be challenged within discourse, and that those challenges can be resolved discursively via argumentation, at least potentially, even if this resolution is not achievable on a practical level.

In mediated discourse, key aspects of context, including temporal, spatial, and social, are typically not shared between participants. In these cases where interlocutors do not have a shared context to support their communication, the relationship between what is meant, what is "said", and what is understood is even more complex. An important tenet of

Habermas's "universal pragmatics", as summarized by Cooke, is the context-transcendence, on a theoretical level, of validity claims:

"Validity claims are always raised by flesh-and-blood individuals and in actual socio-cultural and historical situations, but they always at the same time also transcend all given contexts. This transcendent power is tied to the idealizations to which all forms of argumentation, and hence all forms of communicative action, refer". (Cooke, 1997: 35)

It is this commitment to an idealised context-transcendence, while recognising the highly situated context relations of specific "utterances", that gives Habermas's approach to pragmatic analysis its particular value in assessing claims to transparency and emancipatory potential raised by mediated discourses. This research will therefore consider the status of the digital mediation of healthcare meanings as a discourse in the idealised Habermasian sense:

"Discourses are islands in the sea of practice, that is, improbable forms of communication; the everyday appeal to validity claims implicitly points, however, to their possibility" (Habermas 1982, as quoted in Cooke 1994: 32)

Habermas's view of idealised discourse provides a benchmark against which situated examples of communication can be measured, in order to identify the departures from the ideal that present potential barriers to communicative rationality. Barriers to communicative rationality are also, in Habermas's model, barriers to social emancipation, so the analysis of situated acts of communication against Habermasian ideals of discourse provides a lens for social critique. For the purpose of this research, I will refer to the properties of idealised discourse as *communicative transparency*, which serves as the core concept of my analytical framework.

Some critics of Habermas's communicative rationality focus on the transcendence which gives the theory its power and reach, contrasting this with the historically situated approaches to analysis of discourse proposed by (Foucault 1972 chs. 1-2). Owen (1999:



21) characterises Habermasian critique in opposition to Foucauldian genealogy, saying that (emphasis in original):

“Critique *legislates* an orientation in thinking in which thinking is oriented to a *transcendent* ideal and that it articulates this orientation in terms of the *project* of striving to reconcile the real and the ideal through the *lawful* use of reason”

while, in contrast,

“genealogy *exemplifies* an orientation in thinking in which thinking is oriented to an *immanent ideal* and (...) articulates this orientation in terms of the *process* of becoming otherwise than we are through the *agonic* use of reason”.

This is a lively and productive debate (Ashenden and Owen, 1999), particularly if the reader has no investment in one perspective over the other, and is open to employing both viewpoints, while cognisant of the differences between them, to support different modes of enquiry. Foucauldian perspectives are adept at revealing inequality and disempowerment through rich and situated description, while Habermasian perspectives contribute precise, normative calibration of specific types of disempowerment in a context-transcendent frame. I have found both views to be useful, particularly in combination, and aspects of both will be found in this study.

On a related theme, other critics suggest that Habermas’s idealised notion of communicative rationality bears little relation to the empirically observable communicative behaviour of real people in the real world, with Rienstra and Hook (2006: 314) suggesting in their compelling critique based on empirical psychology that “Habermas’s construction of communicative rationality rests upon an agent role that might only be filled in reality by a self-reflexive critical genius,” going on to observe (ibid.:321) that the Habermasian view of communicative agency:

“requires heightened agent understanding of reflexivity and publicity and universal adherence to these norms. It requires recognition and suspension of private reasons in a world dominated by self-interest. It requires the suspension of

that same self-interest which economic and policy spheres are seemingly built upon”.

It is perhaps of some relevance that empirical applications of Habermasian theory to communication have often been in the spheres of grandly “rational” discourses such as politics and governance. Perhaps deliberative democracy in the political sphere, which by its nature is populated by representatives of opposing vested interests, is not the best place to seek empirical confirmation of Habermasian “good behaviour”. The everyday sharing of healthcare meanings has a markedly different flavour, and perhaps an examination of the broader healthcare discourse as addressed in this study, where the subjective attachment of the agents to particular outcomes is less pronounced, and where presumably a shared belief in the importance of the integrity of the discourse itself, rather than the blind promotion of any particular message, is a strong and unifying motivation, will provide a more hopeful empirical experience.

Public healthcare discourses, especially when these are confounded with debates on aspects of political governance, are too often framed as gladiatorial battles. Perhaps in examining the broader, if more mundane, day to day public healthcare discourse such as the examples examined in this study, we will find more evidence for the possibility of a Habermasian discourse. Perhaps the most appropriate frame for a Habermasian empirical tradition is one focusing less on pure description of macro behaviour – *do people behave rationally in discourse?* – and more on the nuances of micro behaviour – *in what specific ways do people behave rationally? in what ways do they behave irrationally? what circumstances promote the former, and what the latter?* – questions that chime with the research orientation adopted in this study, and the potentiality expressed by its core research question – *Can digital mediation increase the transparency of healthcare communication?*

The remainder of this chapter examines the concept of communicative transparency in the context of healthcare communication and also some of the factors that may impede that transparency in the specific instance of digitally mediated healthcare meanings.

## 2.2 The pragmatic characteristics of healthcare communication

The “sea of practice” in which digitally mediated healthcare discourse sits is shaped by two distinct sets of forces, the first related to the mediating power of expertise, and the second related to the mediating power of digital artefacts. The first set arises from the status of this mediated discourse as an extension of the face-to-face discourse of healthcare. Medical communication occupies a highly specialised social context, characterised by the intersection of different types of expertise. The familiar expertise dichotomy is that between physician and patient, with the first immersed in an expert culture of abstract knowledge, and the second immersed in a lifeworld experience which centres on the fundamentals of subjective human existence. In order to more clearly examine the processes of mediation through the lens of pragmatics, I will first define the *classic health communication encounter*. In its most basic form, this manifests face-to-face, between two lay actors, one of them with a subjective health anomaly such as sickness which they wish to express; “My head hurts”, for example. This situation is represented in fig 2.1, below:



**Fig. 2.1: The classic health communication encounter**

In this situation, the person with the healthcare issue is expressing his subjective feelings to the second person. In Habermasian terms, the primary validity claim is expressive, to subjective truthfulness (“This is sincerely how I feel”), with secondary claims to objective truth (“There really is a pain in my head”) and normative rightness (“It is socially appropriate for me to tell you about this pain in my head”). The communicative action is driven by the experiential expertise of the person with the headache, in the sense that he is the subjective expert in what he is experiencing. In other words, he knows how he feels. The pink line between the two boxes represents this experiential expertise. This is an example of the health communication encounter in its simplest form. In fact, such

simplicity in healthcare communication would be unusual. More common would be a more complex intention on the part of the speaker, combining a presumption of relevance, and a communicative action beyond the purely expressive. The statement carries illocutionary force, in that the first person wants the second person, who is otherwise ignorant of his headache, to understand what he is feeling. The simple diagram above gives no hint of context, and we remain ignorant of the likely relevance of the statement. Imagine instead that the headachey person is a child, and the second interlocutor its carer (Fig 2.2, below):



**Fig. 2.2: The classic healthcare encounter**

The information that the child has a headache takes on a specific meaning, or illocutionary force, because of the context in which it is uttered. If I now say that rather than describing the fact of his headache, the child is *complaining* of a headache, I am ascribing a particular illocutionary force to his statement. In *complaining*, rather than *stating*, there is an expectation of a particular understanding on the part of the listener, who, as carer, carries responsibility for the child's wellbeing. The communication is still driven by the experiential expertise of the child, but it is coloured by the context provided by this specific type of interlocutor, and the relationship between them. I call this variant of the classic encounter the *classic face-to-face healthcare encounter*, to signal the importance of the expectation of care in this sharing of health meanings. It is this classic healthcare encounter, and its next elaboration, the classic clinical encounter (defined on the following page) that I will take as the communicative baseline for this study of digitally mediated healthcare communication.

In addition to the understanding and associated empathy of the carer, various real-world events may be triggered by the child's complaint. The carer may dispense medicine, or sanction a day off school. In Austin's terms, these events demonstrate the perlocutionary force of the utterance; the child's words have "done something" in the external world. In

saying these words (locutionary act), in complaining to its carer (illocutionary act), the child has obtained a spoonful of medicine and a day off school (perlocutionary act). It is worth noting that Cooke (1994: 23) reports Habermas as presenting two different interpretations of perlocution in his work, from an early association of perlocution with strategic action, to a later softening, and acceptance that only in specific instances, when the perlocutionary effect “could not be achieved if the agent were to declare her aim openly from the outset,” is perlocution necessarily associated with strategic rather than communicative action. In this example, so long as the utterance meets its validity claims, particularly the expressive claim of truthfulness, the perlocutionary effect of medicine and a day off school remains the result of communicative action. The action would only be strategic if the child did not actually have a headache, and was knowingly making a false claim.

When the classic healthcare encounter involves a medical professional, it can be considered the *classic clinical encounter*. With the addition of an extra strand of expertise, the context of communication is complicated further. In addition to the experiential expertise brought by the patient, who knows how he<sup>2</sup> feels, the healthcare professional brings her clinical expertise (Fig 2.3). The experiential expertise of the patient is represented by the pink line, and the clinical expertise of the clinician by the purple line.



**Fig. 2.3: The classic clinical encounter**

In contrast to the patient’s subjective experiential expertise, the clinician’s expertise is generic, standardised, and formally sanctioned. During the communication that ensues,

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<sup>2</sup> In this presentation, I use the male pronoun for patients, and the female for clinicians, for no reason other than to help the reader distinguish between them.

the clinician measures the input of the “patient” against standardised clinical norms. What the patient says may express subjective feelings, but set in a context of professional expertise, the meanings ascribed to it by the clinician aim to set it into predetermined categories. The clinician will question the patient about his symptoms. The answers from the patient represent his experiential expertise of his own condition, but to the clinician, they are evidence to be set against her own observation of clinical signs, and her internal theoretical framework of genericised symptoms and their relation to accepted definitions of disease.

The experience of sickness can be isolating. It reminds us that the boundary of our bodies separates us from our peers. The fact that we feel our own sickness, and that they do not, underlines their otherness. To counter this isolation, the observable signs of sickness, such as bleeding, swelling, temperatures, and coughs, communicate a trace of our illness to the outside world. These are signs which can be observed, measured, and consistently and unambiguously represented. Diagnostic medicine makes a science of interpreting these traces in relation to abstract models of disease, and modern diagnostic techniques have found technological means of capturing even those external traces of sickness which are hidden from normal view. By such means, the external referents of disease can be shared, and, though the internal experience remains private, sickness can become a verifiable truth in the social sphere.

In Habermasian terms, an ability to link aspects of illness to external, objective reference points aids in the establishment of validity claims, and therefore supports mutual understanding. It is problematic, then, that not all aspects of illness are equally observable in the objective world, and, therefore, not equally conducive to shared understanding. Introducing a selection of essays on pain, that most ubiquitous, and inexpressible, of symptoms, Kleinman et al. (1994: 4) present the contested ontological status of pain within medical science, and warn that “there is still no consensus on a unified conceptual framework for the diverse types of pain.” This incomplete mapping of the subjective lifeworld experience of illness to the abstract systems of the clinically observable certainly throws down a gauntlet to communicative action within the sphere of

healthcare, and there are further, potentially more serious, challenges to transparency in healthcare communication.

Talcott Parsons' identification of sickness as a form of socially sanctioned deviancy (1951, summarised in Gabe, Bury and Elston 2004) places the physician in a position of power, not only as a potential healer, but as one who, via the tools of diagnosis, can legitimise the social position of the sick. In this account, the awarding of a legitimate "sick role" to a patient confers benefits such as respite from expected activities such as work, as well as access to costly treatment options. The resulting power imbalance at the heart of the physician/patient relationship runs a political charge through medically-related communication. Scambler and Britten (2001: 55) review Mishler's empirical investigations which set doctor-patient interaction against a benchmark of Habermasian communicative action, summarising his conclusion that "the voice of medicine has developed and retains a tendency to suppress and colonize the voice of the lifeworld; lifeworld rationalization and decolonization require patient empowerment". According to Scambler and Britten, strategic action between doctors and their patients is more often concealed than open, and manifests as an unconscious deception resulting from systematically distorted communication, in which doctors participate in good faith, unaware, at an individual level, that the asymmetry of the power balance in their communication entirely alters the nature of the exchange. In recent years, differences in perspectives surrounding healthcare have been framed, more positively, as differences in expertise (e.g. Prior 2003), leading to a more active conceptualisation of the role of the patient, played out in, for example, the notion of shared decision-making (Charles et al. 1997; Dy and Purnell 2012). In spite of such attempts to redress the power balance in the clinical encounter, the fundamental power imbalance occasioned by the awarding of legitimacy persists, as, inevitably, does the associated systematic distortion of communication.

### 2.3 The standardisation of medical practice

Critiques of medical communication have tended to position patients as representatives of the lifeworld, and clinicians as representatives of colonising systems, but in the early 21<sup>st</sup> century, clinicians have been subject to what might be considered colonising forces of their own. Since the latter part of the 20th century, “Evidence Based Medicine” (EBM), also known as Evidence Based Healthcare (EBHC), and defined by a group of eminent early proponents as “the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients” (Sackett et al. 1996) has become a commonly cited methodology, seeking to improve clinical outcomes by identifying and standardising best practice across healthcare professions (Timmermans and Berg 2003a).

The standardisation of clinical practice has not been universally welcomed (Thorgaard and Jensen 2011). On the one hand, it seems rather obvious that modern clinical practice, with its roots firmly, though not exclusively, in a scientific model of knowledge (Malterud 2001), should be explicitly related to scientific evidence and that there is therefore nothing new or controversial about EBM. There remain, however, several points of contention. One arises from the marriage of clinical trials data with cost-effectiveness data which informs the production of many evidence-based practice guidelines. Examples of the controversy this can provoke are regularly provided by the UK based National Institute for Health and Care Excellence (NICE) which seeks to balance benefits and costs of treatments, many of which are commercially produced and sold at significant cost, at a public level. At the time of writing (2013), a new NICE recommendation often makes headline news in the generalist media<sup>3</sup>, with clinicians, patient advocates and economic analysts arguing the issues in the mainstream media news. A major issue here is the perceived tension between the epidemiological basis of

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<sup>3</sup> Debates about the decisions and role of NICE are also common in academic discourse, e.g. Wilmot (2011)



the findings of EBM which can be difficult to reconcile with the ambition to create a more patient-centred clinical practice.

Debates around EBM flourish at the professional as well as the public level. Lambert (2006) distils a helpful typology of critiques of EBM, including the erosion of clinical autonomy and the production of formulaic guidelines, bringing the prospect of deskilled clinicians blindly following standardised recommendations rather than using the professional judgement born from their own clinical experience. Timmermans and Angell (2012) identify two contrasting responses to EBM in their study of resident physicians. The first is a passive “librarian” perspective, an uncritical cataloguing of recommendations produced in the name of EBM, and the other a more active “researcher” perspective involving critical engagement with material. They outline a relationship between the level of critique exercised towards the material and the degree of positive engagement with EBM, with those “researcher” residents who treated the critical appraisal fundamental to EBM as an activity they themselves learned to “do”, rather than as an external force generating results handed down to them to implement, being more likely to embrace and actively participate in the process, despite expressing a vigorous scepticism to the claims of others:

“One of the surprising findings in our interviews was that the clinical examples provided by the most EBM-knowledgeable residents centred around disregarding research, adapting protocols and guidelines, or filling gaps in the literature”  
(Timmermans and Angell, 2012: 32).

This finding shows promise in the potential it highlights for an open and transformative discourse. In contrast, Lambert portrays EBM’s assimilation of explicit critique as fundamentally strategic:

“The branding as ‘evidence-based’ of an essentially social political strategy to unseat professors of medicine as sole arbiters of good practice (...) rather effectively neutralised at the outset resistance from those occupying traditional positions of authority in the medical world. It simultaneously opened a pathway

for the relatively young and—to conventional biomedical wisdom—relatively disrespectful fields of epidemiology and public health, to move into a more central position in biomedical education and practice” (Lambert, 2006).

The public and academic debates about EBM and its role in defining practice continue. For some, standardisation promises transparency in healthcare decision making, and advances emancipation, for others, it is an unwelcome system of control and disempowerment. Such feelings of constraint and exclusions are familiar reactions to standardisation in arenas beyond healthcare, with the very attempt to reveal hidden truths in fact propagating further concealment and inequality as “each standard and each category valorizes some point of view and silences another” (Bowker and Star, 2000: 6).

## **2.4 The contexts of healthcare information**

The role of context in sharing meaning is key to the pragmatic approaches to the analysis of communication introduced in sections 2.1 and 2.2 and, therefore, an understanding of the contexts through which healthcare meanings circulate is crucial for this study. The contexts of mediated healthcare information are both varied and complex. Some contexts are the same as those associated with any generic form of mediated communication, since large amounts of health information resides alongside non-medical information in mainstream channels. Other contexts are unique to healthcare, forming specialist enclaves for health information. These contexts can be aligned along one or more of three dimensions.

### **2.4.1 The social contexts of healthcare information**

The most fundamental dimension of context, the one which underpins, shapes, and drives all of the others, is the *social* dimension provided by the groupings of actors, whether institutional or individual, and their cultures and shared practices, amongst whom the meanings encoded within health information are generated and shared. In section 2.2 I referred to the classic “clinical encounter” between patient and physician, and contrasted this formal context with the private experience of sickness, of the self or of the family. Mediation can itself offer extra contexts for the sharing of meanings around health and

sickness, creating discrete social forums and varieties of publicly shared meaning, as exemplified by patient support forums and patient advocacy media campaigns.

#### **2.4.2 The technological contexts of healthcare information**

A more tangible manifestation of context is found in the *technological* dimension, which includes the hardware and software by which health information makes its way to its end users. Much of the hardware used to disseminate health information is shared with mainstream media; personal computers, television, mobile devices such as phones and tablets, and the hardware infrastructure supporting the internet. Other hardware is specific to healthcare, and includes specialist hospital systems and telehealth devices to be used within the home. In contrast, while it is true that many software contexts, such as the commonly used internet protocols of HTML (HyperText Markup Language), and associated ubiquitous, if proprietary, standards such as Flash and Quicktime, are common to both mainstream and healthcare media, the higher malleability<sup>4</sup> of software has led to a proliferation of software specifically designed specifically to hold, disseminate and manipulate medically related information.

The healthcare focus of critical examinations of technology in this context<sup>5</sup> by no means makes for a narrow frame of reference, since in relation to healthcare “technology” is a broad term indeed. The term “health technology” can cover a range of applications of medical innovation to the improvement of patient outcomes, including diagnostic technologies such as imaging or lab tests, therapeutic interventions including drugs, surgical techniques and medical devices, as well as information systems. Webster (2007) brings a single sociological framework of analysis to bear on topics as diverse as genetics, informatics, and tissue-related biomedicine under the umbrella heading of

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<sup>4</sup> See section 2.7, this chapter, for a discussion of the material properties, including malleability, of digital media.

<sup>5</sup> See Timmermans and Berg (2003b) for an overview of critical scholarship focusing on healthcare technology.

“health technology”. He highlights all of these aspects as deserving of analysis because of the level of innovation and social impact they embody. There is a tendency for health-related information to be defined in active terms, as “words that do things”, rather than as representational. This is particularly evident in the broad spectrum of health technology, where textual coding can comfortably sit alongside the living flesh of stem cells in a shared analytical framework.

Lehoux (2006) focuses her study on the emerging discipline of Health Technology Assessment (HTA), mobilising a broadly sociological framework in the service of a practical, policy-directed endeavour to propose a model for defining what makes one technology “better” than another. She argues the need for a model broader than the clinical outcomes/cost-effectiveness models which currently dominate the HTA discipline, in order to account for the complex political and social forces which come into play in the work of assessing health technologies. Lehoux proposes a categorisation of health technologies which includes not only information systems but, under the umbrella of “health promotion technologies”, such items as vaccinations and specialist media artefacts such as patient decision aids. Again, the emphasis is on real-world action, with the chapter in which Lehoux outlines her approach entitled “What do technologies do?”

Placing media artefacts alongside other types of technologies in order to draw them into a single framework for analysis is a striking promotion in terms of their significance, suggesting that these are not mere statements or descriptions *about* real world entities and actions, they are, in their own right, agents of change causing actions to occur. But in order to be clear about the ways in which mediated healthcare meanings interact with the world, it is necessary to look to a wider definition of action than that provided by the clinical or patient outcomes often recorded in health technology studies, to look at the very specific ways in which media artefacts are mobilised in the service of the sharing of meaning, which I explore below, particularly in section 2.6, without demoting them to a peripheral role in the broader technological landscape.

### 2.4.3 The media contexts of health information

The third dimension of context is the *media* dimension, which relates to the mediated forms used to share health information. Again, some of these media forms, such as clinical decision support products, or patient decision aids, are specifically designed to convey health information, but a degree of overlap with generalist media also occurs in, for example, health “stories” in the mainstream news media, or in fictional media such as soap operas. Media forms also encompass the relatively recently-mediated offerings of providers whose main interests lie outside the media, for example, retailers, some of whom provide extensive healthcare information as part of their online offerings, for marketing purposes.

There is often a strong outcomes focus in the strand of enquiry focusing on specialist healthcare media. Patient information and other forms of public education on health matters are often examined in terms of their clinical efficacy as healthcare interventions, as are clinical information initiatives, including the concept of EBM itself. Studies in this tradition assess mediated healthcare information along the same lines as clinical trials assess biomedical interventions, measuring their impact on improving clinical outcomes. The emphasis is on the “effects” of media artefacts on populations within particular social contexts, rather than on critical study of the artefacts themselves.

A more critical strand of enquiry (e.g. Seale 2002) focuses on mainstream rather than specialist media, and looks holistically at questions around the representation of health topics in relation to broader sociological concepts such as community, trust, and risk. There are areas of the EBM debate (e.g. Moreira 2007, Boivin et al. 2008) which share this critical focus, but apply it to the meaning, relevance and use of the particular information artefacts which are the building blocks of EBM; the randomised control trial, the systematic review, and the evidence-based guideline. This critical arm of the EBM-centred discourse stands in relation to the broader, more policy-oriented strand that examines healthcare information in terms of its efficacy in improving clinical outcomes, with some studies incorporating reflexive, critical elements into a policy-oriented narrative (e.g. Lehoux et al. 2005). Finally, there is a thread of critical enquiry which

examines a perceived bureaucratization of medical expertise and practice via information systems (e.g. Reich, 2012).

#### **2.4.4 Characteristics of specialist contexts for healthcare information**

Specialist contexts for health information, along the social, technological and media dimensions, tend to be heavily regulated by a variety of institutions from the local and the specialist right up to the level of the state. The consequences of misinformation around health issues, serious at both public and private levels, require that specialist health contexts are subject to high levels of governance and control, with clear limitations and accountability.

This governance is manifested in the social dimension in the structured institutional environments operating around healthcare, from national standards-setting bodies such as the UK's National Institute for Health and Care Excellence (NICE), through specialist professional associations such as the UK's royal colleges, via medical education in universities, down to grass roots clinical settings such as surgeries and hospitals, right through to the often highly-organised patient advocacy sector. In contrast, information technology development for specialist healthcare settings is driven, funded and implemented by complex aggregations of public and private interests, combining in different forms depending on local healthcare governance.

If we consider the patient as the ultimate “consumer” of healthcare, then, in contrast to both social and media dimensions, consumer input into decision making around technological development at the systems level tends to be low. Specialist media contexts for health information have their own conventions for establishing validation. Clinical decision support materials for clinicians combine explicit links to the supporting clinical evidence base, alignment with clinical guidelines, expert input from practising clinicians, and rigorous peer review. Information targeted at lay audiences often adopts these same underpinning techniques in order to establish clinical correctness and then overlays this with an extra layer of validation to establish the appropriateness of the information for a non-clinical audience. This might include review by patient representatives (termed

“patient review” rather than “peer review”), patient advisory panels, or formal accreditation by bodies such as The Information Standard or Health on the Net.

#### **2.4.5 Characteristics of non-specialist contexts for healthcare information**

To some extent, the growth of the validation and accreditation industry has been driven by the potential of unvalidated and potentially dangerous health information to flourish in non-specialist settings. These settings have their own characteristics, different from those of specialist contexts, which may influence the nature of the meanings circulating within them. Within generalist contexts, health information is granted no specific privilege, but may exist side-by-side with non-health information, with no formal structural differentiation between the two, although some organisations, whilst operating in the non-specialist space, may choose to adopt similar levels of validation to those required in the specialist space, exploiting validation as a market differentiator.

In mainstream media settings, there is no specialist support for the exchange of medical meanings. This is manifested differently across different dimensions of context. In the social dimension, the established hierarchies of expertise are broken down, so that claims and counter claims can be made and circulated with no need to first cross barriers of scientific methodology, clinical accreditation, expert evaluation, or peer review. Personal opinion can sit side-by-side with the most rigorously-derived scientific conclusion. In the technological dimension, specialist systems of encoding medical knowledge such as the technically-mediated standardised terminologies discussed above, together with the consensus and disambiguation they represent, are absent. Outside specialist healthcare contexts, words, images, videos, in all their fuzzy ambiguity, are all we have to express the realities of health issues. The commercial mainstream media environment is optimised for the easy consumption of commodified information. In the ongoing competition to attract consumer attention, it is driven by an ambition to give consumers the information they want, rather than dispensing the information that is thought best for them to have. The communicative dynamic is very different from that in the classic clinical encounter. However socially valuable they may be, health care messages are often challenging rather than seductive in nature. Such difficult information might be

expected to encounter particular barriers when fighting for attention in the mainstream media space.

## **2.5 The potential of information artefacts to alter the pragmatic dynamics of healthcare communication**

Applied to healthcare information, the concept of communicative transparency can be interpreted as the idealised goal of a rich informational context, offering a range of perspectives, that can support a balanced, growing, and consensual understanding by lay and expert actors of the place and meaning of sickness in our world.

For those personally affected by illness, as patient or as carers, published information may offer access to a richer informational context than that offered by the individual medical professionals they meet in the course of diagnosis and treatment. It is possible that a greater awareness of the general context of an illness might alter the traditional power balance of the medical encounter. Jones (2001) looks at the classic medical encounter within the larger context of health care decision making, theorising it in relation to Habermas's theory of communicative action. He summarizes a literature which places the medical encounter at various points on a continuum between medical control and shared, democratized decision-making. Referencing Coulter's (1997) research on patient information, Jones suggests that a richer informational context might achieve a more symmetrical power relationship between medical professionals and patients. He tempers this potential with a warning:

“It is possible to view the proliferation of patient information as part of a magnification of the medical gaze and an extension of biomedical power”. (Jones, 2001: 75)

At the same time, as discussed in section 2.3 above, the richer, EBM-driven informational context in which clinicians now work raises questions of professional autonomy. With the dissemination of scientific research findings via mainstream media, we are all surrounded by healthcare precedents which circulate not only among healthcare professionals but also among the general public. In such an environment, with



scientifically-evidenced, if journalistically-interpreted meanings in general public circulation, local clinical decision making may begin to seem a risky practice. All the same, the successful implementation of EBM, the often-quoted ambition of “getting evidence into practice”, relies on translation from the global to the individual level.

The medical world is awash with conflicting information from many different sources, and the premise of EBM is that a hierarchy of legitimacy distinguishes levels of validity in evidence (e.g. Greenhalgh, 2010). The precise nature of this hierarchy is a focus of ongoing debate and development, with various models being presented and revised over time (e.g. Bluhm 2005, Haynes 2006, Guyatt et al. 2008, Howick et al. 2011, Luoto et al. 2013, Knaapen 2013), but the general premise is that that more rigorous the scientific method and analysis employed, the higher the value of the evidence. Towards the top of most evidence hierarchies sit the systematic review (SR) and meta-analysis, which bring together the results of clinical studies and combine them using rigorous evaluation methodology to present an overview of the scientific status of a topic based on inputs from multiple trials. Systematic reviews are most often based on reports of randomised controlled trials (RCTs) which use rigorous scientific methods to investigate clearly defined clinical questions. At other points in the various hierarchies we find looser, less rigorous forms of research such as cohort studies, observational studies and case studies. Theories, established practices, and opinions untested by rigorous methods of scientific proof are usually found languishing towards the bottom of evidence hierarchies. The premise is that the evidence found nearest the top of the hierarchy is the best available evidence, and therefore is that which should be looked to first to guide decisions about practice.

The sheer volume of competing information produced makes evaluation and filtration a necessity in any attempt to move towards evidence-based practice. The detail of what is included, and what is excluded, what is considered high-value and what can be discarded, continues to be a topic of debate, especially from defenders of the rare, the individual, and the poorly-defined, none of which are likely to feature heavily in the more rigorously defined forms of evidence found towards the top of most evidence pyramids. To

counteract this, a strand of work in EBM focuses on generating a more open dialogue around the different forms of evidence and the way in which they are put to practical use (e.g. Edwards et al. 1998; Howick et al. 2009).

As presented in section 2.2 above, the classic clinical encounter is that between clinician and patient, each contributing their own context of expertise to the sharing of meaning. Within the environment of healthcare information publishing, a greater range of expert communities is mobilised, as the encounter between the lived experience of illness and formal medical knowledge is technically mediated and brought into the public sphere, and, in the process, transformed. Medical publishing brings together unusual configurations of expertise and of practice. It overlays the classic dichotomy I introduced in section 1.2 of Chapter 1, between “lay” or “patient” perspectives on the one hand, and “expert” or “clinical” perspectives on the other (as discussed below), with perspectives primarily focused on the development and dissemination of information in different forms. The expertise and practices of the information professionals who mediate the gap between clinician and patient add further layers to the expertise mix. When physicians enter the medical profession, they join a community of expertise with its own practices and terminology. Information professionals working in the medical field join a distinct, if related, community of expertise, with its own, separate set of practices and terminology. These may overlap to some extent with the practices and terminology of both the clinician and the lay person, but they are nonetheless distinct from them, and extend beyond them.

Stehr and Grundmann (2011) present a view of expertise that is highly relevant to the holders of professional expertise involved in the digital mediation of healthcare meanings, including clinicians, editors, and, I would argue, developers and implementers of information systems. To Stehr and Grundmann, experts are mediators:

“Experts in modern societies *pass on* knowledge to the apparently rapidly growing groups who require and seek advice. (...) They function as mediators between producers of knowledge and users of knowledge, and thus, between

those who create the capacity to take action and those whose task it is to act (...) Their knowledge alters the work that they operate with.”  
(Stehr and Grundman, 2011: 39).

Clinicians mediate the abstract domain of clinical knowledge and translate it into clinical care at the case level; editors and other workers with healthcare content mediate the work of research scientists and clinical advisors, translating it for a wide readership including clinicians and patients; and systems developers and implementers, via their systems, work on these already mediated meanings and, via their systems, reshape, interpret, and reconfigure them so that they flow smoothly through systems to users. Above, I distinguished between the communities of expertise occupied by clinicians on the one hand, and information professionals on the other. I would further distinguish between the informational expertise held by content workers such as editor and designers, and that held by information systems workers. Here we have three distinct communities of expertise, working together to mediate the same meanings.

Knorr Cetina (1999) described the variance in the building of knowledge by scientists working in two very different scientific disciplines, arising from the wholly different physical and cultural contexts of their work, a variance she portrayed as “epistemic cultures”. Knorr Cetina contrasted the highly individual, embodied work of molecular biologists with the abstract, collective work of physicists. In the latter case, the work of knowledge creation is distributed across such a large and complex group that Knorr Cetina ascribes agency to the experiment itself rather than to any individual working within it. This view seems to run contrary to the discursive rationality proposed by Habermas, but it contributes a vivid illustration of the range in approaches to knowledge that exist even within different branches of experimental science. How much greater variety might there be between patients, with their lived experience of illness; clinicians, with their formalised domain knowledge, oriented to improving patient outcomes; research scientists, carrying out clinical outcomes studies according to strict protocols; editors, authors, and information specialists, sifting and interpreting the results of clinical research to inform patients and clinicians alike; and systems developers and

implementers, building systems to support their own understanding of the communicative actions played out in the sharing of healthcare meanings?

Working in a similar framework to that employed by Knorr Cetina, Mol (2002) examines the various “enactments” of the disease atherosclerosis in a hospital. Mol is careful to distance herself from approaches examining differing “perspectives,” or approaches which describe illness as being constructed via language. Instead, she focuses on the material “enactment” of illness, from cells on slides, through the experience of difficulty in walking, to dissected amputated limbs. In her presentation, this multiplicity is not one of mere terminology or of interpretations, but of lived realities, practices, and contexts. Such multiplicity of contexts and practices is, again, extended when the clinical encounter is extended via informational mediation and this, in turn, has extended implications for the transparent sharing of meaning.

## **2.6 The pragmatics of mediated information**

Mass mediation, whether digital or not, has particular attributes which carry implications for the pragmatic character of its discourse. In combination, these differences prompt Thompson (1995: 85) to classify mass mediated communication as “mediated quasi-interaction”, highlighting differences in the “space-time constitution” of mediated communication, a “narrowing of the range of symbolic cues”, an orientation towards “an indefinite range” of interlocutors, and the monologic quality of mass-mediated communication. With the possible exception of the last option, since digital mediation affords more opportunity for dialogic exchange than non-digital channels, all of these pragmatics-disrupting distinctions apply equally to digitally mediated discourse, but beyond these, there are further distinctions unique to digital channels.

The mechanics of digital mediation are such that the point of origination of any communication can be difficult to identify. Messages are produced and, in the most literal sense, re-produced, as they pass through a range of technological gateways in the course of their creation and dissemination. This “re-production” arises because in order to circulate smoothly across technical networks such as the internet, digital information

must be formed in particular ways. Often, it is adherence to standards, including coding standards such as HTML, that enables digital information to pass through various technological configurations, and often, the act of passing from one technical context to another involves some reconfiguration in the form of the information, in order to comply with a different standard associated with the new configuration. These reconfigurations can alter both the form of information and its relative status with regard to other information, and so need to be considered as acts of interpretation<sup>6</sup>, rather than as simple technical handoffs of robustly-encoded messages. They cannot, it follows, be considered neutral with regard to meaning.

As already mentioned in section 2.4 above, mediated healthcare communication encompasses a wider range of expertise communities than the classic clinical encounter. A defining feature of my approach in this research is to grant to each of the different kinds of participating expert actors, all of whom interact with healthcare meanings in different ways, the status of *interlocutor*. The mediated healthcare discourse, I suggest, is not simply played out between healthcare actors, in which I include both healthcare professionals and patients, via a layer of neutral mediation supplied by informational workers of various types. Instead, I present these informational workers as playing an active role in the mediated healthcare discourse, taking part in the sharing of meaning, as interlocutors in their own right; an important, and novel, distinction.

In digitally mediated healthcare communication, interlocutors can be active even when they are distanced from the particulars of communication temporally, spatially, or by level of abstraction. When I cite the level of abstraction as one of the factors giving rise to disjunction in digitally mediated communication, it is in recognition of the fact that systems designers, for example, may never come into contact with the specific instances of meaning, such as articles, sentences, clinical recommendations, or reports on the status

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<sup>6</sup> Bolter and Grusin's (2002) concept of remediation touches on similar acts of "translation" between media, though with a focus more on changes in form than on the intersubjective sharing of meaning *per se*.

of clinical research that flow through their systems, any more than they come into contact with the individuals who create or read those sentences. Their contribution, as interlocutors, is at a higher level of abstraction, by which I mean that they shape discourse at a higher level, by providing a communication infrastructure within which communicative encounters play out.

Mediated communication, by definition, is enacted via information artefacts, including books, leaflets, websites, and videos, but also via higher level artefacts such as systems and platforms. In digital environments, these infrastructural artefacts, too, can appear to act as though they were interlocutors, shaping and influencing meanings as they transform forms and arrangements. An artefact, such as an article on a healthcare topic, created in one context with a particular context of use in mind, may then be shaped and reshaped by contact with many other, infrastructural artefacts, with the original artefact eventually taking on something of the status of a digital palimpsest, written and rewritten many times, until it takes on a form which might be surprising to its originating “author”. Being quoted “out of context” is often used as a defence in the face of mediated misunderstandings, but when a digital artefact is launched into digital channels of communication, its eventual contexts of retrieval, and even the form in which it will be retrieved, can be hard to predict.

This is a complex picture, and the lack of clarity that arises about the identity and role of interlocutors has pragmatic implications, since communicative transparency cannot be achieved in the face of such uncertainty. For those “on the ground”, actively engaged as interlocutors in digitally mediated healthcare discourse, as clinicians, patients, authors, editors, readers, or systems developers, their co-interlocutors, and the nature of their contribution, may be difficult to distinguish. By setting various interlocutors and their interactions against the benchmark of communicative transparency introduced in section 2.1, my aim is to achieve some clarity about the identity of interlocutors, and the nature of their contributions to digitally mediated healthcare discourse. In the interests of

bringing precision to the assessment of communicative transparency, I will consider informational artefacts, such as leaflets, websites, and systems, as *proxy interlocutors*<sup>7</sup>, carrying traces of the communicative intent of their makers into the wider healthcare discourse.

The term “transparency” has been widely adopted in the analysis of digitally mediated information, but not always with reference to Habermas’s discursive validity claims of truth, truthfulness, and rightness. Hongladarom (2004) argues that, to promote global equality in information value, information must itself be made “transparent” by the development of systems of representation which encourage disambiguation:

“What is needed here is that there should be a system of information about information, a kind of second-order information that deals with the natural and cultural information possessed by the villagers and made available to the world through cyberspace. Closing the digital gap does not only mean bringing in information from one presumably ‘right’ side of the gap to the supposedly ‘wrong’ one. Instead it means a more adequate, equitable and fair way of sharing information between the two sides.”

The argument draws on the “information ethics” set out by Floridi (2002), who advocates the use of digital technology to create a public arena of frictionless information exchange. The approach sees the ambiguity of natural language as a brake on communicative progress, and portrays informational “entropy”, the loss or corruption of information in transference, as an “evil” to be overcome by more efficient system design. The diminishing materiality of digital media is equated by Floridi with a diminishing of mediation itself, leading to the development of a more transparent human communication than has hitherto been possible. Floridi’s “infosphere” is presented as a driver of

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<sup>7</sup> This view is in contrast with approaches which would ascribe agency to artefacts, e.g. Latour (1991).

emancipation, and the maintenance of information systems as an unambiguous repository of encoded knowledge becomes a moral obligation.

The goal of expanding participation is one that is shared with Habermas, but there are important points of difference in the two concepts of transparency. Floridi and Hongladarom's analysis is in some ways typical of systems-centric approaches to digitally mediated communication which, exasperated with the semantic ambiguity and structural intractability of natural language, attempt to circumvent the vagaries of natural language texts by supplanting them with non-linguistic, and hence supposedly transparent, representations. But rather than a simple transparency, this extra layering of alternative representation in the form of metadata, on top of natural language texts, might instead be interpreted as demonstrating the "double logic of remediation" set out by Bolter and Grusin (2000), in which the desire for transparent immediacy triggers a conflicting need for hypermediacy, as new forms of mediation are created to compensate for the perceived representational deficiencies of existing media. In the process of remediation, the logic of hypermediacy results in the masking of ever more complex workings to create an illusion of immediacy. Illusion, being fundamentally strategic, cannot create the kind of communicative transparency proposed by Habermas.

In itself, the goal of adding information with the aim of disambiguation does share something with Habermas's discursive approach. If we consider the type of metadata proposed by Hongladarom as an additive to the natural language text with which it is associated, rather than as a replacement for that text, then we could consider it a step in reaching discursive consensus, a clarification to benefit users of systems that cannot process natural language. Clearly here too there is complexity, as both metadata and the original text are then subject to validity claims, not least surrounding consistency between themselves. But in principle the mechanism is already in place for working through any contested validity claims arising from the layering of metadata on natural language text.



Validity claims in respect of truth could be established with regard to the usual objective referents. Validity claims in respect of truthfulness might be more complex to establish, since the source of metadata is likely to be different from the source of the natural language text, but as a barrier to transparency, this is at about the level of translation into another language, and surmountable by discursive means. The most interesting of Habermas's validity claims to examine with respect to metadata may be rightness. Metadata which is explicitly designed to make texts machine readable, and therefore increase their reach, could be seen as meeting a specific set of rightness criteria, beyond those that can be met by natural language text. In this way, adding metadata to digital information might indeed increase discursive transparency, although this extra dimension to claims of rightness would continue to be context dependent. Meaning, in the discursive model, is not something to be preserved in static form as information passes through neutral mechanical gateways. Instead, each gateway, acting as a proxy interlocutor, layers new levels of meaning into the developing discourse. In this way, with each gateway and each new interlocutor, so long as the validity claims continue to be met, the discourse is deepened and the potential for communicative transparency increases.

The algorithmic approaches often applied to interpret digitally mediated information, described by terms such as knowledge discovery, data mining, and text analytics, are in some ways opposite to the approach to explicit disambiguation set out above. In these algorithmic approaches, systems developers meet semantic ambiguity head on. Rather than trying to create unambiguous representations to supplant or travel alongside natural language texts, developers following these approaches use a variety of artificial intelligence techniques to interpret meaning from large aggregations of diverse data, including natural language texts. Knowledge discovery and data mining techniques, like other techniques of mediation, introduce proxy interlocutors into discourse. These new interlocutors bring together aggregations of proxy interlocutors (information artefacts such as texts and databases) to create new informational contexts. Context, as created by these applications, is fluid, unpredictable, and layered.

In terms of validity claims, these applications can be said to create their own conditions of rightness, by defining their own social contexts. To some extent this is true of all acts of mediation, where media “audiences” choose where and how to access decontextualized meanings (see e.g. Silverstone and Hirsch (eds.) 1992), but in the case of artificial intelligence mediated text processing, the means of contextualisation are particularly opaque to the originating interlocutors and to human users alike, making it almost impossible to assess the validity claims of truth and truthfulness, though mistaken claims to rightness often leap out to the human user by virtue of their obvious incongruity. Because the “rules” of these applications are visible only to the designers of their algorithms, communication mediated in this way could only be said to be transparent in Habermasian terms if the algorithms on which the processing was based were made public, and publicly comprehensible, alongside the results of their processing.

Other approaches to making texts tractable within systems including processing a limited range of structural elements within natural texts according to a defined ruleset, while ignoring the rest, or limiting the natural language forms that can exist within the system to those which can be aligned to reliably machine-processable codes. Both of these narrow approaches might easily meet the validity claims of truth and truthfulness, but would find the circumstances under which they could meet the validity claim of rightness to be extremely limited.

Systems designers must choose between these approaches in the creation of their systems, and choosing one approach over another will have implications for the level of communicative transparency supported by the system. While those who take natural language as their starting point often stress the characteristics of polysemy and the fundamental opacity of language, the advocates of artificial, teleological coding structures are often oriented towards transparent transmission and disambiguation.

It is therefore important to account, within my own broader model of digitally mediated discourse, for the particular model of discourse favoured by the system designer. The complexity that may result from different models of discourse colliding, interacting, and

possibly conflicting within standardised communication environments becomes apparent when one examines the range of available discourse models to be found across the various disciplinary arenas of academic literature. Working from a linguistics viewpoint, Schiffrin (1994) divides models of communication into code models, inferential models, and interactional models, each offering a different analysis of the basic elements of communication. Likewise, the socio-theoretical analysis of communication presents a range of contrasting models of the interaction between social organisation and communication, from Habermas's communicative action (Habermas 1984), which provides the framework for this study, to Foucault's emphasis on historicity and the exercise of disciplinary power (Foucault (1970, 1972, 1973).

These examples are of mostly academic relevance, rooted in the various epistemological positions of different disciplines. Of more interest in this study are the informal models held by those, including clinicians, patients, authors, editors, and other information workers in addition to systems designers, who are involved in the digital mediation of healthcare meanings. Mansell and Silverstone (1996) offer a conceptualisation of *design* which accounts for the encoding of intent within artefacts<sup>8</sup>. According to Mansell, information technologies, as designed artefacts, can be said to encode, or have inscribed within them, the intentional agency of their creators.

This is not to claim that, in use, technological artefacts express the agency of those creators in an exclusive, or even a straightforward, way. According to Silverstone and Haddon (1996), the designer's model of use is only one factor in the actual usage of an information technology. Each of the models of digital information listed above, if taken as a “design principle”, or model of intent, will enter, in the use of the resulting technology, into a relationship with the information models held by the users of that technology. Silverstone and Haddon use the concept of the “double articulation” of media

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<sup>8</sup> Note that the communicative focus of Mansell and Silverstone's account distinguishes it from other accounts of intent within design such as “philosophy of design” (Galle 2002, Houkes and Vermaas 2002)

technologies as both objects and media channels to begin to account for the dialectical relationship between the design of a technology and its use. This concept, touching as it does on the intersubjectivity of communication, on the one hand, and on the formal means by which such intersubjectivity is enacted on the other, chimes with the pragmatics-based theoretical framework of this study. At the opening of this section, I referred to the important role played by standards in the dissemination of information across digital networks. Standards are defined by Hawkins (1996) primarily as technologies of communication, and as such, doubly articulated as both mechanisms for a perhaps imperfect translation, and objects, which, even as they encode the complex intents of their creators, are interpreted and appropriated by their users.

For communication technologies, an important part of what is built into, or interpreted from the technology is the designer's or user's model of the act of communication as performed using the medium of that technology. Thus a standard may be designed to facilitate the sharing of a certain type of information in a certain context, thereby encoding the designer's model of communication, and it may then be appropriated by a user to share a different type of information in a different context. In this way, models of communication are inscribed into technologies as *design principles* and translated into use as *usage models*. The nature of these models can be expected to influence design decisions, and usage practices, as system designers favour areas of functionality that are prominent within their model, while users may seek to subvert the encoded designs by applying their own models of use. Whatever models of communication inform their design principles, at the point of implementation, according to Mansell (1995) digital encoding standards harden into structural entities. This hardening potentially inhibits the directions that discursive elaboration might take, and so is offers potential barriers to transparency, closing some routes to consensus just as it endorses and supports others.

When applied to standardised digital encoding of information, the twin principles of *embeddedness* and *reach* (Star and Ruhleder 1996) underline the essential dialectic between the local contexts of production and consumption of encoded information, and the global ambition, or intention, of standardisation. In order to fully account for the

process of standardisation, both local and global contexts must be examined, along with the dynamics of the dialectic between them. This dialectic may be neglected by studies which operate in the strictly local frames of production and consumption. The danger with a strictly local frame of analysis when applied to an area such as standardised encoding protocols is that the very purpose of the protocols, that of global distribution, would be excluded from the analysis, resulting in a framework inadequate to describe the complex layering of communicative models outlined in this section.

The holism advocated by Deacon (2003) aims to address the dissociation between media production and media consumption, pointing out that by restricting the research vision to one side of the mediation process, the ability to focus on the interactional nature of media is lost, resulting in a form of “media denial” by which macro-level media analysis can only be performed as part of generalised studies of the social. Where studies of digitally mediated information are concerned, the possibilities for such isolationism are further extended by the layering of further spheres of practice which occurs as the design, production, implementation and use of media systems is added to the production and consumption of media objects. Although it would be possible to ignore these spheres, exactly as it would be possible to ignore the spheres of consumption or production, to do so would limit the interactional complexity which could be accounted for in the resulting model of digitally mediated discourse, allowing the intents of unaccounted for agencies to act, unobserved, on the periphery of research. By not accounting for these agencies, and divorcing the study of information systems from the study of mediated representation, large spaces would open up in the available conceptualisation of system-mediated discourse, within which the actions of agents not accommodated within the model could continue unobserved.

## **2.7 Dimensions of materiality in digital media**

In the preceding sections I have focused mainly on the social interactional aspects of digitally mediated information, as though digitally mediated communication was set apart from other forms of communication mainly by the communicative stances taken by its

proponents. While these factors are important, in an analysis of the workings of digital mediation, the materiality of the mediating artefacts themselves should not be overlooked. In section 2.5, above, I assigned to mediating artefacts the role of proxy interlocutors, carrying the intent of their makers into complex mediated discourses. In this section, I will pay attention to the material properties of these artefacts as objects in the real world, examining properties across three dimensions of materiality: weight, malleability, and texture.

It has often been observed that the traditional mass media favour certain topics, forms, and constituencies over others. The drivers of this uneven distribution of media coverage are many and much discussed (see for example Garnham 2000), but historically one major constraint on media coverage lay in the resource-hungry production and distribution of the material goods in which media content resides. Since, in principle, digital encoding of media content enables the production of infinitely replicable, instantly transmissible information, in the early days of the digital transformation of information, it was suggested (by, for example, Negroponte 1995) that digital media technologies, by removing those distribution constraints imposed by the materiality of analogue media, might enable a revolutionary liberation of information. As digital mediation has become ubiquitous, it has become apparent that there is a divergence between the emancipatory promise of immateriality bestowed by the theoretical principle of digital encoding, and the contrasting materiality of its everyday practice. While digitally encoded information itself might be described as immaterial, or ethereal, its creation, storage and access involves a range of hardware, software, and human effort, interacting in physical environments. The technological artefacts and practices by which information is introduced into, managed within, and retrieved from its abstract digital existence have their own particular materiality.

The most obviously material of the technologies brought to bear on digital information is hardware, in its various types such as data storage disks, processors, and network cables. These impose easily measurable constraints on the circulation of digital information, since one can neither create, store, distribute, nor access digital content at all without the

necessary hardware to do so. Beyond this simple dichotomy of have and have-not, the amount and nature of the content one is able to create and circulate is also constrained in quite obviously material ways by the availability of appropriate hardware. In order to create textual digital content, for example, one needs access to some form of processor equipped with keyboard functionality; to store it, one needs a small amount of digital storage space; and to circulate it, a low-bandwidth connection to a publication environment will suffice. To create, store, and circulate digital audio content, the hardware requirements are somewhat different; one needs sound recording equipment such as a microphone; higher-volume data storage; and higher-bandwidth data transfer.

The claim of software to materiality is perhaps less obvious. Software is in itself a form of digital information, consisting of encoded processing instructions. Both hardware and software consume human effort in their creation, but, unlike hardware, software does not directly consume physical raw materials in the course of its creation, so that, in contrast to hardware, the replication of software does not consume proportionately growing amounts of physical resources. Perhaps the strongest claim of software to materiality comes not at the point of production, but at the point of use. Before its encoding, the variation in the potential forms a piece of software might take is huge. Once encoded, although software is more amenable to reconfiguration than hardware, it is not infinitely so, as changing a piece of code consumes considerable human effort. In describing software as “malleable”, Quintas (1996: 77) highlights the particular resistances that are introduced into this ethereal information form during the course of its construction, resulting in a particular kind of materiality, in “the tension between software’s inherent flexibility (...) and (...) the ways in which initial design decisions and sunk investment costs prefigure use patterns and constrain the degrees of freedom for future developments”. The term “soft” in “software” therefore accounts for a particular *type* of materiality, rather than for a *lack* of materiality.

The materiality of software is most in evidence after the stages of design and construction, once it is implemented, when we can see software not only controlling the movements of hardware to produce material effects, but also software in interaction with

human actors in the form of users, who have limited, if any, power to modify its configuration. To its users, therefore, software is a material of uneven resistance, malleable only in certain directions and to limited extent.

The specific types of materiality at work around digital information suggest that digital encoding alters, rather than removes, the kinds of distribution constraints imposed by the materiality of physically-mediated information. This alteration in constraints provides potential for changes in the media environment, without determining the nature or direction of those changes. Beyond the material, in the social frame, digital media are no less bound than analogue media by the complex patterning of interests of those individual and institutional actors who create, hold and access digitally encoded information. In digital media, as in more traditional media, these interests interrelate to form networks of competition and conflict, as well as of consensus. Such relationships impede some distribution pathways while enabling others (see Mansell 2004; Garnham 2000; Winner 1999). Thus, the potential of digital media to contribute to emancipatory change, by harnessing the ease of replication and transmission of information in the service of a programme of increased mutual understanding, is balanced by its potential to propagate further inequalities in the distribution of information. In order to promote the former outcome, and mitigate the latter, it is necessary to develop a model of digitally mediated communication which is able to account for its specific materialities in conjunction with, and in interaction with, their social context.

As discussed in section 2.5, above, systems for managing digital information can take many approaches in their attempts to bring technically-enabled power and reach to the formal intractability of human communication. Many systems are based on principles of unambiguous identity and clearly delineated relationships of and between the pieces of information they contain. It is the application of consistent principles of definition and ordering, more than any ethereality of substance, which most characterises the systematically managed digital media environment in this model.



Much of the distributive power of digital media stems from the flexibility enabled by the increasingly granular encoding of information; in other words, from the identification of ever smaller entities within the information. As an example, take the effect of granular encoding on newspaper information. Although it may contain an aggregation of different topics, perspectives, and authors, for distribution purposes an actual physical newspaper is a single entity, unless torn into pieces, in which case it is no longer a newspaper. In its digital form, the same “newspaper” may exist on multiple levels, for example, as a continuously expanding collection of successive editions; as a number of related articles; as an even larger number of paragraphs, sentences, words, or bespoke teleological structural forms. Independent digital existence, at any one of these levels, can be achieved by the explicit allocation of a persistent identifier, a naming of the parts beyond that achieved, or achievable, within the traditional form of the written text.

Once identified in this way, the parts can be manipulated in automated ways to create fresh configurations of the original information, opening up new possibilities for access. For example, a newspaper might have its headlines extracted and used to create a hyperlinked table of contents. The same hyperlinked headlines might be emailed to subscribers as a newsletter, used to generate keywords for an indexed archive, syndicated as an RSS (Really Simple Syndication) feed to drive readers to a website, or used as web page headers, then appear as headings in pages of search results returned by search engines entirely unconnected to the newspaper itself. This degree of granularity in information, if left unmanaged, would quickly attain an unprocessable complexity. Hence, standards of encoding are employed, in order that the mass of digital information (data) and information *about* that information (metadata) can be better ordered, processed, controlled, and exploited.

As also mentioned in section 2.5, an alternative approach accepts that encoding at the point of origin is a discipline not often followed, and that huge volumes of unlabelled data regularly spill into public and private information spaces. The artificial intelligence techniques used to “mine” or “discover” meaning from these huge bodies of data require human effort, just as encoding requires human effort, and in that respect have the same

claim to materiality as more obvious techniques of control. Rather than residing within coding systems and structures which are used as frameworks for human communication, in these models, materiality resides within the interpretative algorithms which attempt to span the divide between the opacity of decontextualised text and the desire to understand.

The standard languages by which digital information is encoded or queried demonstrate, in common with other kinds of software, a form of materiality perhaps best described as limited malleability. Also in common with other kinds of software, information standards are artefacts created in particular social settings and to serve particular purposes. In order to examine any claims for transparency made for a particular standard, it is necessary to examine the provenance and intent of that standard (e.g. Vincent and Camp, 2004). Some standards are unique to the particular system for which they are developed, creating a purely internal, situated consistency, in the interests of easing the automated processing of information within a defined technical context. Examples are the standards used in proprietary database systems made available as commercial products, such as Microsoft Access. In systems that are themselves replicated, such internal consistency is sufficient to carry granularly encoded information into new contexts, provided that the context in question is furnished with the matching system. For example, if a database is created in a proprietary database management system, anyone with access to both the information and a matching system is able to access and reconfigure that information in a number of different ways, so long as all of these ways are compatible with the original encoding.

Because of the limited malleability of software, the ways in which information can be accessed once encoded may be multiple and unpredictable, but they are not infinite. The systems of internal consistency around which proprietary products for the manipulation of digital information are built often take on the status of *de facto* information standards (Hawkins, 1996). Other information standards are developed with the explicit intention of transcending particular applications to achieve a more generalised information consistency. Such standards are created, agreed and monitored by various social bodies. Examples include the range of markup languages and associated standards maintained by the World Wide Web consortium (“W3”). Standards maintained by “W3” include the

ubiquitous HTML, HyperText Markup Language, which is the standard encoding format underpinning the World Wide Web, along with XML (eXtensible Markup Language) and other standards such as RDF (Resource Description Framework) and OWL (Web Ontology Language) which are intended to support more sophisticated, meaningful data encoding.

The standards themselves take the form of documents setting out the technical specification of the encoding protocol, but it is perhaps more illuminating to see standardisation as a process, of which the specification document forms only a part (e.g. Hawkins, 1996; Shah and Kesan, 2009). Of equal importance are the processes by which the standards are produced and developed, the software applications which adopt, adapt, or ignore the standards as the basis for their own data encoding, and the processes by which the standards are employed in the coding, distribution, and access of digital content. The proliferation of technologies which enables the dissemination of digital information across many contexts rests, paradoxically, on this standardisation of data formats. In order to publish digital information into the wider digital universe, producers must comply with a battery of standards which will enable that information to be translated from one information environment to another. Furthermore, in order to pass from producer to intended audience, this standardised digital information must run a gauntlet of information intermediaries, such as search engines, portals and content aggregators, each exploiting the standardised format of the information to carve out their own niche in the information chain. The result is a complex patchwork of consensus, represented by the standards to which information must conform, and contestation, represented by the divergent uses that are made of that standardised information.

I opened this section by referring to three dimensions of materiality in digitally mediated information. The first of these dimensions, and the simplest, is the dimension of weight, defined as the amount of human effort and raw materials (if any) expended in the creation of information artefacts. The second is malleability, defined as the amount of human effort expended to make changes in information artefacts once they have been created, or the amount of effort needed to appropriate artefacts into unforeseen models of use. The

third dimension is that of texture, and I use this term, following Bowker and Star (1999) in their analysis of information standards and classification, to refer to the details of the ways in which information artefacts are experienced in creation and use.

“What is missing is a sense of the landscape of work as experienced by those within it. (Physical descriptions of standards) give no sense of something as important as the texture of an organization: Is it smooth or rough? Bare or knotty? What is needed is a sense of the topography of all the arrangements: Are they colliding, coextensive, gappy, or orthogonal?” (Bowker and Star, 1999: 40)

Bowker and Star apply textural metaphors to describe the human experience of working with information systems, and introduce the concept of informational *torque* to describe the wrenching force that is brought to bear when the rigidity of a system does not quite accommodate the shape of the lifeworld experience to be encoded within it.

As the medical knowledge base has developed and grown over time, its increasing volume and complexity have given rise to a parallel growth in organisational systems. The resulting plethora of overlapping classifications, nomenclatures, taxonomies and ontologies adds a layer of meta-information to medical communication which, while often invisible to the casual observer, can be powerful in its implications. On the most practical and mundane level, naming is a key part of diagnosis and a necessary precursor to appropriate treatment, but the naming of a disease suffered by a particular patient also serves to relate the personal experience of illness to a higher level classification, an act which, in layering generalised significance onto the personal, carries some political weight.

The International Classification of Diseases (ICD), whose hidden political subtexts were investigated by Bowker and Star (1999), is only one of many standardised terminologies competing for attention in the clinical space. Others include Read codes (heavily used in UK general practice, and named after the GP who first developed them in the 1980s), SNOMED-CT (**S**ystematized **N**omenclature of **M**edicine -- **C**linical **T**erms, managed by the International Health Terminology Standards Development Organisation), and

controlled vocabularies such as MeSH (**M**edical **S**ubject **H**eadings, introduced by the US National Library of Medicine (NLM) to facilitate management of medical information) and UMLS (Unified Medical Language System, another product of the NLM which acts as a mapping tool across multiple terminologies in many different languages.)

Terminologies such as these are large and complex entities, costly to create and maintain, and which, once embedded into systems and practice, can be challenging and costly to dislodge.

Standardised medical terminologies offer a formal representation of a knowledge base, derived from a combination of natural science and practice, which is neither complete nor fully consistent (Hofmann 2010), and as such they are far from straightforward in either their creation or their use. Bowker and Star note the tendency for such informational infrastructures to become “invisible”, by which they mean “not generally noticed at the point of use”. This invisibility is the opposite of the communicative transparency which is the benchmark of this study.

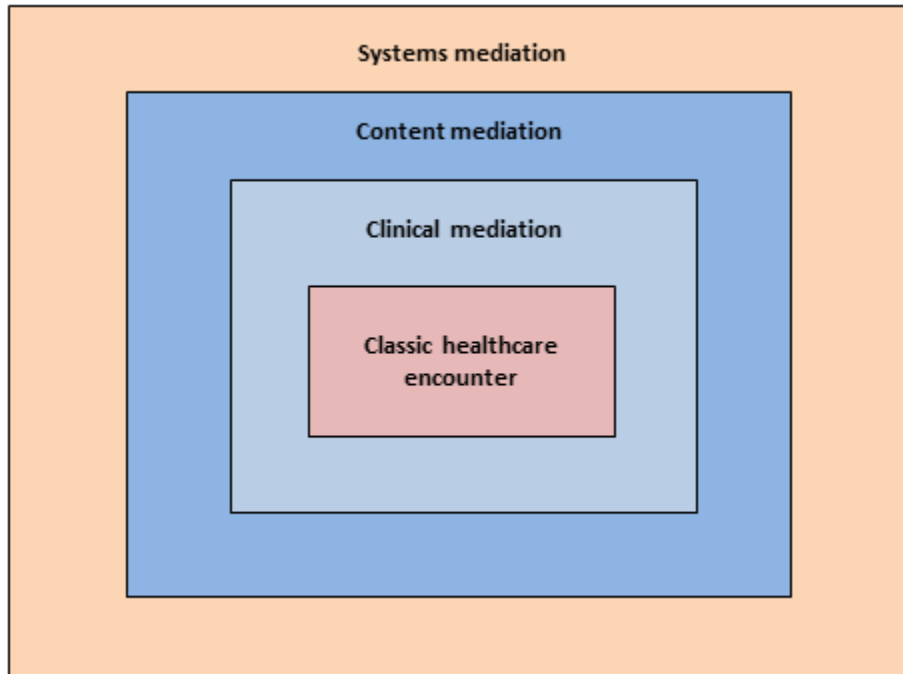
## **2.8 Challenges to transparency in the digital mediation of healthcare meanings: a conceptual framework**

The concept of discourse is central to this study, and the object of enquiry is made up of three macro levels of discourse. The first is the digital mediation of healthcare meanings via information artefacts between clinicians, patients, and information producers, which is conceptualised as mediated discourse. This mediated discourse is presented in relation to a second, underpinning level of discourse, the “communicative baseline” provided by real-world healthcare discourse, which in its most familiar form is enacted between clinicians and patients. These two macro discourses form the background for a third level of related discourse, which takes centre stage as the research progresses, and this is the discourse that occurs between different information producers in their creation of the healthcare information artefacts that mediate the digital sharing of healthcare meanings.

The first component of the conceptual framework is *communicative transparency*. In section 2.1 of this chapter, I related the concept of communicative transparency to

Habermas's idealised notion of discourse. Throughout the study, I intend to examine the potential of various situations and configurations in the sharing of digitally mediated healthcare meanings to reach a discursive resolution, via the opening and resolution of the validity claims to truth, truthfulness, and rightness. In other words, I will assess these situations and configurations in terms of their ability to support, or to hinder, communicative transparency. In another sense, transparency, like opacity, can be considered a material property. I will reserve this material use of the term, in relation to the material properties of information artefacts, to refer to practices or artefacts that are likely to promote mutual understanding based on the apparent satisfaction of validity claims. Aspects of communicative situations which are likely to cloud such transparency, for example, by obscuring validity claims, by favouring strategic action, or by introducing confusing complexity, will be considered as offering challenges to transparency. The origins, typology, and implications of these challenges will be explored.

The second component of the conceptual framework for this study is *the structure of digitally mediated healthcare discourse*. In this study, I consider the sharing of digitally mediated healthcare meanings to be a *layered discourse*. The kernel of this discourse is the classic healthcare encounter, introduced in section 2.2, Figure 2.2, as a face-to-face exchange of health meanings that takes place in the awareness of social communicative expectations surrounding sickness. This acts as the *communicative baseline* for the study. Around the kernel of the communicative baseline provided by the classic healthcare encounter, I will present the mediating factors of expertise and artefacts in concentric layers, in the order shown in Figure 2.4, according to their distance from the classic healthcare encounter.



**Fig. 2.4: The layered mediation of healthcare discourse**

Mediation in this study is defined rather broadly as an indirect shaping of meaning. This might happen via changes in context which alter expectations of meaning, as is the case with mediation via expertise introduced in the example of clinical communication presented in section 2.2 of this chapter, or it might happen when meanings are conveyed via information artefacts, as examined in sections 2.5, 2.6, and 2.7 of this chapter. Although this study presents different aspects of mediation as being layered, in terms of distance from the communicative baseline, I do *not* suggest that individual acts of communication are separated into corresponding layers. In this model, any interlocutor might perform any locutionary act in communicative action with any other interlocutor. It is true that interactions between some types of interlocutors happen more frequently than others, but as a model it is only the expertise and perspectives of interlocutors that are conceptualised as being layered according to their familiarity with the communicative baseline of the classic face-to-face healthcare encounter. As will be seen as the study progresses, this in no way precludes communicative action between, say, a patient and a systems developer, no matter how “distant” they might superficially seem.

Another key aspect of the structure of the digitally mediated healthcare discourse is the concept of information artefacts as *proxy interlocutors*. The identification of artefacts as interlocutors is understood to signal their ability to contribute actively to the sharing of meaning, while the qualification provided by the term “proxy” signals that, although active, artefacts in this framework are not assumed to possess agency of their own, but advance the discourse on behalf of human interlocutors<sup>9</sup>. As mentioned in section 2.6 of this chapter, in this discursive model of digital mediation, each artefact through which information passes layers new levels of meaning into the developing discourse. By this mechanism, so long as validity claims continue to be raised and are understood to be met, proxy interlocutors such as information artefacts can deepen the discourse and increase the potential for communicative transparency.

The third component of the conceptual framework is the notion of *interlocutor models of communication*. The individual understanding held by interlocutors of particular aspects of communication plays an essential part in the sharing of meaning. In section 2.6, I introduced the idea of interlocutor models of discourse, also described as models of communication or, for digitally mediated discourse, models of information. Identifying and analysing these models will be an important theme in this study. Firstly, they include models of other interlocutors, since, as discussed in section 2.1, intersubjectivity requires an understanding of the perspective of the other. Secondly, they include models of intent, since a recognition of communicative purpose is essential to the sharing of meaning, and a prerequisite for the development of mutual understanding. Thirdly, they include models of action, because successful communication depends on recognition of the communicative actions on which it is built.

Fourthly and finally, a particular understanding of *digital materiality* is central to the conceptual framework in this thesis. The concept of materiality in digital information

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<sup>9</sup> My attribution of communicative agency primarily to humans and to artefacts only as their proxies contrasts with the view of non-human communicative agency proposed by e.g. Cooren and Matte (2010) and Cooren (2012)



artefacts was introduced in section 2.7. The materiality of digital artefacts often goes unaccounted for, and yet is capable of exerting considerable force which can contribute to the shaping of discourse. This research examines the materiality of digital artefacts across three dimensions. The first of these is the dimension of *weight*, which refers to the levels of human effort and material resources involved in creating digital artefacts. The second is the dimension of *malleability*, which refers to the levels of effort involved in making changes to digital artefacts, and the third is the dimension of *texture*, which refers to the ways in which information is experienced by people.

Taken together, these four components provide a framework for understanding digitally mediated communication in a way that allows us to address the central research question for this study: *Can digital mediation increase the transparency of healthcare communication?*

Transparency in communication, in terms of its alignment with the normative ideals of Habermasian communication, is an important property to consider in a field of informational study such as healthcare information that is intended to have an emancipatory purpose. The failure to meet validity claims of truth, truthfulness, and rightness, or, perhaps more likely, the failure to even recognise that such validity claims exist, could allow distortion of meaning to flourish in the mediated healthcare discourse, which could lead to potential harm to the health of the interlocutors in that discourse.

Transparency in healthcare information is easily overlooked, or highly simplified. Within the narrow traditional social contexts of healthcare discourse, communication largely falls under the jurisdiction of clinical professionals. In the digitally mediated healthcare discourse, it is released from those constraints, not simply by virtue of the range of contexts through which it now circulates, but also because the complexity of those contexts places them beyond the information expertise of many clinicians. It is vital, therefore, to create normative frameworks around transparency that can be mobilised by the full range of interlocutors in this broader discourse.

In this study, I aim to build a better understanding of this digitally mediated healthcare discourse and the ways in which configurations of expertise and artefact combine to shape meaning within the discourse, as a step towards the creation of such a framework.

In the light of this theoretical framing of the issues, the empirical study is designed to address the following questions:

### **Empirical questions - 1**

*What kinds of **specialist expertise** are involved in the sharing of digitally mediated healthcare meanings? How are these forms of expertise characterised, and how do they interact?*

These questions require an analysis of the different skills employed in the creation and dissemination of digitally mediated healthcare information. In order to answer these questions, access to the interlocutors involved in the sharing of these meanings is needed. These interlocutors could theoretically include the teams involved in the work of creating healthcare information, and the users of this information. The study requires both knowledge of this expertise, and a view of how the different expertises relate to one another in practice. In my examination of expertise, my aim is to go beyond simple measures of academic qualifications or technical skills, to examine more unusual or hidden aspects. To inform a rich and varied qualitative answer to these questions, the study mobilises real world informants.

### **Empirical questions - 2**

*How are **information artefacts** mobilised in the digital mediation of healthcare meanings? How are they characterised?*

These questions require an understanding of the range of information artefacts brought to bear on the digital healthcare discourse. In order to answer them, an overview of the artefacts involved is required. In order to generate a rich view of the interplay between technologies and meanings, the definition of information artefact extends beyond publicly available information products to include other kinds of information artefact,

such as the systems and standards employed in the creation of information products. To answer these questions, access is required both to digital healthcare information products and to the technical infrastructures and practices used to create those products.

### **Empirical questions - 3 and 4**

*How do specialist expertise and digital artefacts work in combination in digitally mediated healthcare to promote or hinder communicative transparency?*

*What factors exacerbate challenges to communicative transparency in the digital mediation of healthcare meanings, and what factors mitigate them?*

The final two questions require the empirical data to be gathered in a single frame for analysis in relation to the theoretical framework outlined in this chapter. To bring expertise and artefacts, the two very different aspects of my research object, into a single frame, I undertake a thematic analysis (Flick 2002: 185-190; Guest et al. 2012) of my data.

In this chapter, I have mobilised the theoretical literature to address questions relating to the implications for communicative transparency of the digital mediation of healthcare meanings. I have set out a conceptual framework for this study, which emphasises communicative transparency, the structure of the digitally mediated healthcare discourse, interlocutor models of discourse, and digital materiality. I have also posed the key empirical questions. In the following chapter, I present the research design and methodology of the research.

## CHAPTER THREE

### A research methodology for investigating the digital mediation of healthcare meanings

In the previous chapter I set out the theoretical basis for this research and developed the conceptual framework that will guide the empirical research. In the light of the empirical research questions set out in Chapter 2, in this chapter I present the research methodology, the research design, and methods used in this study, giving particular attention to the operationalisation of the key concepts of communicative transparency, the structure of digitally mediated healthcare discourse, interlocutor models of communication, and digital materiality, which are central to the framing of this research. The chapter is presented as a reflexive narrative of the development of the methodology over the course of the empirical work, to contextualise and better explain the choices that were made as the research progressed.

#### 3.1 Research design

To respond to the core research question for this study – *Can digital mediation increase the transparency of healthcare communication?* – it was necessary to design a study that would enable me to focus on communication and meaning in order to identify challenges to communicative transparency. This required empirical research which would enable me to engage closely with instances of meaning and suggested that a qualitative study would be the most appropriate.

In Chapter 2, I identified three levels of macro discourse operating around the core research question. I summarise these three discourses again here:

- The “communicative baseline” of real-world, face-to-face healthcare discourse. Empirical enquiry into this discourse would suggest analysis of doctor/patient communication. The analysis of doctor/patient communication is well established as an area of research in medical sociology and medical communication (see for example Mishler 1984, Kleinman 1988, Scambler and Britten 2001, Gwyn 2002,

Greenhalgh et al. 2006, Walseth and Schei 2011). The existing body of work on doctor/patient communication was extremely helpful to me, as a non-clinician, in contextualising the processes of mediation which were of interest. As my own focus was on mediation and its implications for meaning, I chose not to examine doctor/patient communication directly, but rather, in line with my conceptual framework, to focus my empirical research on mediated meanings, keeping the “communicative baseline” as an abstract, idealised benchmark, but leaving it unexamined in an empirical sense.

- The sharing via digital media of healthcare meanings conceptualised as mediated discourse. Empirical enquiry into this discourse would suggest a close reading of media artefacts and the relation of these to the baseline of communicative transparency, perhaps alongside an examination of both producer and consumer perspectives of these artefacts.
- The discourse of information producers on the creation of the information artefacts that mediate the digital sharing of healthcare meanings. Enquiry into this discourse would suggest direct contact with information producers in order to observe and record examples of their discourse and practice.

When I began my empirical research, having discounted including direct observation of doctor/patient communication, I was open to examination of both the second and third discourses from the above list as means to illuminate the mediation of healthcare meanings. I set about the research expecting to include a close reading of information artefacts as well as engagement with the users of those informational artefacts. As the initial phases of the research progressed, practical factors meant that my research focused empirically on the third of these macro discourses, that is, on the discourse of information producers about the creation of the information artefacts that mediate the digital sharing of healthcare meanings.

The empirical object in this research has two defining characteristics. The first is its topic, which is healthcare, and the second is provided by the specific informational factors

arising from its digital nature. In order to answer the empirical research questions for this study, focusing on the sharing of healthcare meanings, as introduced in Chapter 2, section 2.8, I needed to examine:

1. the *interlocutors* involved in the digitally mediated exchange of healthcare meanings. These might include producers or users of information and I needed close enough access to them to support detailed examination of their different forms of expertise and the ways in which these were mobilised in practice;
2. the *artefacts* involved in the digitally mediated exchange of healthcare meanings. I envisaged the range of artefacts as including, but extending beyond, publicly available information products so that I could examine “published” information products in the context of the supplementary artefacts, such as information systems, which were mobilised in their development.

I therefore set out to seek empirical contexts that would produce rich discussion around the interaction between interlocutors and artefacts in the digital mediation of healthcare meanings. As introduced in section 2.1 of Chapter 2, the notion of context is central to the pragmatics of communication. Accordingly, I was keen that my empirical work would be able to explore some of the richness of the contexts in which digitally mediated healthcare information is created. This indicated a case study approach, in which the contributions of informants in the study would not be examined in isolation, but alongside the contributions of those with whom they shared their work of creating information, and where the examination would be informed by the practices and intentions associated with that work.

The conceptual framework introduced in Chapter 2, section 2.8 specifies an interest in “*interlocutor* models of communication”. It was important, then, that my informants were given the opportunity to contribute as interlocutors in a discourse, rather than as representatives of functional roles. To achieve this, I had to allow them to speak freely and at length within the empirical discourse in order to construct their own narratives, within a topical framework about the ways in which they conceived of the information products they created and the place of those products in a broader healthcare discourse.

As discussed in section 2.1 of Chapter 2, pragmatics is concerned with the intersubjective sharing of meaning within contexts. Habermas's version of "universal pragmatics" (Cooke, 1997) seeks to identify normative, context-transcendent rules of idealised discourse. Although context, and the detail of a specific context, is an important factor in any pragmatic analysis, in order to address the normative, context-transcendent aspects of universal pragmatics, I wanted to expand the empirical frame beyond a single organisational context. In order to create a body of empirical evidence at a level above that of a single organisation, I opted for a multiple case study approach. The aim was not to compare the organisations in themselves, but to use a comparative lens to illuminate the intersubjective relationships between interlocutors across multiple, related settings. In opting for a multiple case study approach, I was therefore following the approach used by Knorr Cetina in her 1999 study of scientific settings:

"Using a comparative optics as a framework for seeing, one may look at one science through the lens of the other. This "visibilizes" the invisible; each pattern detailed in one science serves as a sensor for identifying and mapping (equivalent, analog, conflicting) patterns in the other. A comparative optics brings out not the essential features of each field but differences between the fields." (Knorr Cetina 1999: 4)

As a point of contrast with Knorr Cetina, I also hoped that, in addition to surfacing differences, I would surface similarities.

### **3.2 Recruiting the case study organisations**

Having decided to centre my empirical work on a small number of organisations producing digitally mediated healthcare information, I set out to recruit between two and four organisations to the study. My first intention was to focus on organisations working as advocates to bring difficult aspects of sickness into the public eye. Such organisations work to promote awareness of particular aspects of disease, widening the public understanding of those affected by claiming a space for them in the public discourse. The focus on broadening the public healthcare discourse made these organisations a good

starting point for studying digital mediation of that discourse. I first looked for these organisations among charities publishing information concerning painful chronic disorders. I limited my search to organisations based in the UK, partly for my own convenience as a researcher, but also because I hoped that the combination of commonality of interest and geographic co-location would make for tightly- focused research data. The intention was to follow a gradual selection strategy in order to draw up a shortlist of organisations for possible inclusion in the research project.

I expected that the balance of the final sample would need to represent a degree of compromise between purposeful selection and convenience of access, but it was disappointing nonetheless that from a shortlist of around twenty organisations, after some weeks of discussions and negotiations, only one organisation had agreed to participate fully in the study. The type of organisation in the original shortlist was undoubtedly a factor in the low uptake. The small charities on which I initially focused relied heavily on voluntary workers in order to function, and almost all cited lack of time and resource as the reasons they could not participate in the study. The one organisation that did agree to participate fully (referred to as “the charity” throughout this study) did so because, coincidentally, at the time my request reached them, they were undertaking a strategic review of their digital publishing activity. They hoped that participating in the research might help them to crystallise their thinking on the topic and generate fresh perspectives on the work they were already carrying out.

Because of the low uptake amongst the organisations I first targeted, I decided to broaden the selection criteria for participating organisations. As the study was to focus mainly on the production and circulation of digital media artefacts, my basic requirement was to find companies publishing information on the topic of healthcare in a digital environment. On this basis, I recruited a commercial medical publisher (referred to as “the publisher” throughout) to serve as my second case study organisation. The profile of this organisation differed substantially from those I had first sought to recruit. The publisher did not have the single-condition focus of the charity I recruited, and nor did it have an advocacy remit. In addition, it was a profit-making company, a characteristic



which had the potential to change the dynamic of its discourse. More importantly for the purposes of the study, however, the publisher possessed well-developed digital capabilities and presence, and engaged in a high level of digital publishing activity which I could capture and study. The department I chose to work with created and published condition-specific information for both clinicians and patients. This meant that although the overall profile of the organisation was different to that which I had originally sought, with the publisher specifically having a broader coverage of conditions, lacking the advocacy role, and being profit-making, the two case study organisations did overlap in the topics they covered. The publisher took an active interest in the developing area of digital publishing, encouraging staff to present their own research at conferences, and so was happy to support any research that might contribute to the development of the digital publishing industry.

Despite their different statuses as a charity and a commercial publisher, there were many points of similarity between the two main organisations at the heart of this study. Both groups I worked with were departments existing as part of larger organisations. The remit of both departments was to create and disseminate information on healthcare topics. Both were examined as they evaluated digital approaches to the creation and dissemination of their content, finding themselves at different positions on their innovation trajectories as they sought to balance the needs of the patients and health professionals who were their end users with the capabilities and budgets afforded by their organisations, within specific technical environments.

Of course, although many everyday practices and concerns echoed across both departments, the departments themselves operated in quite different contexts. The parent organisation of the first department was a charity whose main purpose was to raise funds for, and commission research into, a particular group of chronic conditions. The department I studied in this research was the education and publications arm of the charity, disseminating information and educational materials on the conditions it covered for both clinical and lay users. The department was small, with only three dedicated full time members of staff, though these were supported by a larger cast of internal and

external contributors, some of whom were interviewed for this research. The work of the department was entirely funded by the parent charity.

The parent organisation of the second department was a large and well-established medical publisher, disseminating a wide range of publications ranging from original scientific research to opinion pieces and news. The department which is the focus of this study was a publishing division with around 50 employees which created and disseminated evidence-based healthcare information in the form of commercial products and services for professional and lay audiences on over 1,000 medical conditions. The department operated as a profit centre within the parent organisation. To support this large scale endeavour, the department drew upon the support not only of individuals and internal teams from elsewhere in the parent organisation, but also of enterprise-level suppliers. Two internal contributors from the supporting technology department were included as informants in this study, as were employees from two supplier companies which were engaged to deliver and implement a content management system (CMS) as part of the department's digitisation activity.

In section 2.4, Chapter 2 I introduced the social, the technological, and the media as three dimensions of healthcare contexts. In relation to the media dimension, both case study organisations operated in specialist healthcare contexts. The media artefacts that they created and disseminated covered a range including specialist information for clinicians, such as systematic reviews, and information for lay audiences, such as patient information leaflets, but all of the various outputs were designed for use either in clinical settings, or by users defined by their position in the healthcare context; by clinicians or other health professionals on the one hand, or by patients or their carers on the other.

The question of social context is less clear. While the activities of the two organisations often crossed into specialist healthcare contexts, particularly via the engagement of expert clinical advisers and authors, only one informant was medically qualified, and the bulk of the day-to-day activity of both organisations took place outside the clinical environment in offices in which the majority of workers were not clinically qualified. Many of the

informants in this research detailed their past experience outside healthcare before they entered the field of healthcare information for the first time in their current roles. The supplier organisations included as satellites of the publisher operated entirely outside the healthcare context, save for their engagement with the organisation examined in this research. For both organisations, the technological context was weighted towards the non-specialist, with a variety of mainstream, non-healthcare focused technologies used to create and disseminate their specialist medical information.

### **3.3 Fieldwork**

The fieldwork to inform this study took place over a relatively extended timeframe, spanning over two years between June 2006 and October 2008. This meant that over the course of the fieldwork, participants were able to reflect on the changes they were experiencing as both organisations moved along their innovation trajectory. At the time of the first round of data collection, the charity was preparing to relaunch its website, and the main concern of the participants in the research was digital delivery. Two years later, in the second round of data collection, the website relaunch had been completed and the focus of the participants had shifted to digital content management. When I first collected data from the publisher, a new content management system had just been introduced; by the second round of data collection, this system was well established in use and much had changed in the organisation.

#### **3.3.1 Sample selection: identifying and recruiting informants**

With each of the participating organisations, the charity and the publisher, I started with a single initial contact person within the organisation. I started the research by carrying out semi-structured initial interviews with each of these informants, to get a better understanding of their organisation and the place of digital mediation within it. As well as informing the research more generally, these first interviews enabled me to better define the research object presented by each organisation and to formulate a plan to broaden the group of informants using these questions from the interview guide:

- *What sort of team develops and manages your electronic publishing?*
- *How many people are in the development team?*

- *What are their roles?*
- *What tools and standards do you use to develop, manage and publish your electronic content?*

Following my first interview with my contact at the charity, I was invited to their head office for a full day of interviewing people with a range of different roles in the creation of their digital publications, all of which were on the theme of the particular disease which was the charity's focus. I was later able to take part in an all-day workshop on the charity's approach to digital publishing, with some of the same participants made up of my original interviewees, and some new participants. My contact at the charity also provided me with documents and publications via email.

My contact at the publisher provided me with contact details for people in various roles who were involved in the publishing of their digital evidence-based medical information products. I set up separate interviews with those from the list who were able to make time to participate, visiting the organisation's offices on several occasions to carry out these interviews. Some of these people I interviewed more than once over the course of a year. In addition, I made contact with the creators of the content management system recently installed to support digital content work at the publisher. I was invited to travel to the offices of the suppliers of this key system where I was able to interview the system developers, managers, and business development people about their work. I was also able to interview some of the team of external information technology (IT) consultants, from a different company, who implemented the content management solution for the publisher.

In the early stages of the research, I was keen to include an element of participant observation in my data collection. Unfortunately, none of the participants agreed to this, other than in the form of a workshop held at the charity towards the end of the fieldwork period to discuss future approaches to digital publishing at the charity. Apart from this, the data I collected was limited to semi-structured interview data, and the informational artefacts supplied to me by the participants. These included:

- the information products themselves, as websites, CD-ROMs, or in print form

- a strategic report, commissioned by the charity, on digital publishing in the healthcare charity sector
- guidelines for the development of digital information resources, created by the charity for the benefit of their developers
- editorial style guides used by the publisher
- topic plans, research search strategies, and spreadsheets used at the publisher to inform the creation of their information products
- detailed specifications of the content management system used by the publisher

As I recruited informants to interview, and collected information artefacts, I assessed both of these in terms of their contribution to the sharing of digitally mediated healthcare meanings and in terms of their interaction with one another. I was keen to include a representative and diverse range of interlocutors in order to generate rich and varied data for analysis. Table 3.1 lists the informants I interviewed from each organisation, by role, against the timeline of the research.

	2006	2007	2008
CHARITY	Education and publications manager Graphic designers (2) Production editor Educational consultant Education and publications manager		Education and publications manager Graphic designer Production editors (2) Information technologist
PUBLISHER		Information technologist Information specialist Clinical editor Clinical editor	Information technologist Clinical editor Content developer
SUPPLIER 1		Implementation consultants (2)	
SUPPLIER 2		Business development director CEO Technical director Developer	Business development director CEO

Table 3.1: Timeline of research and range of informants

Participants in this study were selected on the basis of their professional roles, as holders of particular types of expertise. All of the participants in the study were, to some extent, information workers, in that the main focus of their daily work was the creation or dissemination of information products. But within this category there was much variation. Some were primarily editorial, focusing on words and meanings; others focused on visual elements of design; some were technical developers, working on the code which made systems run; some were qualified librarians with a highly specialist information management remit; one was medically qualified; one a specialist in pedagogy; and some were in management roles, taking a high-level, strategic view of the overall work of their departments or organisations.

In summary, this research examines perspectives on the interactions taking place amongst interlocutors and artefacts (which I characterised in Chapter 2, section 2.6 as proxy interlocutors) in the digitally-mediated healthcare discourse. Participants in the study can be considered as “contributing interlocutors”, immersed in the practices which they describe. These interlocutors, having volunteered to take part in the interviews and workshops, and whose words provide the data which is then the basis for my analysis, provide the voices we can hear most clearly. Surrounding the voices and perspectives of this privileged group, and described and defined by them in this analysis, lies the wider group of interlocutors who are understood to be acting together to shape the sharing of medical meanings. In this way, the core concepts in the conceptual framework presented in section 2.8 of Chapter 2 are operationalised, in line with the need to examine communicative transparency through the lens of interlocutors and the discourse in which they engage.

### **3.3.2 Data collection through interviews and workshop**

As discussed in section 2.8 of Chapter 2, one of the key concepts examined by this research was *interlocutor models of communication*. Since these models are understood as individual to the interlocutors in a discourse, and form an important part of the intersubjective sharing of meaning, it was important to elicit rich descriptions from informants in their own words and using their own concepts to better understand these

individual models. In parallel to seeking these individual and potentially diverse accounts it was necessary, to achieve a level of thematic consistency in the interviews, to gather data on similar topics from a range of informants to support in depth analysis in the later stages of the research. With this in mind, I took a “snowball” approach to compiling interview guides. For each organisation, I began by talking to a single participant in order to get an overview of the aims and structure of the organisation, and to identify a range of other participants to contact in the next stage. In these initial, “seed” interviews, my questions were about the organisation, rather than the products, processes, or teams, and I grouped them around the following themes:

1. Publishing and development aims
2. Scale, variety, and reach of publications
3. Electronic media development
4. Financial status
5. Location

One of the features of the research design was that I used concepts elicited from the participants to drive and guide subsequent investigation. Therefore, the concepts and themes raised in these introductory interviews were an important source informing the guides for the next round of interviews. In this way, these two preliminary interviews, one for each organisation, set the thematic course for the second round of interviews. After the preliminary interview, my contact from the charity forwarded me a report the charity had recently commissioned, written by external consultants, which reviewed the digital publishing strategy of the organisation. I incorporated concepts from this study into the interview guides for the second interviews at the charity.

Since the study was not intended to be a direct thematic comparison between the two organisations, in order to encourage thematic consistency and foster the development of a single research object across the two organisations, I took concepts from the preliminary interviews from both organisations into account when creating the guides for the second set of interviews, thus cross-pollinating the themes into both sets of informants. Though

this might seem a potentially artificial approach, in practice, if a concept in the guide provoked little response from a participant, then it generated little data. This was sometimes the case; in other cases, concepts introduced from one organisation provided a rich source of reflection and data in the other.

The second round of interviews took place in both organisations with individuals carrying out a range of roles, as identified by my “seed” informants in the preliminary interviews. This second round was designed to elicit individual perspectives on the work of creating and disseminating digital information artefacts on the topic of healthcare, within the institutional context captured in the preliminary interviews. The intention was to ask broadly themed questions and to encourage informants to explore issues in depth using their own narrative structure. Questions were grouped around the following themes: Your organisation / Healthcare / Your job / Your contacts / Your audience / Your tools

In the final stage of interviews, I added two further elements to this formula. The first new element was driven by the significant elapsed time between interviews with the same participants, which was between one and two years. I asked participants to recount changes that had taken place since the first interviews and this generated a rich seam of reflective data. The second aspect was a list of high level abstract concepts which I generated from across the body of data gathered to that point, and brought to the later interviews to promote reflection and discussion. Participants were invited to choose those concepts which resonated with them and to elaborate on them. An example list from one of the later interview guides follows:

Clarity	Re-use	Content	Publication
Trust	Component	Knowledge	Product
Influence	Standards	Document	Interpretation
Openness	Proprietary	Data	Process
Transparency	Structure	Information	Context
Flexibility	System	Evidence	



### **3.3.3 Carrying out the interviews**

I recorded, transcribed, and analysed 18 interviews in total, recording them on a digital mini disk, and transferring the digital files to a PC for transcription and analysis. The one exception was my initial interview with the charity. I did not record this interview, but instead took comprehensive notes of the themes and concepts. A wide-range desk microphone was used for recording face-to-face interviews and the workshop, while a phone microphone was used for phone interviews. Interviews were carried out individually or with the respondents in pairs or threes. The workshop had six participants, myself included.

The majority of the interviews were carried out at the business premises of the organisations involved. In November 2006 I made my first visit to the offices of the charity in the English midlands, and conducted four separate interviews with a total of five participants, all of whom had been nominated by my first contact within the organisation. These interviews generated in total five hours of audio. In June 2008 I carried out a 50-minute follow-up phone interview with my main contact at the charity, as a result of which I was able to set up the workshop described in section 3.3.4 below.

I carried out all interviews with the informants from the publisher in their offices in London, beginning in February 2007. I also travelled twice to Rotterdam, once in 2007 and again in 2008, to carry out interviews with members of staff at the systems development company which has created the content management system used by the publisher. In addition, I interviewed the consultants who implemented this content management system for the publisher, at the premises of a third party in London.

While interviewing, I used the interview guide as a starting point, but followed the thematic threads raised by the informants. This meant that often the content of the interviews from respondents diverged, especially when they were from different disciplinary backgrounds or different organisations. Where the respondents belonged to the same organisation, or performed similar roles, then the themes raised in the interviews were more similar. As discussed in section 3.3.2 above, in order to maximise

consistency and coherence across the interviews, I used concepts from past interviews to seed the interview schedules going forward. Thus, once a concept had been raised, it was likely to be carried forward into successive interviews, allowing me to gather multiple perspectives on a concept which otherwise might only have arisen in a small range of interviews. A strategy of elicitation was used in the interviews to encourage the use of constructions and terminology determined by the respondents rather than by my own research agenda. The interviews all had an informal, warm, and friendly feel. There was a lot of laughter, and a sense that we were all co-travellers on what sometimes felt like a strange informational journey through healthcare.

### **3.3.4 The workshop**

As mentioned in section 3.3.2 of this chapter, one of the factors that led to the charity's involvement in the research was that, at the time of the fieldwork, the organisation was reviewing its digital strategy and processes and so welcomed the opportunity to discuss these with an external audience, which I and my mini disk recorder provided. Two years after I completed the first round of interviews, I was invited back to the charity to observe and participate in an all-day cross-disciplinary workshop, the focus of which was future developments in digital publishing at the charity. There were multiple benefits to both parties from my attendance at this workshop. The charity hoped to review again, and consolidate, their thinking around digital publishing, while benefiting from bringing me in to serve as a fresh external interlocutor. On my part, I hoped to generate richer data on the concepts I was investigating by recording dialogue between holders of different roles so that I could observe first-hand the interaction between these roles. I also hoped to gain a sense of change over time as we revisited the topics and projects first discussed two years previously. I recorded the workshop for later transcription.

The workshop was held at the organisation's offices in the north of England. Three of the participants had been included in the first round of interviews; these were the publishing manager, a graphic designer, and a production editor. One other production editor joined the workshop, although she had not participated in the first round of interviews, and an information technologist, who had joined the company only after the first round of

interviews was completed, also took part. One graphic designer and an educational consultant who had participated in the first round of interviews were absent from the workshop.

The workshop differed from the preceding interviews as it allowed me to record dialogue enacted between different roles about the publishing process, in contrast to the interviews, which were largely limited to single roles or closely related roles. The workshop began with the participants discussing the changes that had taken place around digital publishing at the charity since my last visit. From this starting point the group explored the different technical and process approaches they might adopt to support, streamline and develop their digital publishing activities.

The workshop generated over two and a half hours of audio. Much of the recording was not helpful to the research, being taken up with social chat, co-ordination, and conversations of little bearing on the research, so I edited the recording down to 53 minutes of salient comment for transcription.

### **3.3.5 Transcription**

The interview data was transcribed at two levels of detail. In the early stages of the research I carried out a “conceptual transcription” following each interview by listening to the recorded interview data in its entirety and making notes of key concepts around which to build further investigations. I used these lists of concepts as input when designing interview guides for subsequent interviews, to cross-pollinate the two case studies and ensure rich coverage of themes across both organisations.

Once the first stage of interviewing was complete, I set about a full transcription of the recorded data. Of the 19 recordings which were fully transcribed, I carried out 13 of the transcriptions myself. I was then able to recruit a transcriber with a background in digital media, who transcribed the remaining six recordings. Given the specialist nature of the interviews, even though I used the services of a technically literate transcriber, I checked the transcriptions carefully against the audio on receipt. The transcription was entirely manual, with no voice-to-text software used. The level of transcription was aimed at

capturing themes, processes and macro-meanings, to support later thematic analysis. Transcriptions were literal, but to enhance clarity in the transcribed data, I did not record performance quirks such as stuttering, repetition and non-verbal utterances such as pauses when they were not relevant to the thematic analysis for which the data was intended. Laughter was noted only when prolonged. Conventional written punctuation was employed to best capture the rhythm and metre of the spoken utterances. Where interviews were interrupted with non research-related matters, the interruptions were not transcribed.

### **3.4 Data analysis**

Once I had transcribed all of the interviews my research corpus was complete and I was able to begin the work of thematic analysis. In this section I describe the processes I undertook in order to create the thematic analysis which I present in Chapters 4 and 5 of this thesis. These included creation of case summaries, low level thematic coding, and two passes of thematic analysis.

#### **3.4.1 Case summaries**

Following the procedure outlined by Flick (2002: 186) for thematic analysis, I created a series of case summaries, one for every interview. This process helped to orient me as a researcher to the broad themes and concerns of the informants. I include these case summaries in Appendix B, where they may serve three distinct functions. The first is to provide a narrative orientation for the reader to the content of the empirical work and the second to serve as a reference point listing the full range of informants, who are referred to throughout the empirical work that follows in Chapters 4, 5, and 6 by the names I give to them<sup>10</sup> in the case summaries. Thirdly, in the interests of intersubjective transparency between myself as researcher, the readers of this thesis, and the study informants, the

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<sup>10</sup> I have changed the names of participants throughout the study to protect the anonymity of the individual participants and their organisations. A full list of informant names and roles can be found in Appendix A.

case studies seek to represent the communicative intent, or illocutionary force, directly expressed by the informants within the interview discourse. This view has a rather different flavour to that presented in the detailed thematic analysis, the illocutionary force of which is largely my own. The high-level view of themes in the case summaries defines and elaborates the concerns of the contributing interlocutors on an individual level, in broad relation to the conceptual framework I set out in Chapter 2, and serves as a counterpoint to the lower-level thematic analysis which follows in Chapters 4 and 5.

Many topics and themes emerged from the series of interviews and workshops across these very different, yet related, organisations, some of which I will now briefly relate to the conceptual framework and research questions introduced in section 2.8 of Chapter 2. Informants expressed concerns around issues of mutual understanding, both with healthcare interlocutors such as clinicians and patients and with those from different informational disciplines within whom they collaborated, which spoke to the key concept of *communicative transparency* and suggested that the pragmatics-based approach of this study would prove fruitful. The highly collaborative complex social processes, spanning many disciplines, that were described by informants suggested a rich seam of data on which to build an account of the *structure of digitally mediated healthcare discourse*. The high degree of engagement from all informants, and their informed and articulate contributions, strengthened their positioning as interlocutors in the healthcare discourse. Informants demonstrated a high degree of reflexivity with respect to acts of communication, which boded well for my intention to build a reflexive account of *interlocutor models of communication*. Finally, many informants spoke of the expense and effort involved in the creation of digital media artefacts, pointing to the key concept of *digital materiality*.

Informants displayed a high degree of appreciation for the contributions of other disciplines, and collaborative relationships were presented as respectful, harmonious, even, at times, affectionate. In consideration of the core research question – *Can digital mediation increase the transparency of healthcare communication?* – I felt no doubt that the informants in this study, committed as they appeared to be to the success of their

products and projects, would keenly want the answer to be “yes”. But, bearing in mind that the interviews were all based on the same interview guides, the large differences in the themes and foci of the different informants which could be seen even at this level of analysis suggested that the answer might not be so straightforward.

The case summaries can only give the broadest indication of the themes that were to emerge from a detailed examination of the research data. The process of reaching that detailed examination is described in the next sections.

### **3.4.2 Thematic coding**

In order to identify themes to support a precise comparative analysis, I coded the data at the level of the sentence, or short passage, so that the data could then be collated and examined at a level beyond that of the individual case (Flick 2002: 186). Before I began coding, I created a highly generic draft schema. This was quickly modified as I began to grapple with the data, but for completeness I include the initial top level nodes here:

- Entities: Real-world phenomena as presented by the interlocutors. By coding at this level, I hoped to collate different interlocutor representations and perspectives on the same real-world phenomena
- Properties: The characteristics ascribed to real-world phenomena by interlocutors. By coding at this level, I hoped to highlight differences in perspectives on these phenomena.
- Relationships: Patterns and associations arising across perspectives on multiple phenomena.
- Processes: Complex chains of communicative actions.
- Outcomes: Real-world implications of the differences in perspectives and their relationship with communicative actions.

Once I had uploaded the data into NVIVO and began coding, I quickly realised that the higher level concepts of properties, relationships, processes, and outcomes would require a lot of pre-analysis in order to code them reliably. The purpose of the coding, at this stage in the analysis, was to cast an early light on the various themes introduced by the

different interlocutors. With this in mind, I recognised the risk of skewing the findings by a too-hasty mapping the detail of the data to complex constructs in the theoretical framework. For this reason, after some false starts, I recommenced coding only at the level of the entity, leaving the higher level concepts to emerge from the thematic analysis, as reported in Chapters 4 and 5, and in the synthesis with the theoretical framework, covered in in Chapter 6.

I limited the first pass of data coding to the easily defined and distinguished “entities” section. As the coding progressed, the sub nodes of the entities section of the schema were progressively reworked in response to the concepts that emerged from the data. When the first pass of coding was complete, the top level entities schema had developed into the following, with each of the sub nodes at the head of its own hierarchical tree of sub nodes: *functional roles* / *information artefacts* / *healthcare*.

The data was generally coded at sentence level and above, and the purpose was to capture insights into the perspective of the speaker on each coded concept to inform later thematic analysis. During coding, I worked through one sub node at a time, starting with functional roles, followed by healthcare, and leaving information artefacts, by far the largest and most complex set, until last. I began coding by adding in a relatively small number of sub nodes that I expected to encounter; for example, under “functional roles” I started by adding “author”, “editor”, “graphic designer”, and “developer”. During the course of the empirical work the coding schema grew rapidly as I captured, contextualised, and coded entities emerging from the transcribed interviews. No higher analysis was attempted until the full data set was coded at this low level, though I made notes on the emerging themes throughout. Once the full dataset was coded to this level, and the schema was complete<sup>11</sup>, the next level of analysis began.

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<sup>11</sup> The complete coding schema for both functional roles and healthcare can be found in Appendix C. I have not included the coding schema for information artefacts, since it is large, and many of the terms are included in the analysis of information artefacts in chapter 6. In the list in Appendix C, the frequency count of each coded node is included in brackets after the name of the node.

### **3.4.3 Thematic analysis: first pass**

I began my thematic analysis with an examination of the healthcare terms. At this stage in the research, I still considered healthcare, and specifically disease, as the centre of the research. Though disease may indeed have been at the centre of the research, it turned out to present a rather invisible core, and once the interview data was coded, I was left with relatively few explicit references to disease. The total number of references in the interviews to disease and healthcare topics was low, with only 218 references in total across the 19 interviews. Though this might seem surprising, given that disease provided the primary subject matter and impetus for the both of the organisations in the study, it was perhaps less so given that the interviews focused largely on the processes and practices carried out by the informants as they created digital healthcare information, rather than on the subject of that information, so mentions of disease were for the most part incidental. Nonetheless, some mentions of disease did make their way into the discourse and these provided a useful contextual orientation to the rest of the data gathered, since the context of disease and healthcare was a constant factor for informants whether or not it was explicitly mentioned in the interviews. Although strong stories and themes were emerging from the data on informational processes and practice, I felt the lack of the disease context, and whatever the reasons for its absence in the interview discourse, I felt that it should be recognised.

In order to bring a flavour of this context to the analysis, and given the lack of supporting interview data, I turned to the content published by the charity and the publisher. This constituted a very large volume of data. As my aim was to flesh out a context for the interview data, rather than ploughing through a detailed textual analysis, I chose to do an analysis of key terms, starting with the titles of the articles and booklets published by the organisations. This part of the research looked at the output of the two organisations, with the aim of establishing the degree of overlap between their subject matter. With such differing organisations and perspectives, I wanted to establish to what extent their spheres

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of interest were related. Given the differences in the organisations, I expected to find significant divergence in their portrayal of disease and healthcare.

I first did a side-by-side comparison of the two title lists which amounted to around 1500 items in total. Where I found an immediate correspondence across the content at the title level, I assumed a level of correspondence between the content of the articles. With a reduced list of titles that had no apparent correspondence, I then used the search functionality provided by the organisations themselves to look for correspondences at a lower level within the content data. With such a large volume of data to deal with, I was not concerned with a detailed comparative analysis of the scope and perspective of the sets of content, but simply with establishing whether the topics of interest were the same. Working in this way, I was able to establish a much shorter list of the divergences between the coverage of the content sets. The remaining divergences which, once the narrower disease range of the charity was taken into account, were all aspects covered by the charity, and not by the publisher, were limited to three categories: “Complementary Therapies” (34 topics), “Daily life” (3 topics), and “Your stories” (1 topic).

Although there was a sizeable divergence in the range of complementary therapies mentioned by the charity and the publisher, with 34 omissions by the publisher, this was offset by the 13 complementary therapies that were covered by the publisher. Some other complementary therapies from the charity’s list, although missing from the publisher’s coverage of the charity’s disease area, were mentioned by the publisher with regard to other diseases. One explanation might be that the publisher, as a provider of evidence-based information, was more likely to cover those interventions which had been subjected to scientific investigation in relation to specific diseases. The charity had the slightly different aim, of helping sufferers from a particular disorder to make sense of it within the context of their everyday lives. Therefore, the charity could be seen to have a duty to cover those complementary therapies that, though relatively unproven and untested, might be encountered in shops, in conversation, on the internet, or via other means. Some might suggest, though I would argue it would be simplistic, that the material created by the publisher lacked cover of the impact of disease on daily life

because such lifeworld concerns were not relevant to a medicalised perspective. This argument was undermined for me by the fact that, while three “Daily life” topics were missing from the publisher’s coverage, another nine were matched by the publisher. Similarly, the topics of 25 “Your stories” were matched with content from the publisher, the solitary exception being an article about trekking to Machu Picchu as a sufferer from chronic illness which had no equivalent in the publisher’s content.

The publisher used conditions and symptoms as its primary means of organising the material it created, while the charity, working within a more tightly bounded group of conditions and symptoms, organised its content around a broader set of classifications. Whereas the publisher covered a wide range of conditions in a standardised format, the charity covered a narrower range of conditions from a broader range of perspectives. Despite the divergence of coverage this suggested at a superficial level, deeper analysis suggested that the difference lay largely in information design, navigation, and titling, rather than in any deeper difference in the institutionally held concepts of disease.

I next attempted a small scale thematic analysis of concepts of disease and healthcare in the interview data. Here there was indeed a difference in the way the two organisations used disease terms. Informants at the charity used disease terms largely to refer to disease entities in relation to the impact of disease on everyday life. Thus, according to my analysis of the data, for those working at the charity, the disease they covered was *disruptive, ubiquitous, chronic, and varied*, whereas other diseases were more *glamorous, newsy, and headline-grabbing*. In contrast, when the information specialists, editors, and developers at the publisher talked about conditions, it was in relation to information structures, either as shorthand for the informational artefacts referring to those conditions, or in terms of the standardised terminologies used to describe them within information systems. At the publisher, codes, terms, and titles of informational artefacts were used interchangeably with the real life conditions and interventions they described.

I ended this phase of the research by concluding that concepts of disease and healthcare, although undoubtedly a key context of the research, were not directly observable in the

empirical data to hand in any meaningful way. The data had been gathered in environments concerned primarily with publishing activity, rather than in clinical situations. Concepts of disease and healthcare are, therefore, not directly analysed in this research, but should be considered to form an important aspect of its background.

#### **3.4.4 Thematic analysis: second pass**

In my second pass at thematic analysis, I turned my attention to the nodes concerning functional roles, and those concerning artefacts. Once again, faced with a large volume of data, I elected to use frequency counts of the instances of terms and phrases to render the data more tractable and point me towards the most productive avenues for analysis. I decanted the coded data from NVIVO and imported it into Excel where I was able to sort and filter each piece of data by the organisation and the role of the informant who had provided it<sup>12</sup>.

Figure 3.2 presents a top-level view of the categories of roles mentioned by the informants in their interviews. The frequency counts I used here acted as a type of navigational tool, highlighting active areas of thematic reference for further exploration. In all cases, references by the informant to their own role were removed from the figures in the diagram below, so the chart represents the view of other roles, from the perspective of the informants. Although there is an apparent imbalance between the organisations, in that the study did not include data from specialist technical suppliers to the charity, in fact at the time of data collection the charity did not have such suppliers, so the data collected is a robust representation of the more restricted network of interlocutors associated with the charity compared with the publisher.

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<sup>12</sup> Appendices D and E present example screenshots of the data analysis carried out in Excel.

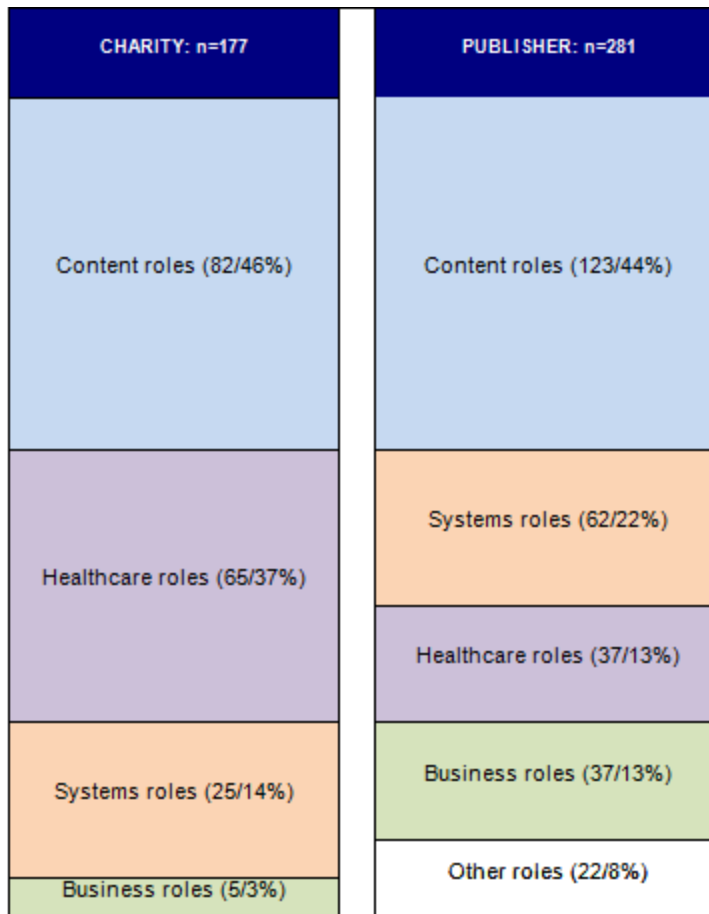


Fig. 3.2: Categories of interlocutor roles mentioned by information professionals, divided by institution

There are several unsurprising aspects to the figures presented above:

- Content roles dominated discussions across both organisations, as expected, given that the business of each organisation was the creation and dissemination of content, and that the informants were directed to focus on this work in their interviews.
- Business roles did not feature heavily in the discourse of those informants connected with the charity, but were more prominent in the conversation of those informants linked to commercial organisations.
- Systems roles featured relatively little in the interviews of the charity informants, consistent with the early stage this organisation was at in its digitisation trajectory, and the small size of the technical team it was able to call upon. Those working in the more

digitally-experienced publishing company, which had a large and active technology department, spoke more about systems roles. When the perspectives of their specialist technical suppliers were factored in, the place of systems roles in the publisher's discourse became even more prominent.

More worthy of comment is the way that as systems and business actors entered the discourse at the publisher, it was the healthcare actors that made way for them. The proportion of content actors remained consistent across the two organisations; its proportional drop in the discourse across the wider network of the publisher and suppliers was balanced by the suppliers' mentions of roles outside of the categorisation presented here. These were generally specialist roles held by non-publishing clients of the suppliers. The frequencies in Figure 3.1 raise the question of whether the wider focus of the discourse in the publishing group might favour systems and business actors at the expense of healthcare actors, with developers and business managers displacing doctors and patients in the perspectives of those engaged in the communicative activity of producing digital medical information.

These initial findings aside, further coding ruled out a more detailed comparison between the organisations as unproductive. Themes tended to have remarkably even coverage across the two organisations. Where they did not, the reasons were generally obvious, such as those from one organisation talking more about patients than the other, because we were discussing the patient information of the first, and the clinically facing information of the second. Notable and consistent numerical differences did appear, however, in the distribution of themes between the broad informant expertise groups (content, business, and systems). Encouraged by this, I organised the data along that division in preparation for the full thematic analysis. The use of these expertise groups as an empirical object helped to avoid the limitations of a presentation based purely on individual perspectives.

In Table 3.3, I use the example of the emergence of “becoming expert” as a sub theme within expertise to illustrate my use of frequency counts to identify areas of interest for

the deepening thematic analysis. The table illustrates the way the key theme of expertise emerged from the data in three broad categories; *expert*, *inexpert*, and the transitional process of *becoming expert*.

Table 3.3: References by information professionals to expertise in relation to healthcare roles			
	Healthcare professional	Nonprofessional (patient, carer)	Total
<b>Expert</b>	17	6	23
<b>Inexpert</b>	19	16	35
<b>Becoming expert</b>	16	26	42

Perhaps surprisingly, in this highly specialised knowledge context, *expert* was the least referenced of the three categories overall in relation to healthcare roles, with 23 references. *Inexpert* was the second most commonly referenced category with 35 references overall, while the most referenced category was *becoming expert*, with a total of 43 references. This focus on the process of gaining expertise, rather than the state of having achieved it, brought into focus the core objective shared by both the charity and the publisher, which was to disseminate factual information; in essence, to distil, cultivate, disseminate, and promote expertise.

I used progressive filtering within Excel to identify patterns such as these in the distribution of themes of expertise and artefacts across the responses of the expertise groups. I then further codified these patterns as the themes that underpin the empirical presentation in Chapters 4 and 5. In these themes, the higher level concepts which I had set aside in the low-level NVIVO coding began to re-emerge. The final high level thematic structure, elaborated in Chapters 4 and 5, emerged as follows:

- Specialist roles in digital healthcare publishing: dimensions of expertise
  - Dimensions of expertise perceived in healthcare roles
  - Dimensions of expertise perceived in content roles
  - Dimensions of expertise perceived in systems roles
- Information artefacts: proxies in the sharing of healthcare meanings
  - Perceived intent in information products

- Perceived action in information products
- Perceived materiality in information products

Once I had created a broad thematic structure, I worked through the coded, rearranged data. For each subtheme, I created data tables to show the categorised themes from the interviews and populated these tables from the grouped themes in my thematic spreadsheet. As far as possible, while still preserving clarity for the reader, I used terminology from the interviews themselves to populate these tables. Condensed extracts from these tables form the basis of the empirical presentation in Chapters 4 and 5. Once the tables were complete, I wrote discursive comment on the data they presented. Selections from this comment are also included in Chapters 4 and 5. Finally, as presented in Chapter 6, I took the empirical findings presented in Chapters 4 and 5 and elaborated them in relation to the theoretical and conceptual framework outlined in Chapter 2.

#### **3.4.5 Relationship of the interview data to the communicative baseline**

In section 3.1 of this chapter, I referred to the concept of the communicative baseline introduced in Chapter 2, and announced my intention to focus my empirical work not on the direct examination of this baseline, which is located in face-to-face healthcare encounters, but on the digital mediation of healthcare meanings. Despite my own empirical focus on mediation, the communicative baseline provided a constant contextualising backdrop to the interviews. In this section, I address that relationship.

The two organisations at the heart of the study, the publisher and the charity, could be considered as specialist healthcare contexts, as defined in Chapter 2, section 2.4, since the information they produced was exclusively on the specialist subject of healthcare and destined for use either by healthcare professionals, or by patients or carers. But as specialist healthcare contexts go, these were rather unusual in that they were populated by many actors taking neither a clinician nor a patient role. While both organisations made use of clinically qualified staff, including currently practising clinicians, in the creation of their materials, only one of the informants in these interviews was clinically qualified, and that one had never practised medicine. As a result of this unusual profile, these

interviews demonstrated perspectives of healthcare from a viewpoint of neither clinician nor patient, but which was, all the same, highly specific to healthcare.

The interviews focused on the creation of information, and consequently the overwhelming majority of references to healthcare roles (96 out of the 109 quotes chosen for thematic analysis) were made in relation to informational processes. The remaining references to healthcare roles independent of their relationship to information provided a slim insight into the perspectives of the informants on the world of healthcare beyond the context of digital publishing. The world of day-to-day healthcare, enacted in clinics, hospitals, and in the homes of patients, was at least one step removed from day-to-day concerns of the informants in this study. That day-to-day healthcare world is, however, both the home of the classic healthcare encounter which serves as the communicative baseline of the study, and the home context of the patients and clinicians who are the users of the information products created by the informants in this study. For that reason, to maintain the relationship to the communicative baseline and the focus on the users of the information products, before I present my findings on digitally mediated healthcare discourse it is important to sum up this view from information providers of the healthcare context beyond the world of digital information.

The majority of references to healthcare outside of the context of the creation of digital information (11 out of 13) came from the charity, and of those, nine from a single informant, the educational consultant Eve, whose role it was to envisage the needs of the users of information, the contexts in which it would be used, and to what purpose, in order to inform the approach taken by the organisation in its educational and publishing programme. At the time of data collection, Eve's view represented an important window for the charity on the external context that its products were designed to serve.

Eve presented clinicians (2 references) in a clinically defined, process-driven role – “to diagnose, to look at the symptoms, to prescribe, to refer” – but also as entering into long-term relationships with the chronic patients under their care. She presented other



health professionals (2 references) in relation to patients and defined their role in terms of the physical and emotional support they offered.

In line with the charity's focus on chronic illness, Eve defined patients (4 references) in relation to their disorders, but not in relation to a single disorder; rather by a range of long term, comorbid ailments which patients needed to be helped to learn to endure, rather than be cured of. To balance this perspective, Eric, the education and publishing manager, highlighted the medical research goals of the charity, including the search for a cure. In this non-informational context, Eve described patients as dependent on carers and health professionals and as recipients of help and support, a perspective which was also found in the contribution of Gerry, the graphic designer, who spoke of patients being hospitalised in the course of their treatment, and even dying.

Only two comments on healthcare beyond the informational context emerged from the publisher interviews and they were both decidedly "unclinical" in focus. Ivan, the information technologist employed by the publisher, spoke of the institutional structure imposed on healthcare by organisations such as Royal Colleges, whereas Theo, the technical director of the systems provider who created the content management system used by the publisher, spoke of clinicians in terms of their expense in relation to a project he had worked on with a health insurance company.

On the whole, there was little explicit consideration in the interviews of the lives, concerns, and hierarchies of clinicians, patients, and associated roles beyond their engagement with healthcare information. Those sparse perspectives I have reported above seemed conventional and distant, lacking the punch of deeply-felt lived experience. This conventionality and distance evaporated when healthcare roles were discussed in the context of informational work. This creates an opportunity, if not an obligation, to elaborate an understanding of healthcare roles in the context of medical information which is distinctly different from the ways these roles might be positioned in their more familiar, day-to-day healthcare contexts. I begin that elaboration in Chapter 4.

In this chapter, I have described the rationale and methodology I followed in operationalising the conceptual framework developed in Chapter 2. In Chapters 4 and 5 I present my detailed analysis of the themes of *expertise* and *artefacts*, as derived from the coded interview data.

## CHAPTER FOUR

### Specialist roles in digital healthcare publishing: Dimensions of expertise

#### Introduction

Digitally mediated healthcare information, such as that which is disseminated by websites or other technological systems, can only be created by drawing on a diverse range of expertise. In this chapter, I examine the theme of expertise, as it emerged from my interviews with informants at the charity and the publisher that were my case study organisations. In Chapter 2, section 2.2, I introduced the notion of expertise as a type of mediating context for communication. In that section, I used the example of clinical expertise to demonstrate how expertise created expectations around the intent of utterances and, thus, played an active role in shaping the intersubjective sharing of meaning. In section 2.5 of Chapter 2, I presented a broader range of expertises brought to bear in the digital mediation of healthcare meanings and in section 2.8 I introduced the notion, as a key part of the conceptual framework, that these diverse expertises can be understood to shape the *structure of the digitally mediated healthcare discourse* into a layered discourse. The data presented in this chapter will inform answers to the first set of my empirical research questions introduced in section 2.8 of Chapter 2:

*What kinds of **specialist expertise** are involved in the sharing of digitally mediated healthcare meanings? How are these forms of expertise characterised, and how do they interact?*

I begin the chapter with a summary of the structure of the digitally mediated healthcare discourse as it relates to the spheres of expertise that emerged from the empirical work. I then consider, in turn, healthcare expertise, content expertise, and systems expertise, as these emerged from the data. The analysis examines the expertises at work in healthcare information through the eyes of actors engaged in that work. There is no single or objective viewpoint to be found here, and none was sought. All of the informants in the

study were involved in, and actively contributed to, the world of healthcare information provision and each informant occupied his or her own position on one or more of multiple continua of expertise. The thematic analysis that follows therefore presents reflexive highlights of those aspects of the interplay of expertise in the creation and dissemination of healthcare information which might influence or shape the communicative transparency of that healthcare information.

A full list of names and roles of informants can be found in Appendix A.

#### **4.1 The structure of the digitally mediated healthcare discourse**

The range of expertises that emerged from the empirical data in this study included specific healthcare expertise, such as the clinical expertise held by qualified physicians, but extended far beyond this. A range of informational expertises were also actively engaged in the discourse. These expertises, which included editorial, graphic design, information systems, and others, were distributed across the range of human actors involved in creating and disseminating healthcare information for the publisher and the charity. All informational work involves specialisation, healthcare information work perhaps more than most, and the level of specialisation required in this work meant that the distribution of the different expertises at play across the actors who hold them was necessarily uneven.

I have grouped the actors in the study into four broad expertise-based groups, or “communities of expertise”, as follows:

- Healthcare roles
- Content roles
- Systems roles
- Business roles

The structure of the study is such that each of these “communities” could have provided both informants and subject matter, but practical limitations meant that coverage across the potential matrix of informants and subject matter was not exhaustive. Table 4.1

summarises the coverage on which the analysis is based. No healthcare actors (with the exception of one clinically-qualified editor, who acted primarily as an informational actor) were interviewed, so the direct perspectives of healthcare actors outside the creation and dissemination of healthcare information were not captured. Business actors were interviewed, and so their perspectives on the expertise of the other groups have been captured, but due to the structure and focus of the interviews, there was insufficient data on the expertise held by the business roles themselves to support an analysis.

Table 4.1: Coverage of informants and subject matter in the collected data				
SUBJECT MATTER	INFORMANTS			
	Healthcare	Content	Systems	Business
Healthcare expertise	no	yes	yes	yes
Content expertise	no	yes	yes	yes
Systems expertise	no	yes	yes	yes
Business expertise	no	no	no	no

As presented in table 3.3 in section 3.4.4 of Chapter 3, the theme of expertise emerged from the interview data in three broad categories:

- expert, expertise
- inexpert, lack of expertise
- becoming expert (transitional process between inexpert and expert)

The focus on the process of gaining expertise, rather than the state of having achieved it, chimed with a core objective, shared by the charity and the publisher, which was to disseminate factual information on healthcare topics; in essence, to distil, cultivate, disseminate, and promote expertise itself.

The “communicative baseline” for this research was defined in section 2.2, Chapter 2 as the *classic healthcare encounter* enacted by face-to-face discussion of healthcare topics. The classic healthcare encounter perhaps most typically occurs between healthcare professionals and non-professionals such as patients; in this case, it might be considered as a specific subtype, the *classic clinical encounter*. But healthcare meanings are exchanged in a wider range of contexts than the purely clinical, so classic healthcare

encounters might also take place between non-professionals, for example patient-to-patient or patient-to-carer, or between professionals, peer-to-peer. In order to provide clear structural alignment with this communicative baseline, the thematic analysis that follows is organised in layers, ordered by proximity to the communicative baseline. Hence, the first section of the analysis examines the perspectives of the study's informants, all of whom were information workers, on expertise in healthcare roles. The second section examines informant perspectives on content roles, which are presented as providing another layer of mediation to the central, classic healthcare encounter. The third and final section examines informant perspectives on systems roles, which are presented as providing yet another layer of mediation to the classic healthcare encounter.

## **4.2 Healthcare expertise in the digitally mediated healthcare discourse**

The data presented in this section represents the perspectives of the study informants, all of whom were information workers, on the expertise of those who hold healthcare roles. Consistent with the discourse framework I introduced in section 2.6 of Chapter 2, I position these healthcare actors as *interlocutors* in the broad healthcare discourse.

*Professional roles cited:* clinician / nurse / doctor / AHP (allied health professional) / specialist<sup>13</sup> / consultant / physio / GP / general practitioner / medical student / health professional

*Nonprofessional roles cited:* patient / carer

### **4.2.1 Dimensions of clinical and health expertise perceived in healthcare interlocutors**

In this research, the exploration of healthcare “domain expertise” is divided into the formal clinical expertise held by healthcare professionals, and the broader experiential expertise gathered by non-professionals such as patients in the course of their illness and

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<sup>13</sup> Term “specialist” used in favour of named specialist role to protect the anonymity of the participating organisation.

care. This experiential type of healthcare expertise is termed “health expertise” in this study. I begin by examining dimensions of clinical expertise. Themes related to clinical expertise held by healthcare professionals, broken down by informant role, are summarised in table 4.2.

<b>Table 4.2: Themes from references to dimensions of clinical expertise held by healthcare professionals, categorised by the informant group</b>			
<b>dimensions of expertise</b>	<b>content perspectives</b>	<b>systems perspectives</b>	<b>business perspectives</b>
<b>clinically expert</b>	<ul style="list-style-type: none"> <li>determining how knowledge relates to patients</li> <li>drawing on evidence, opinion and experience to make decisions</li> <li>creative people out there working</li> <li>bright, cutting-edge, knowledgeable</li> </ul>	<ul style="list-style-type: none"> <li>knowledge holders</li> <li>using “clinician-speak”</li> <li>answering questions that fall outside databased answers</li> </ul>	<ul style="list-style-type: none"> <li>specialist perspective</li> <li>deciding what is good or not</li> </ul>
<b>clinically inexperienced</b>	<ul style="list-style-type: none"> <li>doctors who don’t work clinically, but do research</li> </ul>	<ul style="list-style-type: none"> <li>doctors getting it wrong</li> </ul>	
<b>becoming clinically expert</b>	<ul style="list-style-type: none"> <li>seeking answers to particular clinical questions</li> <li>gathering background knowledge through medical study</li> </ul>	<ul style="list-style-type: none"> <li>becoming equipped with the most current and the most accurate information</li> <li>learning evidence-based knowledge and best practice from information products</li> </ul>	<ul style="list-style-type: none"> <li>being supported in decision-making by information systems</li> <li>using textbooks</li> <li>learning incidentally from patient information</li> <li>learning practical medical skills from interactive simulations</li> </ul>

All of the references to healthcare professionals as experts related to aspects of their clinical domain expertise, and it was informants in content roles who made most references to this; specifically, Elle, the clinical editor working for the publisher, and Eve, the educational consultant working for the charity.

Elle was herself medically qualified, although she had never practised medicine, and provided a more specific and in-depth perspective on clinical expertise, in which she highlighted the bridging role held by clinicians between the generalised expertise provided by their training and reading of research evidence, and the specific application of that expertise to the individual patient:

*You have your background knowledge, that you have gathered through your studies, and your continuing professional development, and so on, but you have to manage your patients and make decisions for the individual patient (...) you not only read about a condition or a treatment, and about the effectiveness of the evidence, and not only try to think about how other patients have reacted to certain treatments, and what you've heard from other colleagues and so on, but also try to determine how all of that knowledge relates to this patient in front of you.*

Elle emphasised the importance of the clinician's personal, localised, real-world expertise when generalised expertise gained from research evidence was missing, ascribing to clinicians an explorer role:

*it is always of value to know that if you don't know anything from research, it's not because you haven't read it, it's because there is none (...) But also, it's also important for clinicians to be aware that in these cases, they have to rely on other sources. Either on observational studies, or on opinion, experience, or just, you know, it's new frontiers for them*

Eve's perspective on clinical expertise was more oblique; she spoke of the expertise of doctors, nurses, and allied health professionals on a rather general level, in categories such as "bright", "knowledgeable", "intuitive", and "creative". In addition to aspects of clinical expertise, Eve made reference to the experiential, intuitive expertise offered by some allied health professionals which she contrasted with the more evidence-based expertise of physicians:

*AHPs would say well, I suppose we've got to go a long way to prove that this makes your pain better. What we do know is just the way people, it keeps them going better*

Eve also situated clinicians as having expertise beyond that required by their specialist clinical role:

*they're very bright people about their medicine, whatever it is, but they're also very bright people about lots of other things as well*



In contrast to the content informants, when the systems informants spoke of the expertise of clinicians, it was in relation to formal or structural aspects of information. Ivan, the information technology manager at the publisher, spoke of clinicians as specialists, having their own language (“clinician-speak”), while Chris, the systems implementation consultant, identified them as the generators of the “knowledge” which he incorporated into systems:

*maybe there is a medical doctor who says okay, chemotherapy is not suitable for infants. And when that's always the case, or you can say please apply this rule, that's knowledge*

Theo, the technology director at the systems development company, spoke of the role of clinicians as escalation points when systems could not fulfil informational demands:

*next to the database, they have like maybe three or four, well, experts, general practitioners themselves, who answer questions that fall outside of the database*

From the business side, Eric, the education and publications manager at the charity, talked of clinicians in terms of their specialist perspective which defined the nature of their contribution to materials development; he described expert contributors to the work of the charity as “having a view *as a specialist*” (my emphasis); a specialism which both enables, giving the specialist a voice in the decision making process, but here also limits, by restricting the scope of that input to the purely clinical. Ben, the business development director at the systems development company, placed clinicians, the customers and end-users of the information products his systems supported, firmly in the role of decision makers: “At the end it’s always the doctor that decides what’s good or not, not the application”.

When looking at references to the inexpertise of health professionals it is important to recognise that in the organisational contexts in which the informants worked, the state of inexpertise did not necessarily have a negative connotation. These were environments in which every gap in expertise was seen as an opportunity to devise new informational or educational methods to plug it. On the theme of perceived lack of clinical expertise, Ivan, the information technologist, referred to “huge numbers of stories where people state that

their GPs or their hospital doctors have got it wrong”, going on to cite his company’s information products as a route to restoring the lost trust between patients and doctors. Elle, the clinical editor, drew attention to the lack of real-world clinical experience of many researchers, leading to a mismatch between the informational needs of practising clinicians and the output of research:

*research is not only done by clinicians, and in a clinical setting (...) There are doctors who don’t really work clinically (...) who don’t practise, necessarily, or who may work in a hospital, but they do mainly research, and then have just one or two clinics, and then have their special focus in research. Unfortunately, these two don’t necessarily match.*

The transitional process of “becoming expert” was the home territory of the contributing organisations, and informants from all groups had plenty to say. Elle, the clinical editor, described clinicians’ gaining of expertise as an active process on their part, in which formal education was only part of a mosaic of learning experiences, with medical school merely the place where clinicians “gathered” “background knowledge”. She described clinicians as actively seeking answers from research to specific clinical queries arising from their practice:

*It can be quite difficult to bring together the questions that are relevant for clinicians and questions that have been looked at in research studies. And I had an example of that, for example, when looking at febrile seizures in children. So for example as a clinician, you would want to know what should you do if a child comes after a first seizure, or after sort of the second seizure, so it is something that is recurring. Whereas studies will not have made that distinction, necessarily.*

Ivan, the information technologist, presented a slightly different slant. Unlike Elle, his professional background was in information systems, not in the healthcare world, and so he had no immediate experience of the clinical contexts in which the products he worked to support were used. In contrast to Elle’s model of the clinician as an active seeker and gatherer, Ivan described the aim of his organisation as to “deliver” knowledge and to “equip” users with information:

*to deliver innovative, useful, evidence-based knowledge, best practice and learning to doctors, other health professionals, researchers, and patients when and where they need it (...)*

*to provide the information such that both the patient and the clinician are equipped with the most current and the most accurate information such that that relationship of trust is re-established*

The business informants were accustomed to modelling the use of the products their companies created, in order to ensure that the products were seen as successful. Ben, business development director at the CMS (content management system) development company, spoke about the “help” offered by informational products in the form of “decision-making support”, while Eric, education and publications manager, described the incidental learning which took place, with clinicians improving their own skill and understanding from exposure to educational materials designed for their patients:

*the information that we put out there (...) primarily aimed at patients, actually also ends up educating, helping to educate (...) health professionals*

Eric talked about the use of textbooks as an information source for health professionals, and also about more “interactive”, digitally-mediated educational products.

*it's got this interactive aspect (...) and it works quite well, (...) it did turn out to be quite an interesting piece of software, (...) but the question of (...) whether it's genuinely useful for a medical student, is another question, I think. (...) I'm not saying that they'd learn any more from a book, (...), I doubt they would learn as much as from a consultant sitting down with them. (...) If you're going to put interactive things in (...) where is it worth spending the resources.*

In the next section, I examine informant perspectives on dimensions of healthcare expertise held by non-professionals such as patients and carers. Themes related to this type of expertise, broken down by informant role, are summarised in table 4.3.

Table 4.3: Themes from references to dimensions of healthcare expertise held by nonprofessional healthcare roles categorised by the informant group			
type of expertise	content perspectives	business perspectives	systems perspectives
becoming expert in healthcare	<ul style="list-style-type: none"> <li>• long term sufferers from chronic conditions building up detailed knowledge of their particular condition through personal experience</li> <li>• learning to recognise signs of disease to report to doctor</li> </ul>		
	<ul style="list-style-type: none"> <li>• seeking healthcare information from multiple sources</li> <li>• being better informed leading to less anxiety and feeling better</li> <li>• learning about conditions to prepare for communication with consultants</li> <li>• information empowering patients to be less of a drain on the NHS</li> </ul>	<ul style="list-style-type: none"> <li>• learning from patient information booklets</li> <li>• learning from media such as television</li> <li>• newly diagnosed patients seeking general information</li> <li>• long-term patients seeking particular detailed information</li> </ul>	<ul style="list-style-type: none"> <li>• learning from published information</li> <li>• patients making decisions based on information from multiple sources</li> <li>• using information to improve patient understanding</li> </ul>

One of the core aims of the charity Eric and Eve worked for was to provide patient education for a particular chronic illness, and both spoke about the long experiential and informational journey sufferers from the condition made from being diagnosed, described here in Eric's words:

*you might get somebody coming along who's completely distraught because they've just been told they've got (name of condition<sup>14</sup>), and they don't know anything about it, and they think it's going to be, you know, destroy their life (...). But you've got somebody else who might have had it for ten years*

Eve spoke of the way the changing experience of having the condition might mean the same information is interpreted differently at different points in the journey:

*even the same sentence, you might read it in a different way two years down the line, because it's now relevant to you, or you've understood that better*

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<sup>14</sup> The actual name of the condition has been replaced to protect the anonymity of the participating organisation.

All three informant groups, content, business, and systems, talked about patients learning about their condition from health professionals, and from the information provided by their organisations. In addition, both Eve, educational consultant, and Chris, technology implementation consultant, talked about patients actively seeking knowledge from other sources. Chris's words, below:

*if you look at medical situation, of course you can give some advice from some doctor, but for example when a parent have to make a decision, normally he listen to the doctor but he listen also to all his friends, anything you can think of, maybe a newsletter or whatever*

Eve highlighted the benefits she saw in such information-seeking:

*(...) People were going to other places anyway. And (...) it didn't particularly cause anxieties to know other things. It caused more anxiety not to know things than it did to know them.*

*... research (...) was done on the patient evaluation, that people with more information are else anxious, and that their pain is less. And their pain can't be metabolically less, but their perception of pain is less, because they feel better (...) It's all those slightly softer things about coping, which gives people a better attitude, and if you've got a better attitude, you feel better, you're more likely to cope then with the metabolic things that are happening to you*

Eve also described the way patient education could improve clinical communication between patients and doctors:

*having a specialist nurse who will spend time with the patient and, you know, show them leaflets or explain things and answer questions and so on is very valuable for the patient, and probably for the consultant as well. It probably means that the patient comes to them with a better frame of mind*

*you go to your clinic appointment next time, and maybe you're telling your doctors things that they're not asking you, so all sorts of ways, I think, people, there's this huge understanding that patient education is not only a nice thing to do, good, I mean it is actually clinically a good thing to be doing*

Finally, Eve demonstrated a strong belief in the potential of information to “empower” patients, hence, she felt, improving health and making treatment more cost-effective:

*if people are more informed they may be less of a drain on the NHS in the end. I mean that's a very long term quite difficult thing to prove, but there's some evidence that people who are empowered are much less likely to end up long term patients in beds in hospitals*

Although clinical and healthcare expertise could be seen as the defining expertises of the healthcare actors who held them, the informants in the study also referred to other expertises in relation to healthcare roles, in particular, to forms of informational expertise. These are explored in section 4.2.2.

#### 4.2.2 Dimensions of informational expertise perceived in healthcare interlocutors

This section begins with an examination of informant perspectives on the dimensions of informational expertise in healthcare professionals. There were no references to healthcare professionals as expert in this area; discussion centred on the lack of expertise, or on the process of becoming expert. This type of expertise was only discussed by informants in content roles. Themes related to this type of expertise, broken down by informant role, are summarised in table 4.4.

Table 4.4: Themes from references to dimensions of informational expertise held by professional healthcare roles, categorised by the informant group	
dimensions of expertise	content perspectives
<b>informationally inexperienced</b>	<ul style="list-style-type: none"> <li>• clinicians withholding information from patients to reduce anxiety</li> <li>• practising clinicians as creative but not grounded in delivering information products</li> <li>• clinicians unfamiliar with standardised medical terminologies</li> <li>• clinicians lacking skills in evidence-based medicine</li> </ul>
<b>becoming informationally expert</b>	<ul style="list-style-type: none"> <li>• clinicians seeking information from multiple sources</li> <li>• nurses attending EBM workshops</li> <li>• nurses and physios attending conferences to learn patient education techniques</li> </ul>

Eve, the educational consultant, described what she perceived as a historical lack of understanding some clinicians had of the informational needs of their patients:

*there was a thing on behalf of the clinicians which was don't give people too much information, it will raise anxiety levels, only tell them what they need, you know, they don't need what they need to know, we know what they need to know, and we must only tell them what we think they need to know. And that was quite a common thought among clinicians, and it's a very worthy thought, I think. I don't think they*

*were being at all protective, actually I think they genuinely thought that was the case.*

She also referred to the lack of practical expertise held by the clinical contributors to the products she worked on, highlighting the need to balance creative ideas with practical ability to evaluate and deliver information products:

*these are the bright, bright cutting edge people to have the good ideas, actually, very creative. But somehow the organisation's got to be grounded as to where to take all those good ideas, and move them forward in a way which is handleable as well*

Elle, the clinical editor, spoke about the lack of expertise clinicians and nurses might have in two areas that were central to her work. The first was in understanding the practical application of clinical terminologies, typically carried out in hospitals by clinical coders. This, which she described as a “behind the scenes” task, was not a lack that she felt need concern practising clinicians. The second area was the evaluation of research evidence:

*in former years I would have been much less critical, and consider a piece from (...) one of the products out there that are written by unqualified clinicians, and have looked at references, at the end of their pieces, and I would have been very much impressed by that. And that may very well be valid contributions, but not necessarily evidence-based as we understand it. They are reference-based, and opinion pieces, in a way. Because we really try to keep the authors in a way out of the loop of the inclusion/exclusion of the articles. (...) And this ensures that what is actually part of the review is not influenced by beliefs or preferences of the authors. Whereas these opinion pieces very much are.*

When Elle speaks about “unqualified clinicians” here, she is not suggesting that the clinicians were *medically* unqualified, but rather than they were somehow *informationally* unqualified, presenting opinions as scientific evidence to a possibly indiscriminating clinical audience. This, she felt, was a lack of expertise on the part of healthcare professionals which did need to be addressed:

*the distinction between the randomized control trial and observational evidence, and the evidence hierarchy, it's like a little pyramid of evidence, it has been, this is published. It's well known within the evidence based medicine world, it's less*

*common knowledge among clinicians (...) They need to understand. Because the higher quality your study, your evidence, are, the more reliable that piece of information will be. So it is definitely important to understand what quality your evidence is for a certain answer you are giving to a clinical question.*

Elle spoke about the process clinicians went through in becoming more informationally expert in terms of identifying gaps in research evidence and seeking out appropriate alternative information sources for themselves, thereby learning to place research evidence in a broader informational framework:

*it is always of value to know that if you don't know anything from research, it's not because you haven't read it, it's because there is none. I think that is definitely a valuable addition to knowledge. But also, it's also important for clinicians to be aware that in these cases, they have to rely on other sources. Either on observational studies, or on opinion, experience, or just, you know, it's new frontiers for them*

Both Elle and Eve described workshops they had been involved in with nurse practitioners (Elle) and nurses and physios (Eve). Elle's workshops had focused on "the basics and limitations of evidence based medicine" while Eve's had focused on a "move from information to education":

*it had all sorts of ideas on what to do with the leaflet, like you shouldn't just give it, you should sit down with somebody and say now, when you come to clinic next time, it would be really helpful if you've read the first section, and perhaps looked at the symptoms, or look, I'm just going to underline these words for you, because these are obviously key. Now that's the name of your drug you've been given, and those are the side effects they might have, and this... so you've done something with it with the patient. Or you say to them, take it home, read it with your daughter. Get your daughter to read it, and talk about it, you know, in the next week or something. So it's how you use it. And so I think we know that. Now, you know, again you can't control that, but that's about educating professionals to be better educated of their patients.*

Next, I look at informant perspectives on the dimensions of informational expertise in non-professional healthcare roles, such as patient and carer. Again, there were no references to these roles as being informationally expert; discussion was centred on the lack of expertise, or on the process of becoming expert. Themes related to this type of expertise, broken down by informant role, are summarised in table 4.5.



Table 4.5: Themes from references to dimensions of informational expertise held by nonprofessional healthcare roles, categorised by the informant group			
dimensions of expertise	content perspectives	systems perspectives	business perspectives
informationally inexpert	<ul style="list-style-type: none"> <li>patients and carers having low levels of literacy</li> <li>older patients not being well versed in using the internet</li> </ul>	<ul style="list-style-type: none"> <li>patients having a reading age of 8</li> <li>patients being undiscerning about information found on the internet</li> </ul>	<ul style="list-style-type: none"> <li>patients having low literacy level or not speaking English</li> </ul>
becoming informationally expert	<ul style="list-style-type: none"> <li>older patients having more experience of computers than 10 or 15 years previously</li> <li>including questions for patients to ask their doctors in patient information</li> </ul>	<ul style="list-style-type: none"> <li>improving the ability of patients to retain information from clinical consultation</li> </ul>	

Informants across all three categories referred to potentially low levels of literacy in patients, using terms such as “low reading ability”, “struggle with written text”, “low readers”, “not very literate.” Eve, the educational consultant, also mentioned low literacy in relation to carers. Only Eve spoke about patients in terms of their informational abilities, both in terms of independent information-seeking and in terms of their computer literacy:

*older people, now, have had more experience of usage of computers than they had ten or fifteen years ago. Because you can't say, well we won't do electronic resources because people with (condition<sup>15</sup>) are older and they can't use computers anyway. So none of that applies now, and it certainly won't apply in another ten or fifteen years*

In contrast, Pat, the production editor, described older people as “not so well versed in how to use the internet”, while Ivan, the information technologist, had little faith in the general discernment of patients in evaluating information found on the internet:

*when you're talking about patients, though, they perceive it very very differently, because they just enter a term in a search engine, and whatever comes out is*

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<sup>15</sup> Name of condition removed to preserve anonymity of informant organisation.

*considered to be good quality, trustworthy information, which is dangerous firstly and secondly probably not the best thing for them to be doing.*

Ivan also considered the potential for information to be used to improve retention by patients of what they are told in clinical consultations:

*there are statistics which say somewhere along the lines that if you go for a GP consultation you'll remember about 10% of what was actually said to you. And so the issue is how can you use information to improve the level of retention and level of understanding such that actually you'll remember 80% of what was shared with you.*

The data above presents the views of information workers engaged in the creation and dissemination of healthcare information on the healthcare roles whose interaction provides their “communicative baseline” in the form of the classic healthcare encounter. The following section looks at the perspectives of information workers on the next layer of mediation applied to this communicative baseline in the process of creating digital healthcare information products, which is the mediation provided by content roles.

#### **4.3 Content expertise in the digitally mediated healthcare discourse**

In this section I present the perspectives of the study informants on the expertise of those who hold content roles. Holders of many of these roles also acted as informants, providing data on their own expertise and that of close colleagues. This introduces a higher degree of reflexivity into the data in this section on content interlocutors than was found in the previous section, on healthcare interlocutors. Within the digitally mediated healthcare discourse, content interlocutors worked to determine the scope of information, define the ways in which it would be presented, and generate the text, images, and other media which would convey healthcare messages.

*Roles cited (healthcare specific):* author / clinical editor / clinical researcher / medical informaticist / peer reviewer / clinical coder

*Roles cited (non-healthcare-specific):* patient editor / educational consultant / information manager / electronic media specialist / information specialist / production editor / graphic designer

#### **4.3.1 Dimensions of expertise perceived in authors**

Amongst the content roles included in this research, the position closest to the communicative baseline of the classic healthcare encounter was held by the role of author. In both the charity and the publisher, the role of author was held by healthcare professionals, who were often practising clinical specialists. The authors provided their services either for free, or for nominal payments, and their role was to ensure that content was medically accurate and appropriate for the intended audience. As such, they provided a bridge between the day-to-day world of healthcare and the technically mediated world of healthcare information provision. This role was not represented in the informant group, and so the perspectives presented below were all gathered from other roles. Themes related to expertise held by authors, broken down by informant role, are summarised in table 4.6.

Table 4.6: Themes from references to expertise in the role of AUTHOR, categorised by the informant group			
Expert in...	content perspectives	systems perspectives	business perspectives
<b>Domain expertise</b>	<ul style="list-style-type: none"> <li>clinical specialist</li> <li>providing clinical context</li> </ul>	<ul style="list-style-type: none"> <li>content expert</li> <li>knowledge holder</li> <li>provider of information</li> </ul>	<ul style="list-style-type: none"> <li>clinical specialist</li> </ul>
<b>Process expertise</b>	<ul style="list-style-type: none"> <li>setting content scope</li> <li>deciding what evidence to include</li> <li>writing text</li> <li>approving content</li> </ul>	<ul style="list-style-type: none"> <li>suggesting references</li> <li>writing clearly from detailed clinical knowledge</li> </ul>	<ul style="list-style-type: none"> <li>writing to deadlines</li> </ul>
<b>Lack of expertise</b>	<ul style="list-style-type: none"> <li>writing for lay audience</li> <li>working within scope</li> <li>typography, presentation</li> <li>working to deadlines</li> </ul>	<ul style="list-style-type: none"> <li>writing text in the wrong way</li> <li>overwhelmed by considering multiple contexts of use</li> <li>finding it hard to work on componentised content</li> </ul>	
<b>Becoming expert</b>		<ul style="list-style-type: none"> <li>learning to express clinical knowledge simply and clearly</li> <li>learning to work with structured content</li> <li>learning to write context independent objects</li> </ul>	

Informants spoke about the expertise of authors in two areas. The first was related to their “domain expertise”, the clinical expertise they brought to the development of healthcare information from the external healthcare settings where they worked. The second type of expertise centred around the processes by which authors made their contributions to the digitally mediated healthcare discourse.

When speaking of domain expertise, both business and content informants described authors as clinical specialists. Pat, the production editor:

*They'd usually be consultants<sup>16</sup> with a particular interest in the topic that we're dealing with. In some cases it would be a surgeon (...) One or two would be written by an occupational therapist, if that's the nature of the booklet. But yes, they're all specialists in their particular field.*

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<sup>16</sup> Edited to remove the type of consultant to preserve anonymity of participating organisation.

Elle, the clinical editor from the publisher, described the way clinical editors drew on the clinical expertise of authors in the creation of information:

*Sometimes we may go back to the author and say, okay, you know, this question has come up, and which direction would you suggest (...) if it's completely unclear or we're not certain, then we would draw on clinical experience from the author. They may, if they don't have a clue either, they might look it up somewhere or ask another colleague. But mainly, they would just say ah, do it this way.*

From a business perspective, Eric, the education and publications manager, stressed both the expertise and the eminence of the authors the charity used:

*the people that we tend to use for writing our material are the same people that are writing the Oxford textbook, say. It's usually people that, because they come into contact with (name of charity<sup>17</sup>) as, say, a leading researcher. (...) They may have been a member of the education subcommittee because they were a specialist (...), and therefore they are the people, you know, when our publications group, who also consist of a lot of doctors, they say well who's the best person on (condition name<sup>18</sup>), well they might mention (name of clinician<sup>19</sup>), or, you know, (...) an important name*

Theo's software development company supplied CMS (content management systems) to support the creation of many types of information product, including technical documentation and educational materials for many subjects, and accordingly his view of the author was more generic. Rather than clinical specialists, he spoke of authors as "the content experts, the material experts", whose role in the process was to "provide the information" so that it could be shared; not always, he felt, an easy process:

*it's quite hard, especially for publishers, to get the knowledge out of the, let's say the authors, who are really the knowledge holders*

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<sup>17</sup> Name of charity removed to preserve anonymity of participating organisation.

<sup>18</sup> Condition name removed to preserve anonymity of participating organisation.

<sup>19</sup> Name removed to preserve anonymity of participating organisation.

Speaking specifically about the medical publisher, Theo characterised authors as the providers of “content”, in contrast to “context”:

*They have their authors, who are the content experts, the material experts, to put it in other words, and internally their editors and their peer review staff, who basically provide the context*

In contrast, Pat, the production editor, described the role of the author in updating as providing a view of the external clinical “context,” so that the content could be brought into alignment with that context:

*All of our booklets are revised on a regular basis anyway, so depending on the nature of the subject, they’d be updated every two years or every three years. And that would be a case of going back to the original author, where possible, saying can you update it, and bring all the information into line with new drugs, new treatments that are available*

Elle the clinical editor spoke about specific process expertise of the authors, applied in three discrete parts of the process: setting content scope, selecting and appraising evidence, and writing.

*we commissioned clinical authors to advise us on the topic plan, which was like the remit for the review, and then we went away (...) to run the searches, do a first and second appraisal in-house, and then gave the lists of research papers that resulted from that appraised search to the authors for their appraisal*

*we would go away and write little evidence summaries based on the raw data, and that would be a Word document. Possibly sort of very simple tables, and we give those to our clinical author, and she would then write the text*

Louis, the information specialist, whose team was responsible for running searches and carrying out initial appraisal of results, provided a little more colour in his description, highlighting the decision-making power of the author:

*the rule of thumb is if you’re not 100% sure that it’s irrelevant, then send it and the author or the expert will decide whether it should be in. And once they’ve made their choices, they send them back to us and let us know what they’ve decided.*

Aspects of power and control held by the author were also mentioned by Pat in her description of the authorial process expertise used in the final stages of content creation, that of “approval” of content. Her quote below illustrates her view that this power was not exercised in a straightforward way, and might involve negotiation.

*We do have instances where the author will not approve the changes that are made, either in the subediting or at the medical editing stage. It does happen. There will then be, what can be a fairly lengthy process of negotiation, just trying to reach a compromise*

In essence, this “final approval of content” constitutes acceptance by the author of the mediating discursive contributions which have been attached by other actors to his or her initial intent, as it had been encoded in the scope.

Theo, describing from a systems perspective the process used by the medical publisher, for which his company had provided the content management system, displayed a different understanding of where the decision making power resided between authors and internal staff. According to his account, the expertise of the author lay in identifying and making suggestions, but not in making the final decisions:

*the author puts out suggestions for references, but then there's the internal staff who actually make the decisions on whether to put in that reference, based on a lot of things including whether that's fit into the, for the intended audience*

Ivan, the information technologist employed by the publishers, spoke about the writing expertise held by authors, and the ways in which this necessary expertise could be obtained in instances where it was not held by the relevant clinical specialists:

*(authors) are either professional authors or subject specialists. And if they are a subject specialist who is not a professional author, then we may also supplement them with a sort of mentor type role, to enable them to, someone to work alongside them to ensure the quality or the writing style is appropriate*

From a business perspective, Eric, the publications manager at the charity, also distinguished between subject specialists and “professional” authors, selected for their writing ability, in particular their ability to work to deadline:

*we have sometimes paid (...) professional writers, where we would, instead of asking the doctor to write it we might go to a professional journalist/writer (...), potentially that has some advantages. (...) but I think on the occasions where we have tried using a professional writer, although they do write to the deadlines and so on, and one of the things we thought might happen is that that professional writer would come up with text that needed much less editing, because it was written in more of a lay language anyway than the doctor would write it, and that was, that was partly true. But I think it didn't save us quite as much effort as we thought (...) so if it comes in a lot faster as a manuscript, it doesn't necessarily arrive as a printed copy a lot faster.*

Content and systems informants also highlighted what they saw as particular lacks of expertise on the part of the authors. Pat, the production editor, characterised the difficulty some authors had in writing for a lay audience:

*Failing to explain the jargon, I think. They will tend to slip back into using terms which are very familiar to them, but which are not going to be so familiar to the public*

In addition to highlighting issues with authors failing to work to deadline, Louis, the information specialist, described a phenomenon he called “author creep”, the failure of the author to work within an agreed scope which could potentially affect the integrity of the work:

*the end review from the author might include information that we didn't agree, and if that's the case – sometimes it's happened that the consequences of that is that it gives us extra work because we then have to go and do additional searches to make sure that we've captured what they've already included. Because if it's left alone and we don't do a back search, then we will have excluded maybe other relevant studies. It doesn't happen a lot, but other times the editor...depending on what's actually been done, the editor will contact the author and say 'look, we're taking this out because it wasn't agreed'.*

Finally, from a content perspective, Gerry the graphic designer spoke about the proliferation of fonts in multimedia submissions which could result from authors' lack of expertise in typography.

On the systems side, lack of authorial expertise was characterised by misalignments between authorial practice and the wider, system-enabled context in which their words



were stored and used, with Curt, the CEO of the CMS company, noting wryly that “it’s sort of the nature of an author to write text in the wrong way”:

*The risk is more on the author side. Are they able to write content independent of the context. Because if you have a component, and then you could tell them well this component is for instance reused in 3 other contexts, then when you’re writing that particular piece of text, you have to be aware that it’s going to be reused in three contexts. But if you allow total freedom at the fragment level, then suddenly a title could be used, for instance, or a para, could be used in a totally different context as well. And sometimes that’s overwhelming for authors.*

David, the developer at the publishing house, agreed, questioning the feasibility of the approach, and pointing towards the commitment required to make such an approach work, in the form of training:

*(authors) still find it hard to write context independent objects. (...) If you take any author and ask him to write a context independent fragment, well you only have to look at the content and at some point the fragment becomes so small that it’s not context independent anymore. To a certain degree it’s not do-able, but at a certain granularity level, you can do it. It really requires extensive training, it’s not easy.*

Curt also recognised the skills issue authors faced in working with componentised content:

*We have customers where document creation is almost not writing any more, but it’s more mathematics. It’s almost becoming mathematics. (...) You have to be a real data-oriented person to actually write the content, because you have to switch between the parameters and the context where that particular information is used. And be aware that, if this condition applies and it’s reused in that particular context, then the content should look like this (...)*

He identified this as lack of systems experience, and like David, felt that it could be rectified with training:

*Most authors come from a world where they have Word or they’ve got paper and a pen, and they simply write something they have in their mind, and they’re not used to it. But there are huge benefits of it, of course. It can be a huge money save. But you shouldn’t drive it into extreme, there’s a limit with what you can do with it. You’ve got to train them, that’s basically it.*

Finally, Ivan referred to the training that had been undertaken in his organisation to counteract the problems some authors had with producing clear text:

*we've effectively had to build up the skillset both internally with our internal authors and with some regular external authors, such that they can take detailed clinical knowledge and write in a very simplistic and clear way.*

#### **4.3.2 Dimensions of expertise perceived in clinical editors**

Typically one step further from clinical practice than the authors, and correspondingly closer to the concerns of the information providers, were the clinical or medical editors. Often, but not always, medically qualified, these actors were less specialised than the authors they worked with, generally working across a range of topics. At the publisher, they were in-house employees or external freelances, whereas at the charity they were entirely external. This role is represented in the informant group by Elle and Emma, who worked for the publisher. Themes related to expertise held by clinical editors, broken down by informant role, are summarised in table 4.7.

Table 4.7: Themes from references to expertise in the role of CLINICAL EDITOR, categorised by the informant group			
Dimensions of expertise	content perspectives	systems perspectives	business perspectives
<b>Domain expertise</b>	<ul style="list-style-type: none"> <li>medically qualified</li> <li>qualified in health informatics</li> <li>understanding of EBM methodology</li> <li>approving manuscripts</li> <li>agreeing text written by production editors</li> <li>clarifying queries from non-clinicians</li> <li>checking content by going back to research papers</li> <li>determining topics and scope</li> <li>identifying questions of clinical relevance</li> <li>linking research evidence to clinical pathways</li> </ul>	<ul style="list-style-type: none"> <li>checking clinical validity and accuracy of content</li> <li>verifying clinical content</li> <li>signing off content</li> <li>providing context for authored content</li> <li>directing information specialists on questions that need to be asked of the literature</li> </ul>	<ul style="list-style-type: none"> <li>medically qualified</li> <li>checking booklets written by non-clinicians</li> <li>approving text</li> </ul>
<b>Process expertise</b>	<ul style="list-style-type: none"> <li>managing content teams</li> <li>negotiating with authors</li> <li>dealing with “author creep”</li> <li>deciding which author and reviewer comments to include</li> <li>agreeing revisions quickly</li> <li>editorial validation</li> <li>validating content</li> <li>editorial structuring</li> <li>data extraction</li> <li>editing for style</li> <li>applying codes to content</li> <li>technical troubleshooting</li> <li>product expertise</li> </ul>	<ul style="list-style-type: none"> <li>managing content and metadata</li> </ul>	
<b>Lack of expertise</b>	<ul style="list-style-type: none"> <li>non-scientist</li> </ul>	<ul style="list-style-type: none"> <li>not having knowledge of audience types</li> <li>poor understanding of XML</li> <li>poor understanding of technical limitations</li> </ul>	

All three informant groups recognised the medical domain expertise of the clinical editor, and each described their view of how this was mobilised in the work of creating healthcare information. “Checking”, “approving”, “agreeing”, “validating”, and “verifying” were terms used to describe the process of applying clinical knowledge as a layer of quality assurance to content written by clinicians or non-clinicians. This was

conceptualised by Theo, the technical director of the CMS development company, as “providing context” to the content supplied by authors. Of particular importance to Carl, the implementation consultant was the sign-off role the clinical editors had, authorising content as fit for publication.

Elle, the clinical editor, spoke at length about her work, and much of the specific detail in this section was supplied by her. She highlighted the role of the clinical editor in identifying questions of clinical relevance which could then be answered from the research literature. Firstly, she described the process of transforming product content into a decision support tool:

*First of all (we had) to work out what are the relevant questions to ask. So what are the questions that from the current state of the evidence would make a difference to the management of that disease. (...) And then also how to weight certain interventions, so that when you get the output at the end, it makes sense to the clinician, so that they get the most important first. (...) We had to go through all of the evidence summaries and the benefits and harms sections to identify certain populations where the results were different, for example. This would be something like other medications that people were taking, allergies that they had, certain age groups. It might be ethnicity or age group or gender, it might be other conditions that they had, the co-morbidities*

This skill, of identifying questions of clinical reference to then inform the contents of information products, was also acknowledged by Ivan, the information technologist, and by Theo, the technology director of the CMS company:

*there's the internal staff who actually make the decisions on whether to put in that reference, based on a lot of things including whether that's fit into the, for the intended audience and stuff like that*

Elle went on to describe a project she had worked on where she had used her understanding of clinical context to link existing product content to standardised clinical pathways:

*we've been involved in a pilot project with one of the system providers, where they created a stroke pathway, and we had a look at it and identified certain decision points where we could create a little link to some relevant content that we have*

She also described the factors and interested parties the clinical editors took into account when identifying topics of interest to cover within the product:

*first of all would be that the (...) editor would decide which topic would be covered. So it would be sort of the title of it. (...) So we say, okay we would like to cover this, because it's important. (...) There are several ways of input into that. It could be that we have a customer who would like it covered. It used to be the NHS, or it might be one of our other major customers. (...) We have contracts with other countries. They may say, okay, for us, this is a really relevant disease, could you please cover it in detail. (...) We also have suggestions from our authors, who say "I would love to cover this, because I'm already writing this other chapter for you" and we'd consider that.*

As well as setting the scope for topic coverage, Elle spoke about the decisions made by clinical editors to ensure that, though the necessary amount of detail was used in putting together information, only that detail which was useful to the clinical user was included in the finished product. She described the process by which detail was filtered out by clinical editors prior to finalising and publishing content:

*We in medical publishing, we have to (...) make sure that we are as explicit as need be for the clinician, in order to make those individual decisions. So we need to make sure for example we talk about the effectiveness of an intervention, what population group was studied, and whether that group was in any way different from the normal general patient group that the clinicians will be seeing. (...) It can be quite blurry in clinical publications, in research publications, even. And we are usually not that explicit within the review, within the chapter, within the definition and so on, or even in the methods section, as we are with our information specialists, because they have to make sure that they include everything that is relevant and exclude everything that is irrelevant, in order to reduce the workload for editors and authors. So I think at this point in time, they want that clarity and they want that explicit coverage. Whereas we then, when we go towards publication, we just take that away, filter it out again (...) For the clinical context, the subtlety that is required when you read through abstracts and try to find out whether some is relevant, that's not necessarily required in making clinical decisions. (...) Especially when you talk about non drug treatments, when you talk about behavioural therapy, exercise, diet, those definitions are usually different from chapter to chapter. And in some chapters we tend to define those specifically for a certain condition, because of that ambiguity that exists around those. That needs to be very clear for the information specialists; so, what kind of exercise are they thinking about? Is it just sort of weightlifting with one arm, or*

*are we talking about walking exercise? Whereas for clinicians, they don't really care, as long as we have looked at everything and are telling them what works.*

Elle also described what she called a “loop back” into the research community, whereby clinical editors fed back evidential gaps uncovered in the compilation of information products into the research commissioning process:

*We work together with the HTA, the Health Technology Agency of the NHS. So we would give them a publication, and they go through the new interventions and conditions, and look at those interventions that have been categorised as unknown effectiveness, and let us know that they would be interested in looking at that area in detail, because they're also research funders. So they feed that back to us, and we submit that intervention, as a research suggestion, back to them, to their website, giving the information that we have gathered through the review, with that submission.*

Elle also spoke about the knowledge of EBM methodology she had gained via her work as a clinical editor, which she contrasted with the sometimes uninformed approach taken by non-editorial clinicians:

*Working for such a high-quality evidence-based medicine publication has definitely given me a very different view of what is possible to achieve with evidence-based medicine, but also for its limitations. And also for the limitations of other publications. (...) I mean looking at really consistent methodology, and the consistency with which we approach each condition, in a very systematic way. I think that rigour is really necessary in order to say, this is really an evidence-based publication.*

In contrast to Elle, Emma was not medically qualified, and had moved into her clinical editor role from a previous career as an information specialist. Nonetheless, she cited the medical domain knowledge she had gained in that previous role as crucial in enabling her to fulfil the clinical editor role:

*I think that if I hadn't been an information specialist, a medical information specialist, I couldn't do the job. We've had somebody else who wasn't medical at all try, and they weren't able to do it. I think it was my information specialist background that enabled me, as a non-scientist, to be able to do it.*

Many of the people in Emma's team had worked as clinicians, and in recognising the value of their clinical expertise, she drew attention to the difficulties she found in finding individuals who encompassed both the domain and the process expertise required by the role. She contrasted the high numeracy skills and attention to detail required in terms of process expertise with a striking view of clinical domain expertise which she characterised as "flair (...) and willingness to be brave":

*I think so, yes. I think the numeracy, being very number oriented, but obviously we need that but we also need clinical skills. Whether that skillset goes together is something that we've found a challenge to find out, because that level of detail orientation is not, it isn't always accompanied with a great deal of flair, and expertise and willingness to be brave in your clinical area. So, it's quite a challenging skillset, I think, and it's not found that easily, so we may have to think differently about it, say, you know, the way that people work, have the people who are detail focused working on one element of the product, and other people working on other elements, as opposed to now, where one editor does everything for a particular review.*

*We're thinking about changing the way we present data, and that will change the way that editors work. Because at the moment, it's very text focused, and it's a lot about, you know, explaining rather difficult concepts in words. And if we move to graphical representation, it will be simply the data extraction. So the editorial goal (...) may change quite dramatically. This obviously impacts our recruitment and our selection of staff, in terms of what skill sets we want, and what can we focus on, that we're good at, versus what can we get from outside. (...) So, I imagine, I think the character of our team will change.*

Emma's distinction between the editors' clinical domain expertise, and the different sorts of process expertise that were being increasingly required of her team, brings us to the wider question of process expertise in the clinical editor role. Informants in content roles in particular and, to a lesser extent, informants in systems roles, recognised a wealth of process expertise on the part of the clinical editor, expertise employed to ensure that the information products complete their journey from first ideation through compilation to completion.

From the systems side, the detail of this process expertise was rather sketchy, and was expressed in generic terms by Chris the implementation consultant. His distinction, quoted below, between what he saw as the process-driven role of editorial staff and the

more customer-focused roles of other staff was somewhat at odds with the presentations of the externally-focused domain expertise of the clinical editor described in the preceding section:

*you get a real separation of concern between the editorial staff, that only has to manage the content, and the metadata, and the more customer-oriented people, which have knowledge about audience types*

In contrast, references to process expertise from the content side, particularly from the clinical editor themselves, were more detailed and covered many aspects, including co-ordination of the different contributing actors, both internal and external; “policing” of the final content to balance quality and timeliness of output; formal structuring of text and data; and familiarity with the detail of products. Elle described the editorial process step by step, firstly in general terms:

*The clinical editor role would be somebody who co-ordinates the creation of the topic plan, would chair the meeting to get the clinical input from the (patient product) team, the information specialist team, would then come up with the topic plan, sign that off, in a way, would resolve any questions with the information specialist, around the search, then would receive the submission from the clinical author, read through, check whether it has been written along the lines of the topic plan, and point out any irregularities; would, if necessary, make suggestions for restructuring, splitting up a review, and then would eventually also edit for style. Because we have this very rigid and consistent style on (name of product), and that's sort of the final stages, when you go through each of the sentences, and check both for style, and also for content, by going back to the original papers*

Elle also went into some detail on the process she was using on a particular product, detailing the type of data extraction process that Emma highlighted, above, as a driver for skills change within her team:

*Currently I'm looking at the evidence base for smoking cessation and also for type 2 diabetes management, especially around group based education interventions. That means that I will run some searches, and I'm second appraising those, so I need to filter out the relevant ones for our paper. (...) So then I take the original articles and data extract from them into a spreadsheet, an Excel spreadsheet that a colleague has come up with. (...) Well you know you can't really capture all data. The spreadsheet itself feels already to suggest what you should data extract. Now at this stage I will not fill in all of that, I will only fill in what is relevant for our work now, but by linking that in the new content*



*management system, eventually, to both the review and also the references, that spreadsheet will be available to future generations of editors who might want to add to it or check whether they need any more data. (...) And then we would go away and write little evidence summaries based on the raw data, and that would be a Word document. Possibly sort of very simple tables, and we give those to our clinical author, and she would then write the text, also in a Word document. (...)*

Like Emma, Elle highlighted the challenges of data-centred work for editors more accustomed to text-centred work:

*There is definitely a problem. And also a big change for editors, who have only worked in and around Word documents so far, to see that now what they do is really part of a database system, an XML database. (...) And people who have started working with it had their problems, because they didn't know what to fill in and so on. Now, how that will then eventually connect to the database of the content management system, I don't think anybody has a very clear overview of that, but that's the exciting bit about it, to make it really happen, so that you can reuse what somebody else has done for future projects.*

For the clinical editors, and indeed for all of the internal content roles that follow, expertise was defined generally in positive and static terms. References to lack of expertise were few (only five in the whole dataset) and other than the references to qualifications and training already listed above, there were no references to the transitional process of becoming expert.

Informants mentioned other medically-orientated actors feeding into the content creation process, including clinical researchers, who carried out research and wrote up the results in the academic papers cited in the content produced by the organisations in this study, and peer reviewers, generally practising clinicians, working for free or for nominal payment to quality assure content from a clinical perspective prior to publication. Data on these roles was sparse and so I have not included them in this analysis.

The other content roles held by or referred to by informants were not in themselves clinical, although the holders of these roles in the organisations in this study had by necessity developed a medical focus to the way the roles were carried out. These roles included patient editor, information specialist, production editor, and graphic designer.

The dimensions of their expertise, as reported by the informants in the study, are outlined in the following sections.

#### 4.3.3 Dimensions of expertise perceived in patient editors

The patient editor existed as a specific role only at the medical publisher. Holders of this role were often journalists by training, who specialised in expressing healthcare information in ways that made sense to patients and other lay actors such as carers. They were not represented in the informant group, so the view of them in this research is entirely through the eyes of other roles at the publisher and its technology suppliers. Both content and systems informants expressed views about the expertise of this role. Themes related to expertise held by patient editors, broken down by informant role, are summarised in table 4.8.

Table 4.8: Themes from references to expertise in the role of PATIENT EDITOR, categorised by the informant group		
Dimensions of expertise	content perspectives	systems perspectives
<b>Domain expertise</b>	<ul style="list-style-type: none"> <li>• understanding patient expectations</li> <li>• identifying outcomes and interventions of interest to patients</li> </ul>	
<b>Process expertise</b>	<ul style="list-style-type: none"> <li>• translating clinical information for a lay audience</li> <li>• tailoring information to the language and interest of patients</li> </ul>	<ul style="list-style-type: none"> <li>• good understanding of Word</li> <li>• understanding the benefits of a good content management system</li> </ul>
<b>Lack of expertise</b>		<ul style="list-style-type: none"> <li>• abusing XML schema</li> <li>• poor understanding of technical restrictions</li> <li>• inexperienced in technology</li> <li>• unwilling to expand on direct job</li> </ul>

#### 4.3.4 Dimensions of expertise perceived in production editors

Both the publisher and the charity made use of production editors to manage content through to publication and provide quality assurance from a non-medical perspective. Production editors had often worked in non-medical environments prior to joining the organisations in the study. All of the expertise ascribed to this role by the informants was process expertise rather than domain expertise. This role was represented in the informant

group by Pat and Penny, who both worked for the charity. Themes related to expertise held by production editors, broken down by informant role, are summarised in table 4.9.

<b>Table 4.9: Themes from references to expertise in the role of PRODUCTION EDITOR, categorised by the informant group</b>			
<b>Expert in...</b>	<b>content perspectives</b>	<b>systems perspectives</b>	<b>business perspectives</b>
<b>Ensuring accuracy</b>	<ul style="list-style-type: none"> <li>• editing</li> <li>• being precise in definitions and explanations</li> <li>• searching databases such as MIMS or BNF</li> <li>• checking proofs</li> <li>• tweaking text to improve layout</li> <li>• checking web versions against hard copy</li> <li>• picking up things that need to be changed or looked at again</li> <li>• checking symbols</li> <li>• checking data transferred between systems</li> <li>• checking new versions created by designers</li> <li>• checking style</li> </ul>	<ul style="list-style-type: none"> <li>• dotting every I and crossing every T</li> <li>• checking spelling</li> </ul>	<ul style="list-style-type: none"> <li>• spotting commas out of place</li> <li>• checking what the graphic designers create</li> </ul>
<b>Co-ordinating processes</b>	<ul style="list-style-type: none"> <li>• commissioning authors</li> <li>• corresponding with medical editors</li> <li>• circulating manuscripts for assessment</li> <li>• managing negotiation between author and medical editor</li> <li>• co-ordinating review cycle</li> <li>• organising timely updates</li> <li>• getting drafts back from authors on time</li> </ul>	<ul style="list-style-type: none"> <li>• moving content on, making sure the right people are looking at it</li> <li>• taking a pragmatic approach to delivery</li> <li>• interacting with authors</li> <li>• dealing with technology team to resolve issues</li> <li>• coordinating resource</li> </ul>	
<b>Working with technical formats</b>	<ul style="list-style-type: none"> <li>• converting information across formats from InDesign to HTML</li> <li>• keying changes into HTML</li> <li>• updating web pages</li> <li>• working with HTML</li> </ul>		

#### **4.3.5 Dimensions of expertise perceived in information specialists**

The publisher, with its strong EBM focus, high volume of content, and the wide range of its coverage across a number of clinical specialties, had a dedicated team of information

specialists carrying out search and appraisal of clinical research literature to inform content development and updating. These were qualified librarians or information scientists, who had developed a specialised focus on medical information through their work at various medically-oriented institutions. The majority of the data to inform this section (37/52 references) was supplied by the information specialist informant himself, Louis, with most of the remainder coming from the two clinical editors, Elle and Emma. Themes related to expertise held by information specialists, broken down by informant role, are summarised in table 4.10.

Table 4.10: Themes from references to expertise in the role of INFORMATION SPECIALIST, categorised by the informant group		
Expert in...	content perspectives	systems perspectives
<b>Qualifications</b>	<ul style="list-style-type: none"> <li>qualified librarians</li> <li>trained as information specialists</li> <li>specialists in medical information</li> </ul>	
<b>Setting content scope</b>	<ul style="list-style-type: none"> <li>planning topics</li> <li>tweaking topic plans to pick up subtleties</li> </ul>	
<b>Searching for research literature</b>	<ul style="list-style-type: none"> <li>constructing coded search strategies</li> <li>performing literature searches on databases such as MEDLINE and Embase</li> <li>translating search strategies for different databases</li> <li>using terminologies such as MeSH to locate literature</li> <li>using different search techniques</li> </ul>	<ul style="list-style-type: none"> <li>finding literature to answer clinical questions</li> </ul>
<b>Working with abstracts</b>	<ul style="list-style-type: none"> <li>skimming abstracts for quick exclusion</li> <li>interpreting abstracts</li> </ul>	
<b>Appraisal of research literature</b>	<ul style="list-style-type: none"> <li>determining the relevance of research literature against criteria</li> <li>appraising search results against PICO<sup>20</sup> criteria</li> <li>appraising unfamiliar topics based on criteria</li> <li>critical appraisal</li> <li>authoring systematic reviews</li> </ul>	
<b>Rigour</b>	<ul style="list-style-type: none"> <li>ensuring rigour of methodology</li> <li>insisting on clarity and explicitness</li> <li>clarifying specifications</li> <li>raising questions for clarification</li> <li>pointing out lack of clarity and omissions</li> <li>making sure things are laid out properly</li> </ul>	
<b>Being pragmatic</b>	<ul style="list-style-type: none"> <li>focusing searches to get more relevant and manageable results</li> <li>carrying out less defined searches and background web based searching for patient topics</li> </ul>	

The work of the information specialists centred on the searching of third party databases to locate and retrieve information relevant to the publisher's own publications. The work

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<sup>20</sup> Population, Intervention, Comparison, Outcome.

required a high degree of familiarity with the structure of the third party databases and the presentation of research papers, and, crucially, the quirks and inconsistencies found within in them. Louis described the process of translation he went through to adapt search strategies to particular databases:

*some of the MeSH terms that are used in MEDLINE won't be applicable to EMBASE – they'll bring up zero. So you need to remap the term and see if there's another way of saying it*

He also described the process of moving up and down the MeSH hierarchy of terms, seeking out a term which is neither too broad nor too narrow, in order to home in on the “best” level to identify papers on a particular topic; here he concludes that, due to inappropriate application of MeSH codes, it was in any case necessary to look at every paper to be certain of its relevance:

*if you explode that MeSH term you will pick up everything under that tree. Or you can leave it unexploded and you'll just search for anything that has that, just those words in it. Or you could focus the MeSH term – you can put a little asterisk before it so that you only find papers that have...that are indexed by the asterisk and the MeSH term, and if you focus the MeSH term what you're doing is that you're telling the search to find only those papers which are predominantly about that topic. When you explode it you're making your search results as broad as possible and you're less likely to miss things but you're also more likely to have to wade through irrelevant stuff, because MeSH terms and subject heading within the tree...although there's some connection to it, quite often they might be indexed in papers which aren't really about what you're looking for so you have to look through them all*

The appraisal work of the information specialists, during which unsuitable papers were rejected, or “excluded”, and potentially useful ones put forward to the author and clinical editor to consider for inclusion in the publications, was heavily driven by criteria set by the clinical editor and the author.

*I first started doing appraisal of abstracts about six months before I started working here (...) and I thought 'how am I going to do this? I don't have a clue about these topics' and so...generally you pick things up, you become familiar with certain terminology and you become more comfortable with doing it. But you basically follow the topic plan. You read an abstract and you make sure that the coverage of that abstract is being picked up...you make sure...yeah it's going*

*to be picked up by the topic plan, you make sure that it's matching it. There's tricks*

Despite this, it was work that involved a surprisingly high degree of interpretation, due in part to the variable nature of the paper abstracts which were the first port of call for the information specialists in making their decisions:

*In terms of interpretation, some abstracts can be a bit...written in a way that are harder to understand*

*you get a title and it's this grand title and you think that's exactly what I'm looking for but I look at the abstract and I'm like...it doesn't mention anything about randomisation, it doesn't mention anything about the population size, it doesn't mention anything about anything and you're thinking why? Why haven't you done that bit?*

#### **4.3.6 Dimensions of expertise perceived in graphic designers**

Both the publisher and the charity made use of graphic designers, though only the charity supplied graphic designers as informants; this group was represented in the informant group by Gerry and Gill. Both informant designers were from generalist design backgrounds, but had learned to focus on medical information due to the needs of their current work. Informants from all three communities of expertise (content, systems, and business) referred to aspects of the expertise held by graphic designers. Themes related to expertise held by graphic designers, broken down by informant role, are summarised in table 4.11.

Table 4.11: Themes from references to expertise in the role of GRAPHIC DESIGNER, categorised by the informant group			
Expert in...	content perspectives	systems perspectives	business perspectives
<b>Handling technical work</b>	<ul style="list-style-type: none"> <li>dealing with technical problems</li> <li>using software packages such as InDesign, Illustrator</li> <li>converting files between formats</li> <li>using style sheets</li> </ul>	<ul style="list-style-type: none"> <li>moving content between formats</li> <li>manually reformatting content</li> </ul>	<ul style="list-style-type: none"> <li>defining software tools needed</li> <li>converting from print applications to web applications</li> </ul>
<b>Design</b>	<ul style="list-style-type: none"> <li>typesetting</li> <li>typography</li> <li>medical illustration</li> <li>adding pictures</li> <li>copywriting</li> </ul>	<ul style="list-style-type: none"> <li>visualising content</li> </ul>	
<b>Improving content</b>	<ul style="list-style-type: none"> <li>making things look better</li> <li>prettying things up</li> <li>making things look nice</li> </ul>	<ul style="list-style-type: none"> <li>make content visually appealing, intuitive, and accessible</li> </ul>	
<b>Building publications</b>	<ul style="list-style-type: none"> <li>assembling content into booklets</li> <li>laying out content to standardised formats</li> <li>producing proofs</li> </ul>		
<b>Working independently</b>	<ul style="list-style-type: none"> <li>organising work</li> <li>thinking on their feet</li> <li>coming up with ideas</li> </ul>		

Finally, there was a range of other, more peripheral, generalist content roles which had taken on a medical flavour by virtue of the institutional context in which they were now working. These included Eve, the educational consultant, trained in pedagogy, who advised on effective educational approaches to presenting healthcare information. Eve reported briefly on her expertise and training, but none of the other informants referred to her role at all, and so it is not examined in this analysis.

#### 4.4 Systems expertise in the digitally mediated healthcare discourse

The final layer of mediation in the digitally mediated healthcare discourse is provided by technical or systems roles. In this section I present the perspectives of the study informants on the expertise of those who hold such roles. As with the content



interlocutors reported in the previous section, systems interlocutors also acted as informants, so in this section too there is a high degree of reflexivity in the data. References to the expertise held by holders of systems roles fell into two distinct categories. The first concerned the “hard” technical skills which were the specialist preserve of the holders of the systems roles; the skills, in fact, by which those roles were defined. Systems informants themselves were the group who referred most often and in most detail to the specific technical expertise connected to their roles, so the richest seam of data on the technical aspects of systems expertise comes from holders of systems roles themselves. The data on systems expertise is presented in two sections, the first covering the hard technical expertise related to each area, and the second focusing on softer process and communication expertise.

*Roles cited:* technical content developer / information technologist / systems implementation consultant / systems developer / technical standards developer

Of the three types of systems roles, only one was mentioned in terms of expertise by all three informant categories, and that was the technical content developer. Holders of this role worked more closely with content workers than any other systems role, and therefore it is not surprising to see it high in the awareness of other expertise communities. The specific technical expertise related to information technology roles was referred to by both business and systems informants, but not by content informants, who interacted with information technologists less frequently. Finally, only systems informants themselves referred to the specialist technical expertise associated with systems development.

#### **4.4.1 Dimensions of technical expertise perceived in systems interlocutors**

Within this section, I present the different contributions of systems interlocutors along a continuum of abstraction, progressively further firstly from the content roles and, beyond them, from the communicative baseline of the classic healthcare encounter. In ascending order of abstraction, the types of contribution offered by systems interlocutors are:

1. Technical content development
2. Systems implementation

### 3. Systems development

Closest to the content creators lay the work of technical content development which provided the technical builds for digital content products. This work was creative in its own right, and could involve hands-on coding to build original applications, though content developers also used third party systems and applications as a vehicle for their creative development work. The developers mentioned by the informants at the publishing team worked in-house, but those mentioned by the charity were engaged as external consultants, and worked out-of-house. This role was represented in the informant group by David, who worked for the publishing company. Themes related to expertise in the area of technical content development, broken down by informant role, are summarised in table 4.12.

Table 4.12: Themes from references to specific technical expertise in the technical content development area, categorised by the informant group			
Expert in... (specific technical skills)	content perspectives	business perspectives	systems perspectives
technical content development	<ul style="list-style-type: none"><li>• Practical</li></ul>		
	<ul style="list-style-type: none"><li>• Arcane "wizardry"</li><li>• Discrete, external, standalone</li></ul>	<ul style="list-style-type: none"><li>• Difficult to assess</li></ul>	<ul style="list-style-type: none"><li>• Core internal skill</li><li>• Specific (e.g. Java, XML)</li><li>• Automating content change</li><li>• Converting content to different structures</li><li>• Working within system restrictions</li></ul>

Informants across all groups agreed that the expertise of technical content development was essentially practical in nature; these were *doing* roles, concerned with making things work. Two non-systems informants described the mysterious nature of this technical expertise, with Eve (content, charity) referring to “technical wizardry” and Eric (business, charity) referring to the difficulty in recruiting and managing developers without having the specialist knowledge to evaluate their expertise. In both cases the concern was around the potential for misalignment between this little-understood expertise and the goals and needs of the charity with respect to creating digital content products. Both Eve and Karen (content, publisher) used the term “standalone” to describe the skills of technical content

developers, with Eve locating this as an essentially external skill, and Karen reporting, with some trepidation, the growing organisational distance in her company between content and technical development teams, resulting from a restructure which had moved the technical developers out of the content team into a separate, centralised department. In contrast to this view, for Ivan (systems, publisher), there was no question that the technical content development expertise was as core a skill to the business as content expertise. From a systems perspective, technical content development roles were also described as having expertise in automating content change and converting content, using terms such as “strip out”, “tidy up”, “reverse engineer” and “re-factor” to describe skills enabling system-level content change. Finally, from the systems perspective, knowledge of the limitations associated with particular technical environments was an important dimension of this practical expertise.

The information technologists lay one step further from the content creators, taking systems built by systems developers and implementing them for practical use in the processes of content creation and dissemination. These implementations might be limited to system selection; they might include simple set up and configuration; or they might involve extensive customisation including hands on coding of supporting applications. Informants in this role included Carl and Chris, who worked for the specialist consultancy company engaged to implement the CMS for the publisher; Ivan, from the publisher’s technology department; and Ian, from the much smaller 2-man IT team supporting the charity. The role of David, mentioned above as a developer, also spanned elements of the information technologist role, as he was responsible for maintaining and developing the in-house implementation of the content management system, as well as creating the digital content products which that system supported. Themes related to technical expertise in the information technologist area, broken down by informant role, are summarised in table 4.13.

Table 4.13: Themes from references to technical expertise in the information technologist area, categorised by the informant group		
Expert in... (specific technical skills)	business perspectives	systems perspectives
<b>tool selection</b>	<ul style="list-style-type: none"> <li>identifying and providing what is needed</li> <li>knowing the best systems to use</li> <li>understanding business and user requirements</li> </ul>	<ul style="list-style-type: none"> <li>advising on feasibility and limitations</li> <li>understanding implications of open source v. proprietary software</li> <li>suggesting standard toolsets</li> </ul>
<b>managing technical infrastructure</b>	<ul style="list-style-type: none"> <li>running software on remote computers</li> </ul>	<ul style="list-style-type: none"> <li>managing servers and server environments</li> </ul>
<b>systems integration and adaptation</b>		<ul style="list-style-type: none"> <li>building technical infrastructure</li> <li>integrating applications from different providers</li> <li>customising third party systems</li> </ul>

Expertise in this area broke down into three main sub-types, of which two, tool selection and managing technical infrastructure, were referred to by both systems and business informants, and one, systems integration and adaptation, was referred to only by systems informants. From a business perspective, this expertise was expressed as something on which the business *relied*, as without it they would be “at the mercy” of system providers. The choice of tools was described as something owned by the IT department, on behalf of the company. In contrast, the information technologist informants themselves described the expertise in terms of providing advice, and explaining limitations and implications of particular solutions, rather than making outright selections. From a systems developer informant came the suggestion that IT departments would seek to standardise solutions, perhaps inappropriately, “to minimise effort”.

The nitty-gritty skill of managing server infrastructure was little touched on by either business or systems informants, with the business informant referring in layman’s terms to an enhanced hosting package which was being introduced, and the systems informant listing server management alongside other mundane technical tasks, but not elaborating on the detail. The more intricate skill of systems integration and adaptation was described variously by systems informants in terms of collaborative process, of service

provision, and as being laborious, “painful,” and able to be carried out only by a limited group of people, due to its complexity.

Occupying the point on the continuum most distant from the content creators were systems developers. These interlocutors were involved in the design, build and maintenance of the systems used by content interlocutors to create and disseminate their information. Systems development was represented in the informant group by the staff of the supplier company which built the content management system used by the publishing company. It is important to note that this group, though privileged in the data by virtue of providing informants to the research, was only one of multiple development groups whose systems were used by the content creators in the study. For the most part, these system development groups existed out-of-picture, not only in terms of direct representation in this research, but also in the awareness of the content teams making use of their systems and applications. The even more shadowy role of the standards developer, mentioned only twice in the data, is included in this category. The most abstract forms of technical systems expertise discussed, systems and standards development, were only discussed by informants in systems roles. Themes related to these forms of expertise are categorised and summarised in table 4.14.

<b>Table 4.14: Themes from references to specific technical expertise in the systems development area</b>	
<b>Expert in... (specific technical skills)</b>	<b>systems perspectives</b>
<b>supporting implementation</b>	<ul style="list-style-type: none"> <li>• supporting implementation teams with technical detail</li> </ul>
<b>systems development</b>	<ul style="list-style-type: none"> <li>• working collaboratively</li> <li>• co-ordinating outsourced functions such as testing</li> <li>• working with non-user friendly technologies</li> <li>• carrying out research and development</li> <li>• building applications to support content work</li> </ul>
<b>systems design</b>	<ul style="list-style-type: none"> <li>• working collaboratively</li> <li>• conceptualising solutions</li> <li>• designing straightforward, elegant and clear solutions</li> </ul>
<b>standards development</b>	<ul style="list-style-type: none"> <li>• negotiating group consensus</li> </ul>

The first of the skills in this group was applied at the interface between systems development and implementation, and consisted of helping information technologists to interpret the systems they were implementing. Dee referred to the communication chain via a dedicated “support person” who would escalate queries to developers as required.

The skill of collaborative working was referred to as important both in terms of system development (working within teams of developers to share concepts), and in the earlier, more conceptual process of system design (working across technical teams). Discussion and trust were highlighted as key factors. This collaborative approach was in contrast with the more directive approach to outsourcing well-defined functions such as testing to remote locations, where the goal was to select tasks which “(didn’t) require too much communication because it (was) clear what (had) to be done”. Curt referred casually to the challenges of the “not very user friendly” technologies his developers had to grapple with: “developers of programs can handle that.” He also spoke positively about the benefits of his team being repositioned since acquisition as a research and development centre, free to concentrate on their “core activity (of) building products”, insulated from commercial and administrative distractions. The perceptions of the developers of the interface between their applications and the content work those applications supported follows in the next section, on the softer skills employed by systems roles.

Dee described the skills used in designing systems, employed in a process which started from customer requirements, and involved building concepts, and then working collaboratively with other developers to build up systems from technical foundations:

*First you look at (...) what is needed outside and then you try to translate that back into what is to be programmed. And first you build that bottom layer, that core layer and then you build GUI on top of that.*

She also defined important characteristics of a good system, from her perspective:

*very nice clean and good code, not too much, not too little (...) a good framework for extending it in a later stage. (...) It should be (...) clear code. (...) Must be very straightforward.*

Finally, Dee also spoke of the specialised demands of standards development. Working on technologies based on open standards, she was aware of the skills involved in creating those standards, and contrasted them with her own, more practical skillsets:

*that's a very special kind of interest you must have...it's very tough, very tough (...) you can talk for days or months about one single little thing (...) Develop programs and (...) making standards is very, it's a very different thing I think.*

#### 4.4.2 Dimensions of softer expertise perceived in systems roles

In contrast to the hard technical skills demanded by systems work, which were largely discussed in the interviews by, and possibly only visible to, systems informants themselves, there were also many softer skills ascribed to systems interlocutors. It was these skills which were referred to by the content and business informants as the main expertise of systems interlocutors. Only one area was referred to by all three informant groups (content, business, and systems) and that was the skill of interpreting requirements. Themes related to this form of expertise are categorised and summarised in table 4.15.

Table 4.15: Themes from references to expertise associated with interpreting requirements, categorised by the informant group		
content perspectives	business perspectives	systems perspectives
<ul style="list-style-type: none"> <li>helping content people to see solutions</li> </ul>	<ul style="list-style-type: none"> <li>making a bridge between technology and what it means to a customer</li> <li>being visionary</li> </ul>	<ul style="list-style-type: none"> <li>advising on feasibility of requirements</li> <li>translating ideas into practical implementations</li> <li>translating what the customer wants into what is to be programmed</li> <li>understanding requirements which don't make sense</li> </ul>

Eve (content, charity) spoke of her desire to work alongside someone with systems expertise, whose contribution would not lie simply in implementing according to her instructions, but in “helping (content workers) to see” potential options for realising their communicative goals. Ben (business, CMS development company) also used a sight metaphor, as he described the capacity of systems roles to bring specialist technical knowledge and the lifeworld of customers into a single frame as “visionary”.

Systems informants spoke about the deeply practical aspects of the skill of taking high level requirements from business and content interlocutors and using them as the basis for coding work. As mentioned in the previous section, this was described as work of “translation”, moving from the modes of expression used by business and content interlocutors to the practical step-by-step language of development work. It was also a task of evaluation, with some requirements failing to pass success criteria determined by the developers, who might respond by “saying no to over-zealous requirements”, or conclude that they “don’t want to implement that because it does not make sense”. In a similar vein, developers might also question the strength and validity of the requirements passed down to them, as David did with a requirement to append SNOMED coding to content: “The problem I have with SNOMED coding is that we have no business requirement to deliver it.”

A wider range of these “softer” systems skills, beyond the transference and interpretation of requirements, were discussed by both content and systems informants. These two groups needed to collaborate regularly on many aspects of their work, and so had to engage with each other across a range of different contexts. Themes related to these softer skills are categorised and summarised in table 4.16.

Table 4.16: Themes from references to softer skills held by systems roles, categorised by the informant group		
Expert in...	content perspectives	systems perspectives
<b>process design</b>	<ul style="list-style-type: none"> <li>identifying process issues</li> <li>minimising "faffing"</li> <li>minimising reformatting, cutting out formatting problems</li> <li>working magic</li> <li>providing advice which may be ignored</li> </ul>	<ul style="list-style-type: none"> <li>creating automatic and straightforward processes</li> </ul>
<b>communication</b>	<ul style="list-style-type: none"> <li>communicating technical limitations</li> </ul>	
<b>addressing challenges</b>	<ul style="list-style-type: none"> <li>responding to user problems</li> </ul>	<ul style="list-style-type: none"> <li>fixing customer problems</li> <li>offering technology-based solutions to business problems</li> <li>troubleshooting, testing, and fixing</li> <li>cleaning up code abused by editors</li> <li>hiding details of solutions from users</li> </ul>



At the charity, graphic designers and production editors worked together with information technologists to agree the systems-enabled processes they would all follow in order to produce content for dissemination in the most timely and cost-effective way. Both content and systems informants portrayed the systems skills involved in this work as providing simplification and streamlining, usually via automation. Ian, the information technologist at the charity, spoke rather briefly about this aspect of his role in the workshop where it came up. His contribution to the discussion was practical, and carried an assumption that adopting a streamlined process would be straightforward, once the detail was worked out:

*We need to sit down and work out a structure and a guideline to ship out to everybody and say, we need it like this to make our jobs a lot easier.*

While both graphic designers and production editors expressed an appreciation and enthusiasm for the intended benefits of the streamlined approach, this was set against scepticism with regard to the realisation of those benefits: graphic designer Gerry, after describing in detail one proposed process, concluded “I’ve yet to see that happen, but I’m sure it can happen”. Penny the production editor described a proposed method for formatting text, rather doubtfully, as “just like magic.” Both graphic designers and production editors referred to times when they had ignored the recommendations for process change, even when recognising that the proposed process would have been more efficient, as Gill noted:

*I never had the time to actually sit down and get behind it and do it, so we just carried on, because it was quicker to carry on the way we were doing it.*

This resistance to process change from the holders of content roles demanded quite a subtle expertise on the part of the information technologists.

Both content and systems informants spoke of the expertise used by systems interlocutors in communicating technical limitations to content interlocutors; informants in both groups referred to this as “saying no”, and both recognised the importance of the skill, as well as the difficulty in getting it right. Graphic designers Gerry and Gill described the

interaction between an information technologist (“Isaac”, not part of the informant group) and a production editor:

*“Gill: It’s quite interesting, though, that (the production editor) can accept that on the web, that that’s the limitations of the technology, so you can’t make it sit where you want it to sit.*

*Gerry: Well it might have something to do with Isaac’s attitude as well, turning round and saying ‘sorry!’.”*

From a systems perspective, technical content developer David talked about the different approaches he took to convey technical limitations to content workers:

*with some people you can say it once and say you can’t do that because XYZ, other people you have to tell them ten times before it sinks in.*

David put his success at conveying limitations down to the trust he had established with his content colleagues through his track record of successful delivery.

Systems and content informants both identified problem solving as a key expertise for systems interlocutors. Emma (content, publisher) defined this skill simply, from her perspective as a customer, appreciative of an efficient service: “they’re very responsive and very quick if there’s any problems.” Systems informants themselves went into more detail about the methods they applied to problem solving which was an area they defined largely in relation to customers, in that problems were described as originating with customers. David described one aspect of this work as “cleaning up” code that had been “abused” by the editors using systems incorrectly, while Ian spoke of making systems “transparent” to hide the detail from their users: “we’ll figure out a way for you just to write your content in and hit a button, basically, and the computer should do the rest.”

One type of expertise was discussed almost exclusively, and in great depth, by the two information technologists who had worked to implement the content management system used by the publisher. These were highly specialised skills around analysis and representation. Themes related to this form of expertise are categorised and summarised in table 4.17.

Table 4.17: Themes from references to analysis and representation expertise held by systems roles, categorised by the informant group		
Expert in... (softer skills)	systems perspectives	business perspectives
analysis and representation	<ul style="list-style-type: none"> <li>• making knowledge explicit <ul style="list-style-type: none"> <li>○ making systems and processes visible</li> <li>○ making the knowledge in research papers visible</li> <li>○ modelling the decision process for interpreting clinical research</li> <li>○ visualising relationships between businesses, systems and processes</li> <li>○ modelling from different perspectives</li> <li>○ modelling relationships between content and context</li> <li>○ building audience models for audience types</li> <li>○ developing generic meta models</li> <li>○ bringing context models to business users</li> </ul> </li> <li>• proposing optimisation strategies</li> <li>• facilitating novel uses of content by customers</li> <li>• providing specialised knowledge-intensive solutions</li> <li>• building dynamic applications on flexible context models</li> <li>• identifying limits to automation</li> <li>• identifying those things best left implicit</li> <li>• support definition of unique concepts and language</li> <li>• hiding complexity from users</li> </ul>	<ul style="list-style-type: none"> <li>• understanding publishing requirements</li> </ul>

Aside from the holders of these specialist skills themselves, only one informant referred to these skills, and that was Ben, the business development director of the systems company with whom they worked. From his perspective, the fact that the implementation partners had these skills meant only that his own staff did not need to engage with this area, and he did not examine or discuss this expertise in detail, saying only “(the implementation consultants) know about publishers, about those processes, the issues you see, and the things you want to do.”

For the implementation partners, these skills formed their core contribution to their customers, and they spoke about them in detail. They referred many times to their skill in “making knowledge explicit”, “visualising” and “making visible”; from business processes to scientific research, they applied their generic knowledge modelling techniques to create representations of “knowledge” which could then be used as the basis for decision making. They described the way they incorporated different

perspectives into their models, to create faceted models which could be used to present content appropriately across multiple contexts:

*“when you have knowledge it is normal case that you want to see it from several viewpoints.(...) We have content, and the content is just actually these instances. (...) But then you have some context above it, some modelling. (...) This is actually what we offer by our tooling, is that you can model several relations between content and the context you have (...) and that’s actually also the case where you look at knowledge, every day someone’s knowledge is changing, look outside the door and speak with someone, it’s another knowledge, it’s changed.”*

The informants acknowledged the representational limits of the technological solutions they implemented:

*It’s just a model of the real world, but not the same. It hides some effects. But that’s the constraint of each model, each explicit making of knowledge, you forget something.*

They identified another aspect of their expertise as the recognition of reasonable limits for automation and for explicit representation: “Some things you don’t want to make that explicit, because you say actually, that’s just human behaviour, and please keep it there.”

As mentioned above, there were many more references to expertise on the part of systems roles than inexpertise, but those themes that did emerge in relation to inexpertise are categorised and summarised in table 4.18.

Table 4.18: Themes from references to inexpertise held by systems roles, categorised by the informant group	
content perspectives	systems perspectives
	<ul style="list-style-type: none"> <li>inexpert in communication</li> </ul>
<ul style="list-style-type: none"> <li>inexpert in content</li> <li>inexpert in publication requirements</li> </ul>	<ul style="list-style-type: none"> <li>inexpert in medical terminology</li> <li>inexpert in understanding user requirements</li> <li>unable to model complex moral issues technically</li> <li>inexpert in representing meaningful relationships between content elements</li> <li>unaware of the messy reality of technical infrastructure in practice</li> <li>inexpert in implementing specialised technologies</li> <li>inexpert in standards development</li> </ul>

Both content and systems roles commented on lack of expertise held by systems interlocutors, with both sides highlighting a lack of communication skills. In both instances, this was limited to problems in communicating technical information in a business context via email rather than to any more general lack of interpersonal skills. Content workers also highlighted a lack of familiarity on the part of systems people both with the high level aims of the content products, and the specific requirements the products had with regard to systems, leading to a need for close collaboration with content workers when troubleshooting and selecting tools.

Systems informants acknowledged their lack of medical domain knowledge, and their inability sometimes to make sense of user requirements. The systems implementation informants who specialised in knowledge modelling admitted to an inadequacy of their methods in modelling medical issues with a complex moral dimension, such as abortion, and also highlighted an inability of systems developers to model the relationship between content elements and meaning. Meanwhile, the systems developers highlighted poor understanding of the reality of their own technical infrastructure on the part of some information technologists, and one information technologist pointed out that highly specialised system implementations needed specialist support, beyond what could be supplied by a generalist information technologist.

There were many references to holders of systems roles gaining expertise. Themes relating to this dimension of expertise in systems roles are summarised in table 4.19.

Table 4.19: Themes from references to becoming expert by systems roles, categorised by the informant group	
content perspectives	systems perspectives
<ul style="list-style-type: none"> <li>learning to collaborate effectively</li> </ul>	
<ul style="list-style-type: none"> <li>developing an understanding of the educational perspective</li> <li>exploring new approaches</li> </ul>	<ul style="list-style-type: none"> <li>sharing knowledge collaboratively</li> <li>learning medical terminology</li> <li>learning about new kinds of knowledge requirements (research papers)</li> <li>exploring new technologies</li> <li>playing with new approaches</li> <li>working freely when little is there</li> <li>finding new technical challenges to address</li> <li>painfully finding ways to use new technologies</li> <li>picking up XML skills through practice</li> <li>developing solutions through trial and error</li> <li>learning from technical communities</li> </ul>

Content informants described some of the learning pathways on which they saw systems interlocutors embarking. For educational consultant Eve, learning, for systems interlocutors, centred on gaining a better understanding of the educational aims of the information being produced, in order to “try and bring the two pathways back together (...) to make sure that this technical wizardry is serving the purposes of all arms of the organisation”. She talked about the need to develop collaborative skills, “to break that fudgy area between you down, so there’s a bit more understanding.” This theme of effective collaboration as a skill to be progressively learnt was echoed by the systems informants themselves.

On a more practical note, graphic designer Gerry described the process of exploration his information technologist colleague went through to investigate new approaches. This theme of exploration was also referred to by systems informants, who referred to the challenge of learning new systems in positive terms such as “exploring” and “playing”. Developing technical expertise in new directions was described as an important motivating force by systems informants. “I mean, relational data, it’s all figured out, right, there’s nothing new to do. But the document-oriented world is still relatively new, so we like that.” Set against this was the observation that breaking new technical ground

could sometimes be “painful”. The approaches used for gaining new knowledge were informal and unstructured, with skills “picked up” on the job rather than being formally taught, and processes of trial and error used in developing:

*it’s never perfect, so you then go through it and see what it’s done and you delete stuff and move stuff around and decide actually that would be better to have it that way and then change your original content to meet that.*

#### **4.5 Conclusion**

In section 2.8 of Chapter 2, I posed the empirical questions *What kinds of **specialist expertise** are involved in the sharing of digitally mediated healthcare meanings?* and *How are these forms of expertise characterised, and how do they interact?* In this chapter, I have explored some of these different kinds of expertise and related them to their positions in the layered *structure of digitally mediated healthcare discourse*, also introduced in section 2.8 of Chapter 2. In the current chapter, I have presented examples of a profound engagement with healthcare meanings demonstrated by interlocutors without healthcare domain expertise. The range of different expertises brought to bear on this complex but single discourse and the, at times, mysterious nature of them for other interlocutors, suggest implications for mutual understanding and communicative transparency which is the focus of this study. Those implications will be further explored in Chapter 6. Next, in Chapter 5, I will look at the perspectives of the three informant groups shown here – content, business, and systems – on the information artefacts through which they share healthcare meanings in the digitally mediated healthcare discourse.

## CHAPTER FIVE

### Information artefacts: Proxies in the sharing of healthcare meanings

#### Introduction

In Chapter 4, I examined the diverse range of expertises that have a bearing on the digital mediation of healthcare meanings. Following the framework I introduced in Chapter 2, I conceptualised the holders of these expertises as interlocutors in the broad healthcare discourse, actively engaged in the sharing of healthcare meanings. What unites this diverse group is their common engagement in the provision of healthcare information to a range of audiences, mediated by a range of informational artefacts. The data presented in this chapter will inform answers to the second set of my empirical research questions, introduced in section 2.8 of Chapter 2:

*How are **information artefacts** mobilised in the digital mediation of healthcare meanings? How are they characterised?*

For the purposes of this study, and particularly in this chapter, I treat information artefacts as “utterances”, or locutionary acts, in the healthcare discourse, from which it follows that, in the view I present here, information artefacts can carry the pragmatic characteristics of utterances, embodying communicative action. The range of informational artefacts that emerged from the empirical data, organised in order of their distance from the communicative baseline of the classic healthcare encounter introduced in section 2.2 of Chapter 2, included:

1. Information products: the websites, booklets, and other products created and disseminated by the informants, either directly or using systems created by them, to circulate healthcare meanings
2. Information systems: the tools, databases and systems used by the informants to create, store and disseminate the information products



3. Standards: standardised methods and formats, both informational and healthcare, used by the informants in the creation and dissemination of the healthcare products.

In this chapter, I examine the way information artefacts were engaged as *proxy interlocutors in the sharing of healthcare meanings*, a concept I introduced in section 2.6 of Chapter 2, and can be understood to be carrying the intent of their creators and contributors into new contexts. Informant contributions on informational artefacts are grouped and examined from the following perspectives:

1. Perceived intent, or purpose: What and whom are the information products for?
2. Perceived action: What is done with the information products, and what do they themselves do?
3. Perceived materiality: What are the information products created by the informants made of, and how are they made?

A full list of names and roles of informants can be found in Appendix A.

### **5.1 Perceived intent in digital healthcare information products**

As discussed in Chapter 2, particularly in sections 2.1, 2.2, and 2.6, communicative intent and interlocutor perception of the intent of co-interlocutors are key components of the intersubjectivity that leads to the mutual understanding which is, in turn, the aim of communicative action, and is conceptualised in this study as illocutionary force.

Following the notion that information artefacts are treated in this study as utterances within the digitally mediated healthcare discourse, this section explores the intent, or illocutionary force, of information artefacts as reported by those interlocutors in the healthcare discourse who also acted as informants in the study.

Of the wide range of informational artefacts referenced by the informants in the interviews, perhaps the most recognisable to the outside eye were the information “products” created or facilitated by the informants in the course of their work to share healthcare meanings. Constituting a touchpoint between interlocutors in the healthcare

discourse, within which term I include both information creators and their audience, these artefacts embody a shared reality. This section examines the perspectives of the different expertise groups who create and disseminate healthcare information products, to examine the ways in which nuances of perspective across these groups may result in a reality that is not straightforwardly transparent, even between the information producers themselves.

References coded to the following information artefacts were used as the basis of this analysis:

website / booklet / information product / evidence review product / patient  
information product / technical manual / point of care product / decision support  
product / information resource

### 5.1.1 What is the information product for?

Table 5.1 summarises the perspectives of the different expertise groups on the purpose of the information products they work on.

Table 5.1: Perspectives on the purpose of information products, categorised by the informant group		
content perspectives	business perspectives	systems perspectives
To inform To educate To interact		To deliver content To contain content
To make explicit To summarise research To disseminate scientific fact To update	To facilitate the clinical relationship	

The basic purpose of the information product, from which indeed the term derives, is surely “to inform,” and yet, although mentioned in passing, this fundamental aspect of purpose was little explored in the data. Gerry (content, charity) described the charity’s website as “the place people are going to go for the information”, while Eric (business, charity) partially explained the purpose of the charity’s website as follows; “we obviously want more people to know about (the charity).” Perhaps this purpose was so obvious to informants as to become almost invisible, or perhaps the term information, being so

broad and unspecific, had little meaning for informants whose day to day concerns took them deep into the specifics of meaning.

More explicit attention was paid to the nuances of the objective “to educate”, particularly by the charity informants, and in particular to the ways in which electronic media might be engaged to optimise this objective. Eve (content, charity) expressed the hope that “the leaflet can do it, but the electronic resource has got the potential to do that **even better**” (my emphasis). The assignment of a performance value judgement to information artefacts here confirms the perception that there is a task to be done, which may be achieved with varying degrees of success, and is an indication of the role of the information artefact as proxy, used as a tool by human actors (here the content teams of the charity) in the service of their communicative intention.

The particular characteristics and mechanisms of media artefacts in their role as proxies were examined further by the informants when discussing the concept “to interact”. The concept of interaction in relation to media artefacts implies (at least) dual strands of action, suggesting that actions are carried out by both users and artefacts, and that the combination of these two strands of action is more than simple accumulation. Interactivity was explored by both business and content informants from the charity, along the following lines:

- Using visual and information design to encourage users’ cognitive engagement with material, so that information goes “between the brain, the eye, and the hand” (Gerry, content, charity)
- Acting as proxy for health professional, “a bit like you can talk to your nurse any time of the day or night” (Eve, content, charity)
- Organising information along dimensions of depth and breadth aligned with the expected experiential journeys of users, “so people could really become as knowledgeable as a consultant if they felt they wanted to get to that, if they wanted to go that deep” (Eve)

Enthusiasm from content informants around the “potential power” of such interactivity was tempered by scepticism from Eric (business, charity) about the limitations, and the importance of “knowing (...) how much interactivity you need, and how much **just information** but better presented and better linked you need” (my emphasis).

The concepts of interaction listed above highlight the models of use held by informants for the information they produce. Eric displayed a sophisticated understanding, in a quote already partially discussed in Chapter 4, of the contexts in which the charity’s information products were used:

*you’ve got people coming to resources with so many different expectations. You know, you might get somebody coming along (...) because they’ve just been told they’ve got (name of condition<sup>21</sup>), and they don’t know anything about it (...). So they want, probably, reassurance, and they want (...) some information and so on and so forth. But you’ve got somebody else who might have had it for ten years who wants to know something very detailed about the risk of cancer or something, or the risk of a certain drug that they might be using, that sort of thing, which (...)the person who’s newly diagnosed might not want to know right then*

This sophisticated understanding of multiple contexts of use was coupled with doubts about the potential of “interactivity” to successfully serve these multiple contexts:

*to try and make it work for all those audiences might make it too difficult, whereas really to do it through separate parts would be much simpler, and be equally as good for each of the audiences.*

The value placed here on the ability for an informational resource to adapt to the different contextual needs of its reader is another example of implicit reference to the communicative baseline of the classic healthcare encounter. This reference was made explicit in the desire expressed above by Eve for the information product to act as a literal proxy for a healthcare professional; a nurse you can talk to at any time of the day or night.

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<sup>21</sup> Name of condition removed to protect the anonymity of the organisation.

Elle, clinical editor at the publisher, highlighted the role of the information products she worked on in making details explicit, for example, the detail of a specific research study, in order that clinicians could see clearly how it related to the specific clinical contexts they worked in.

*we in medical publishing, we have to (...) make sure that we are as explicit as need be for the clinician, in order to make those individual decisions. So we need to make sure for example we talk about the effectiveness of an intervention, what population group was studied, and whether that group was in any way different from the normal general patient group that the clinicians will be seeing*

This touched on a broader theme, raised by both business and systems informants, which described the purpose of healthcare information products for patients as facilitating the clinical relationship between doctor and patient. Eric described a potential scenario in which doctors might “dispense” digitally mediated healthcare information direct to patients at the clinic:

*one of the aims of that Department of Health project is that the doctor can download it straight into, you know, at his surgery, and give it to them then, so it would come off the computer, you know he'd have it on the screen and then he would print it out and give it to you*

Ivan, the information technologist at the publisher, gave statements of purpose with regard to the part information products played in the clinical relationship.

*to provide the information such that both the patient and the clinician are equipped with the most current and the most accurate information such that that relationship of trust is re-established and that the patient and the doctor can make joint decisions together*

*encouraging acceptance by the doctors that the information the patient is reading is accurate and appropriate, providing the connection between the clinician and the patient's version, and allowing the doctor to clearly share with the patient the information they feel they should be reading*

The first of these two quotes places the clinician and patient on equal terms in terms of decision-making power, with the role of the information product to foster power equality and hence trust. The second quote places the clinician very much in a position of control, with the role of the information product to serve the agenda of the clinician.

Another purpose ascribed to information products designed for use by clinicians was to disseminate scientific fact by summarising clinical research. Clinical editors Elle and Emma spoke in some detail, already discussed in Chapter 4, about the steps their teams took to ensure methodological rigour and therefore the scientific accuracy of content. In addition, Louis the information specialist, whose daily work involved sifting through hundreds of recently published scientific papers, stressed the role of the information products he worked on in updating clinicians with the latest scientific research:

*doctors and clinicians and whoever, there's so much new information coming out that they just don't have the time to read it, so evidence based medicine, evidence based organisations like Cochrane, like NICE, (...) and other organisations, online organisations do the work for people so we review information and we present it, so people instead of having to read individual trials – which there could be hundreds of – will read our review, because we've already read them for them.*

One final view of the purpose of information products was quite different to those already presented here, in that rather than focusing on the information product in use, the meanings associated with it, and the social context, it focused on the mechanical structure of the products, seeing them as containers for meanings in a generic sense. This view was expressed only by systems workers, including Ian, the information technologist at the charity:

*you have a template that you drop that story into a book, and you drop that story into a web page, and it says oh, I'm a book now, so the heading, what is the headline, it needs to be like this, the rest of the story needs to be like this. And you drop that same story into a website, and it says I'm a website, the heading should be like this, the rest of the story should be like this.*

### **5.1.2 Who is the information product for?**

Another important facet of the concept of purpose is interlocutor perception of the eventual users, or audience, of the information products. The information workers in this study rarely met the users of their products, who therefore existed for them as imagined interlocutors. Perceptions of these interlocutors shaped the communicative events taking place between content creators and users, via the proxy of the information artefact. Table

5.2 summarises the perspectives of the different expertise groups on the users of the information products they work on.

Table 5.2: Perspectives on the users of information products, categorised by the informant group		
content perspectives	business perspectives	systems perspectives
<ul style="list-style-type: none"> <li>patients</li> <li>doctors</li> </ul>		
<ul style="list-style-type: none"> <li>anybody</li> <li>people with low literacy levels</li> </ul>	<ul style="list-style-type: none"> <li>medical students</li> <li>experts or average users</li> </ul>	<ul style="list-style-type: none"> <li>to service the need of a specific organisation</li> <li>personal subscribers and organisations serving groups of subscribers</li> </ul>

At a high level this is a simple question to answer for healthcare information; the products are for doctors, and for patients, and there was consensus across all informant groups on that. The nuance of what it might mean to have patients as an audience was more puzzling. Eric, the education and publications manager at the charity:

*we don't know exactly what the average patient wants to know. I mean obviously we produce a lot of material and we answer a lot of the questions that come up over and over again because we know those are the ones that came in the letters and come in the phone calls and email and so on...*

In contrast, Gerry the graphic designer at the charity, provided a poignant insight from personal experience about the impact the generalised information in his products could have on individuals:

*even though when you look at the booklets, the information appears to be incredibly general, they can be of great help to somebody who thinks they're the only one who've got that particular problem*

Informants also focused on the literacy levels of users who were patients. Perceptions of the literacy levels of patients have already been discussed in Chapter 4. Here, I will add the perceptions of Louis and Ivan, information specialist and information technologist at the publisher, on the way product design was seen to respond to these perceived low levels of literacy. They presented products as being designed and written so that “anybody can access (them)” (Louis) and “anyone can understand” (Ivan). This

conceptualisation of “user” interlocutors could hardly be more generic. It stands in contrast to the perspective expressed by Eve on the same topic, which demonstrated an ambition to produce products which, rather than being aimed at a generic “anyone”, could be built in such a way as to reach a quite specifically defined “everyone”:

*having written it, you know, you can go into it as a (...) consultant, you can go into it as a little old lady who's not very literate but who's caring for somebody who has, you know, and so you've got this body of information but you can access it at all sorts of levels*

Somewhat symmetrically, and as already mentioned in Chapter 4, Eric touched upon the incidental use of patient information by clinicians. These were not seen as the primary user group for patient information, but all the same were one that the content creators were aware of, and tried to accommodate.

On a contrasting note, for the publisher's employees at least, there was a commercial aspect to user-interlocutors, who were in some cases also purchasers. Ivan, the information technologist, explained;

*that content is now freely saleable, both to personal subscribers, but more importantly to organisations serving groups of personal subscribers, or groups of patients. So, health insurance companies, people like Tesco and Sainsbury's, car insurers, private medical organisations. So where they can provide it as a member benefit*

Finally, it is worth noting that for the systems development company that supplied the publisher, not all the products they supported dealt with healthcare meanings. Ben, their business development director, described the users supported by his company as airlines, motorcycle manufacturers, and the mechanics that worked for each. This type of user lies beyond the scope of this investigation, but provides a useful contextual insight on the perspectives of systems developers.

## **5.2 Perceived action in digital healthcare information products**

As I mentioned in the introduction to this chapter, in this study, information artefacts are conceptualised as utterances, or locutionary acts, within the digitally mediated healthcare discourse. In this section, I examine the ways in which study informants perceive the



locutionary actions of the products they create, from two perspectives. The first subsection looks at informant perceptions of the ways user-interlocutors use the information artefacts to support their own communicative actions. The second subsection examines informant perspectives of locutionary acts carried out by the information products themselves. Under the framework of this study, where information artefacts carry out communicative actions such as these, it is as proxy interlocutors, enacting the communicative intent of their creators.

### 5.2.1 What do users do with the product?

Table 5.3: Perspectives on the use of information products, categorised by the informant group			
	content perspectives	business perspectives	systems perspectives
<b>seeking information</b>	<ul style="list-style-type: none"> <li>access information when you need it</li> <li>underuse as an educational tool</li> </ul>	<ul style="list-style-type: none"> <li>find what they want to know</li> </ul>	<ul style="list-style-type: none"> <li>get information to support you in what you're trying to do</li> </ul>
<b>accessing and navigating information</b>	<ul style="list-style-type: none"> <li>keep it at bedside</li> <li>get information from internet rather than in print</li> <li>read online information in same way as printed information</li> <li>search for conditions in EPR system using codes</li> </ul>	<ul style="list-style-type: none"> <li>search for mechanical "fault codes"</li> </ul>	<ul style="list-style-type: none"> <li>navigate by selecting conditions</li> </ul>
<b>disengaging</b>	<ul style="list-style-type: none"> <li>only read top level messages</li> </ul>	<ul style="list-style-type: none"> <li>struggle with navigation and terminology</li> </ul>	<ul style="list-style-type: none"> <li>don't follow navigational links</li> </ul>
<b>giving feedback</b>	<ul style="list-style-type: none"> <li>make suggestions to creators for improvement</li> </ul>	<ul style="list-style-type: none"> <li>recommend improvements</li> </ul>	<ul style="list-style-type: none"> <li>communicate needs to publisher</li> </ul>
<b>bridging content and context</b>	<ul style="list-style-type: none"> <li>change understanding over time</li> <li>nurse takes patient through leaflet to explain it</li> <li>nurses hand out instead of discussing</li> <li>answer questions about patient to inform decision support</li> </ul>		<ul style="list-style-type: none"> <li>check patients into hospital electronic healthcare system</li> <li>filter content according to patient diagnosis</li> <li>use navigational structure to filter results for relevance</li> <li>give own profile to configure personalised products</li> <li>personalise products tailor made for you</li> </ul>

Informants from all three groups identified what might be seen as the primary activity users engage in with information products, which was to seek specific information

relevant to their particular situation; expressed by Eve as the information users “need”, by Eric as information users “want”, and by Ivan as information to “support (them) in what (they’re) trying to do”. An important commonality here was the recognition by all informants that users came to the information products from real-world contexts, with specific, real-world questions to be answered. These were not the sort of information products that people might idly browse for entertainment on the chance they might discover something of interest. Eve also mentioned that she felt the products were “underused as an educational tool”; perhaps because of the very specificity and urgency of the particular questions with which users approached them.

When discussing the ways in which information products fitted into the lives of their users, Eve cited the booklet as “brilliant” in the way that it could be kept “in the bedside table” to be at hand whenever the user needed to access it. That data was collected in 2006, before mobile devices such as tablets, smartphones and readers were commonplace, when the devices more commonly used to access digital content, such as desktop or laptop PCs, would not have fitted neatly into a bedside table. Pat, production editor at the charity, in an interview carried out on the same day, was looking to the future when she said:

*we do need to be moving towards electronic forms of communication, because people are becoming more internet-aware, as sort of younger generations start to fall into the age groups that are more affected by (name of condition). I guess they will expect to get the information via the Internet more than in printed form. (...) At present, we’ve just got the booklets on the website, and people read them in much the same way as they would read the printed version*

The users of Pat’s products were patients. In an interview recorded four months later, Elle, clinical editor at the publisher, described a potential future scenario for access to information using standard terminological codes in a professional healthcare environment:

*We would create content, give that content a certain code, and at the other end, a clinician may be working within an electronic patient record system, and would be looking for a condition or an intervention, and would search that. And the system would then search that term, using the codes.*

This scenario was similar to that described by Ben, the business development director at the CMS development company, who spoke about airline mechanics accessing information prepared in his company's systems by mechanical "fault codes", the mechanic's equivalent of the clinical condition or intervention codes.

Emma, clinical editor at the publisher, spoke about a tendency for users to skip reading complex text in the product she worked on:

*we have massive benefits and harms sections, with loads of text, that take a long time to create, and we know that people don't read. We know that people read the top level messages, they don't read underneath.*

Eric also acknowledged the problems users found with accessing information on the charity's website, problems which had come to light during formal user testing.

*people were still struggling to find their way through it (...) they were struggling with the headings, and they were struggling with some of the terminology like complications, they found that a bit off-putting*

Ian, the information technologist at the charity, described a similar situation which stopped users engaging fully with the product:

*Because it was a direct text taken from a printed publication, people were reading that on a website, and were thinking they were going to go through to a book or something like that, so they were stopping*

Users did not suffer these problems in silence. It might be expected that the flow of information from these fairly traditional information producers would be one way, as they created and disseminated information for their "audience". But informants from all three groups noted the level of feedback coming in, invisible to the external observer, from the other direction, that is, from the "audience" back to the information producers.

Ivan the information technologist commented:

*they are very vocal as to what they want. So you have to recognise as a publisher that these needs are going to be communicated to you in various ways, either direct or indirect.*

Moving away from the mechanics of information product use, and back to the context of use, Eve noted the way that a user's understanding of an information product might change with the progression of illness:

*even the same sentence, you might read it in a different way two years down the line, because it's now relevant to you, or you've understood that better*

She also noted the particular situation of use of the leaflet within a clinical situation, with an information product used as a prop to support an otherwise classic clinical encounter:

*the leaflet is the resource, it's how you use the resource that really is significant, to move from information to education. And in that leaflet, it had all sorts of ideas on what to do with the leaflet, like you shouldn't just give it, you should sit down with somebody and say now, when you come to clinic next time, it would be really helpful if you've read the first section, and perhaps looked at the symptoms, or look, I'm just going to underline these words for you, because these are obviously key*

Pam, the production editor, had a rather pithier take on the use of patient information products within a clinical context:

*it suits nurses for example to hand out the information in a printed form rather than discussing it*

Elle, clinical editor at the publisher, described a rather more technologically advanced, not to mention radical, use of an experimental information product she had worked on for healthcare professionals, which formed part of an electronic clinical decision support system:

*you have first to answer certain questions about the patient, and then the whole thing zipped through this black box of the decision support system, and then out came an output with the treatment recommendations*

Business informants did not comment on this aspect of product use at all, but systems informants had plenty to say about the ways in which context and content came together in product use. Ivan, the information technologist at the publisher, looked ahead to a time when the "content" produced by the publisher would be fully integrated into systems used to manage clinical work within clinical "contexts" such as hospitals:

*(...) clinicians will want to access, and patients will want to access, information anytime, any place, anywhere, and therefore we have to manage our content in such a way that it can be served via any delivery channel to any user at any point they need it. So for us it's flexibility in how we structure and manage and deliver our content, and increasingly as per most commercial publishing, certainly professional publishing, it's actually integrating that content into the clinical workflows, such that if doctors work in a GP system, and they've diagnosed that someone has certain identifiable things, then that can be used to filter our content, such that the doctor then just sees the pertinent content relevant to their specific diagnosis. Equivalently, if you're in a hospital electronic healthcare system, and you're checking somebody in, and they have to have a series of procedures run on them by different departments in the hospital, then it's delivering the appropriate content to inform the person who has to make the decision at the point at which they need to make the decision, based on where they are in that care pathway through the hospital.*

In the comment above, Ivan is covering all bases, including a generic definition of context (“any time, any place, anywhere”) as well as the highly specific contexts of use at the point of care and care pathways within hospitals.

Chris, the implementation consultant, described navigation in terms of “modelling relation(ship)s between content and context”, considering the users’ selections as providing the “context” into which selected content was served by the system:

*you can model several relations between content and the context you have. So in this case for example, we use that for navigation structure, so building dynamic navigation structures. And there you see for example you can select the audience type, you can select the intervention type, you can select the disease, actually, the section where it's belonging to, and the age of that. A user is able to select and navigate any of these things, and say okay, I want to have only the interventions for surgeries, I want to have the men's health section, the audience type is 35 years old, actually the age group, then give me the interventions which are suitable*

Chris was clear about the direction in which digital publishing was moving in terms of contextual need driving content, concluding that “the ideal situation is that customers are able to configure their own products.”

### **5.2.2 What does the information product do?**

Informant perspectives on actions performed by information products are summarised in table 5.4.

Table 5.4: Perspectives on the actions of information products, categorised by the informant group			
	content perspectives	business perspectives	systems perspectives
<b>helping people</b>	<ul style="list-style-type: none"> <li>go out to try and help people</li> <li>help when something is up with you</li> <li>sustain you over time</li> </ul>	<ul style="list-style-type: none"> <li>improves people's care</li> </ul>	
<b>interacting with user</b>	<ul style="list-style-type: none"> <li>prompt you to ask questions</li> </ul>	<ul style="list-style-type: none"> <li>tell you what you've looked at</li> <li>record your expertise level</li> </ul>	
<b>static v. interactive</b>	<ul style="list-style-type: none"> <li>be total information, and not attempt to do anything else</li> <li>produce electronic versions of the hard copy</li> <li>do things that can't be done by the printed word</li> <li>give information in a more interactive way</li> </ul>		
<b>linking and redirection</b>	<ul style="list-style-type: none"> <li>link to related content across products via codes</li> </ul>		<ul style="list-style-type: none"> <li>take you off to a related product</li> <li>expose and deliver related content</li> <li>lose people</li> </ul>

Both business and content informants spoke of information products as enacting real world change. For Louis, the information specialist at the publisher, this was part of what motivated him in his job: “I like the health factor, that there’s products going out there to try and help people.” Gerry, the graphic designer at the charity, also expressed his belief in the power of his products to effect beneficial change: “any information can help you when something's up with you.” Eve spoke about the ability of booklets to “sustain” patients through the trajectory of their illness, while Eric also expressed a cautious belief in the beneficial effects of the information his organisation produced on patient care:

*it can also have a direct effect on people being better looked after by them being better educated (...)it probably improves people's care in that way as well*

*Eve: And the charity is to help people with this condition live their lives more easily. (...) And to cure them, well yeah, but in the meantime, of course it is, of course it is. But with (this condition), we know that's been quite a slow but*

*nonetheless worthy line of pursuit. But in the meantime there's this huge business of helping people with a chronic disease*

*Gerry: The charity continues to bang on about finding a cure for (this condition), and the best of luck to them, but I think it's the treatment, like a lot of diseases, it's living with it in different ways, and coping with it, and getting that information out to the public, that's the important thing*

Identifying situations when information products interacted directly with their users, Eve spoke about the way patient information products prompted users to ask questions about their conditions, while Eric spoke about “things that the website will do for you as a user, like telling you what you’ve already looked at, or recording your expertise level.”

At the time of data collection, the charity was engaged in rethinking its digital product strategy to create active, rather than static, products, in response to a feeling that “electronic resources (...) could do things that couldn’t be done by the printed word” (Eve). Eve summed up the existing website, based very much on content originally produced for print, like this:

*You know, it's total information, and it doesn't attempt to do anything else. Fine, that's okay. How could it be improved to make it more attractive, more user friendly? What's the current use of it? How could it be more interactive, is the word?*

Penny, production editor at the charity, commented rather drily on this ambition to create more active content:

*at the moment, which is going to change, the web essentially just produces electronic versions simultaneously of the hard copy, identical. The theory is that this isn't going to be our new practice. The web content is going to be quite different, more layered and sexy and interesting and vibrant and colourful and attractive (laughter).*

Linking between resources was identified as way that interactivity could be achieve, in relation to which products were portrayed as actively taking users into informational contexts they might not expect. Ivan, information technologist:

*irrespective of which site you come in on, which front door to our content you come in at everything which is related to that which might be of benefit to you as a user of that content is exposed and delivered at the same time.*

Finally, Ian, informational technologist at the charity, referred to occasions when poor product design might lead to the rather alarming action of “losing” people.

### **5.3 Perceived materiality in digital healthcare information products**

To this point, this chapter has focused on communicative intent and action, as reported by informants. Intent and action, though key to a pragmatic understanding of communication, are in themselves idealisations. Empirical pragmatic enquiry reveals that communicative intent and action enter the real world through the mediation of material elements, ranging from the structures of language to the technologically complex artefacts which are the subject of this thesis. As discussed in section 2.7 of Chapter 2, there is a particular, complex materiality at work in respect to digitally mediated content, and in this section I will examine informant perspectives on this materiality, looking at the material composition of information products, as reported by informants across different expertise groups.

#### **What are healthcare information products made of?**

Informant perspectives on the material composition of information products are summarised in table 5.5.



Table 5.5: Perspectives on the material composition of healthcare information products, categorised by the informant group			
	content perspectives	systems perspectives	business perspectives
common components	<ul style="list-style-type: none"> <li>text / data / information / content</li> <li>PDF/HTML/XML</li> <li>question and answer</li> <li>document</li> <li>page / section / paragraph / link / heading / graphics</li> </ul>		
generic low level components	<ul style="list-style-type: none"> <li>title</li> <li>line / sentence</li> <li>element / chunk</li> </ul>		
		<ul style="list-style-type: none"> <li>component</li> </ul>	
	<ul style="list-style-type: none"> <li>caption / symbols / numbers</li> </ul>	<ul style="list-style-type: none"> <li>fragment / information block</li> <li>tag / facet / metadata</li> <li>character / headline</li> </ul>	
generic high level components	<ul style="list-style-type: none"> <li>chapter</li> <li>topic</li> </ul>		
		<ul style="list-style-type: none"> <li>configuration</li> </ul>	
		<ul style="list-style-type: none"> <li>knowledge</li> <li>story / entry</li> <li>assembly / composition / amalgamation / bucket / category</li> <li>model / navigation structure</li> <li>decision tree</li> </ul>	<ul style="list-style-type: none"> <li>sublayer</li> </ul>
domain-specialist components	<p>LOW LEVEL</p> <ul style="list-style-type: none"> <li>reference</li> <li>guideline</li> <li>clinical code</li> </ul> <p>HIGH LEVEL</p> <ul style="list-style-type: none"> <li>(systematic) review</li> <li>condition</li> <li>intervention</li> </ul>		
	<ul style="list-style-type: none"> <li>evidence summary</li> <li>clinical question</li> <li>evidence grade</li> </ul>		
non-textual components	<ul style="list-style-type: none"> <li>tables</li> </ul>		
	<ul style="list-style-type: none"> <li>illustrations / pictures / artwork</li> <li>diagram / forest plot</li> </ul>	<ul style="list-style-type: none"> <li>images</li> </ul>	<ul style="list-style-type: none"> <li>illustrations / pictures</li> <li>diagram</li> <li>audio / video / moving images</li> </ul>

### 5.3.1 Common components

In table 5.5, I use the term “common components” to describe, not a set of components common to all information products, but rather a set of terms used by informants across all information groups (content, systems, and business) in their descriptions of the healthcare information products they create and disseminate. It is, perhaps, a surprisingly short list, and ranges from very low level basics, such as “page”, “paragraph” and “heading”, through the structural “document” and the semantic/pragmatic concept of “question and answer”. By far the most discussed themes in this category, and the most variously defined and adopted, were the high level generic concepts listed in the first line of the table: “text”, “data”, “information”, and “content”. The ways in which the terms were variously applied is presented below.

**Text** was the simplest, and the least contentious, of the terms used. Informants across content (including graphics and editorial), systems, and business all used this term to refer to the written, linguistic component of products, generated by authors, and curated, revised, and finalised by editors. When speaking of text, informants defined it in contrast to other aspects of content. These included graphics, and numerical data, as in the following, from Emma, clinical editor at the publisher:

*(our current format is) very text focused, and it's a lot about (...) explaining rather difficult concepts in words. (...) What we would like to do is (...) graphically represent the data. But in order to create forest plots or graphics representations, you have to have the numbers underneath;*

Informants also contrasted text with structured data, as in the following, from David, technical content developer at the publisher:

*you can say 'this is a section which contains text and this is its title.' So that's fine for our (patient) content. It doesn't work so well for more detailed structured content (...) you can't really wrap that up in a title flowing text kind of construct.*

Business and systems informants also spoke of text as a resource that could be “databased” and shared between products in different media, print and digital. Eric raised efficiency issues around increasing the amount of text to be quality checked:

*I think we've got to have some sort of half way house probably, between the two, so that text does go between both, but maybe not in exactly the same way*

Agreeing that “re-using chunks of text across booklets, I don’t think would be that much use” Ian positioned text as a kind of generic component carrying meanings across formats:

*Instead of spending two weeks creating a booklet, and then another two weeks creating a website, you would just create text, and then it would be very simple to create a booklet and a website from that original text*

Business and content (design) discussed text in practical terms, as something to be transferred between applications. Only Chris, the systems implementation consultant, discussed text as an enabler of searching, though he compared full-text searching unfavourably to more structured methods of surfacing relevant information:

*when you have full text search there's almost no knowledge bringing in the system. And when you go to bring in more knowledge from your customers in this way, you don't have the full text search*

Finally, Chris described text as a kind of sense-making device, bringing cohesion to combinations of components: “you make a combination of the information components and they need some glue text, some context related text to glue together”. I will look further at this “aggregation” view of the creation of information products in the subsequent section on high-level components.

Content informants Eve, Elle, and Emma used the term **data** to describe a concept of generic information which underlay product content; to quote Eve: “that idea of, you’ve got the basic, and then behind it you can access it and use it in different ways.” Emma and Elle used the term with a more precise meaning, to describe the information that they “extracted” from paragraphs or flat tables in research papers, where it was “not re-usable or easy to find”, and used to “underpin” their products. Similarly, both Eric and Eve

spoke of data as something that “drove” their products, though Eve identified the charity’s products as “only medium data driven.” Although systems informants used the term data a lot when talking about the functioning of their systems, they used it rarely in relation to information products and their contents. David used the term quite narrowly to describe information that was structured or tabular, in contrast to text-based information.

The term most used to describe the generic components making up information products was **content**, and it was also the term associated with the most diverse meanings. Firstly, content was often defined in contrast to other concepts – by what it was not. To summarise, informants took pains to distinguish content from:

- Presentation and style

Informants from all groups distinguished content from presentation. Elle and Eve spoke of the need to check both to assure quality; Eric spoke of the mismatch that could occur between these two measures, leading to appealing, well presented products which were light in content, or, conversely, less appealing products with a wealth of content. From a systems perspective, Ian spoke of the need to “split content from presentation” as a principle to bear in mind during systems selection.

- Systems and documents

Informants from all groups made this distinction, separating the systems which contained and processed content from the content itself. Systems and business informants spoke about the ability to change and manipulate each of these two elements independently from the other, so that content could be changed without changing systems, or systems could be altered without changing the content. The single content informant who made this distinction, Eve, focused on the separation in expertise, identifying those expert in content as not being expert in systems, and vice versa.

- Context and usage

Only systems informants made the distinction between content and its context and usage, but it was a distinction made frequently, by four individual informants spread

across the publisher and its two technology suppliers. Both Chris and Theo expressed a distinction they perceived between people who worked on the material aspects of content, and those who understood the context of its use. Interestingly, though both expressed the distinction, in relation to the same activity in the same company, they attributed the roles differently. Chris:

*you get a real separation of concern between the editorial staff, that only has to manage the content, and the metadata, and the more customer-oriented people, which have knowledge about audience types*

Theo:

*They have their authors, who are the content experts, the material experts, to put it in other words, and internally their editors and their peer review staff, who basically provide the context*

Additionally, both Theo and Ivan placed explicit value judgements on the relative worth of context expertise set against content expertise, with both prioritising context or usage expertise over content expertise.

Ivan:

*we're still focused too much on content and not focused enough on solutions and while we've got really top quality content anyone can produce top quality content – you just have to throw enough money and time at it to get it done*

Theo:

*let's say you gave me one euro and I have to divide it between someone who's good in writing the content and the other one in describing the context? I think that in due time I would probably pay more for the guy who was doing that context then who was doing the content*

Informants from all groups, but primarily from systems, spoke of content as a product, asset, or commodity. On this theme, Eric alone spoke of the importance of creating the “right” content or product. More prevalent, and all from systems people associated with the publisher, were mentions of saleability, and of monetary value. Ivan asserted that his company had “really valuable content that people want”, and spoke of the need to “monetise the value of our content” and “maximise the profitability of the content”, though Theo also drew attention to initiatives to give away the publisher’s content as a charitable donation to “poorer countries”. Louis spoke about the practicalities of the

intellectual property rights of the content, while in contrast Theo, on a more abstract level, asserted that “in this Google era, it’s clear that the content is never going to be stored in one specific spot, owned by one specific person or organisation”. On the topic of content value, Chris spoke of “the relation between content value upgrade and better use of content,” linking “better use” of content by customers to increased revenue. Following on from the concept of use is the concept of reuse, the carrying of content into multiple contexts of use, cited by Curt, Ivan and Chris as a key goal for publishers.

Content was most frequently referred to in terms of its materiality, as something that needed to be created, managed, maintained, and delivered. Informants from all groups portrayed content as a liability, as well as an asset, but different groups focused on different aspects of this materiality. All groups, including content informants, spoke of content in terms of the effort involved in creating and enhancing it, including the cost of this effort, and initiatives to control such costs. Similarly, all groups spoke of the effort involved in maintaining content, in terms of technical maintenance and updating, again in terms of controlling cost and effort, but also, from the systems perspective, in terms of the dissemination possibilities opened up by flexible content management techniques:

*we have to manage our content in such a way that it can be served via any delivery channel to any user at any point they need it. So for us it’s flexibility in how we structure and manage and deliver our content*

Both companies had accumulated a large body of content in a variety of formats, and both were actively engaged in operations to rationalise and streamline the systems used to create and maintain content. The accumulation of content in legacy formats necessitated material work of migration of content into the new systems. Twice Ivan referred to the act of “pouring” content into a content management system to facilitate this, while Ian referred to the process of migration to a content management system as “more or less just copying and pasting”, and Eric referred to it as “cleaning up”. The prospect of undertaking this process manually was greeted unenthusiastically by production editors, coloured by their previous experiences of content migration. Penny:

*Pat and I no doubt share horrible, horrible memories of when we went on to the “new website” however many years ago it was and we had to sort of give up about two or more months of our time just checking everything through because it hadn’t transferred properly. (...) We cannot spend our time doing that sort of thing. (...) Obviously nobody likes to spend vast amounts, but really that’s not the issue that’s uppermost in my priorities.*

Content workers did not speak about content in terms of its delivery to users; this was discussed primarily by systems workers, though mentioned by Eric as an area of concern:

*one of the things we want to know from our point of view as people looking after the content is the best way of getting it up on the website*

Curt and Ivan spoke in high level terms of delivery “mechanisms” and “channels” whereas David, from a more hands-on perspective, described a messier reality. Ivan, speaking about delivery to a particular commercial customer breezily asserted:

*we had the publishable content and the (name of company) deal effectively was just another delivery channel*

David reported the same delivery project somewhat differently:

*when the (company name) deal was signed, there was quite an aggressive deadline to deliver the content and the unfortunate thing, if there’s an aggressive deadline, was that they wanted the content in a new XML format (...) which we haven’t implemented*

In addition to the stages of the content lifecycle at which material impact was most likely to be felt, other themes emerged from discussions on the material aspects of content, predominantly from systems informants. One theme mentioned lightly, and only by Curt, was content as something that could be broken down into smaller parts, and re-aggregated. I will examine this theme in more detail in sections 5.3.2 and 5.3.3. More heavily discussed was the theme of content as something that could be manipulated, even generated, by systems. When Eric spoke about content in these terms, human actors were still very much in the frame, controlling the process, grooming the content to ensure a smooth technical journey:

*the movement of the content, obviously it’s good for us to have some control over it, but also especially if we’ve got it in a state where it can go more smoothly*

*through systems as mentioned earlier, without those glitches, that makes more sense as well, doesn't it?*

When Curt and Ivan spoke of content in terms of systems, human actors were notably absent, with a machine interface sitting between content creators and content users, selecting, processing, and delivering content to them.

Curt:

*The great thing about XQuery is that the result of an XQuery is new content.*

*XSLT is another component that actually manipulates the content, right, it transforms it into, not just a readable layout, but it can filter out content as well. And so for end users there's a huge consequence, because they can look at the same content and see something totally different, and not aware of that. So an end user experience is that he can look at 10 different documents, which are in fact the same content*

Along similar lines, Ivan spoke of “dynamic content rendition as opposed to pre-existing product”, explaining further that “you derive your product at the point at which you need to deliver”. Finally, both David and Curt spoke of the to-and-fro that went on during the development of abstract content structures, or schemas, between the content itself and the schema, with the content often being changed to match the schema, even as the schema was being developed to fit the content. David:

*you then go through it and see what its done and you delete stuff and move stuff around and decide actually that would be better to have it that way and then change your original content to meet that*

Different views arose in the interviews of the relationship between content and meaning. For Louis, who worked at the “coal face” of research evidence surveillance, locating, analysing and summarising research findings to inform healthcare information products, there was a close relationship between real world meanings and the meanings encoded into content. Speaking of setting the scope for topics, he said “the issues are such hot potatoes within a certain topic that that drives the content – you would need to include certain things”. Ivan used the term content to signify the meaning behind the products, a sort of generic basic fact that could be “translated” into different text renditions: “(our clinical product) was written in clinician-speak, and the patient view is rewriting that



same content with the same evidence-base, but in plain English”. Somewhat in contrast, Curt spoke of meaning, or “semantics”, as something that did not generally reside within the content, but which could, with effort, be encoded into it:

*if the semantics are brought into the content, then you're sure that the meaning, what you mean, is actually described there, right. And you can automate the reasoning around the content as well*

Ivan spoke of content as something that could be integrated or embedded into clinical workflows, a coming together of content with a very specific real-world use, while both Ivan and Curt emphasized the potential for content to be personalized, or customized, within systems which took into account the needs and desires of customers, and behaved accordingly. Curt:

*if you look at the parameters you need to produce that customised content, is, you need to have the core content supplied by a team. But the end user needs to supply the parameters to actually get it served up in that particular way*

Finally, content was also described by systems roles as something that was certified, accredited, or validated, for example clinically, or against readability standards; and, on a different tack, and by both systems and content roles as something made to be appealing  
Ivan:

*Graphic designers, they purely apply a graphic representation of the content. So they're lifting words and spaces and making it visually appealing, intuitive, accessible*

Penny:

*The web content is going to be quite different, more layered and sexy and interesting and vibrant and colourful and attractive*

Another term used with various meanings by all the informant groups was **information**. This term, too, was used with multiple meanings. Most commonly (21 uses), the term was used to refer to the *meaning* of the products, as shared with users. More than half of the uses of the term with this meaning came from content informants, including graphic design (Gerry), information specialist (Louis), educational consultant (Eve), and production editor (Pat). Of the content roles included in the study, only the clinical

editors did not use the term in this way. Gerry, Eve and Pat talked about the way information, in this sense of healthcare meanings, was “imparted”, “given”, and “got out” to users by providers, while being “needed”, “expected”, and “accessed” by users. Their descriptions conveyed a sense of the active sharing of healthcare meanings, between those with something they wanted to say (the providers), and those with a particular desire to hear it (the users). Louis’s use of the term information in this sense focused on his work of ensuring that “correct” meanings were conveyed; when he spoke of users, it was in the context of the “translation” of meanings “into patient friendly language”.

In a similar vein, speaking as a business informant, Eric referred to clinical experts as being the “source of the information,” providing meanings that were captured in the products. Also like the content informants mentioned above, he spoke of information in this sense as something that his organisation “presented”, “delivered”, and “put out there” for patients to “get”, while Ben, also speaking from a business perspective, spoke of users “finding the right information”. Chris, from a systems perspective, used the same term, while Curt spoke of information in this sense as something to be “distilled” for users.

Beyond the simple sharing of information-as-meaning between producers and users, informants from each category spoke of more active and complex interactions. For Gerry (graphic designer) information-as-meaning could “help” patients; for Ivan (systems), it “supported” users; and for Eric (business) information-as-meaning was “aimed” at patients by producers, and in a sort of happy communicative misfire, ended up “educating” healthcare professionals as well.

In contrast to Eric’s view of information imparting incidental education, Eve took pains to contrast information with education, with information itself presented as a passive and less valuable entity:

*there should be a focus on not only providing information but striving to educate, which brings about greater understanding*

*it's how you use the resource that really is significant, to move from information to education*

*make it in a way which is much more educational rather than just pure information*

At a more mechanical level, informants from all groups used the term information to refer to digital formats; information in this sense was something to be “extracted”, “reformatted”, “stored” or “entered”.

Some uses of the term information were used only by systems informants. Both Ian and Theo spoke of information as, not an equivalent to the underlying meaning, but an encoded, genericised artefact carrying that meaning into multiple contexts. For Ian, information seemed to simultaneously be both the meaning, and the encoding of that meaning:

*Once the information's in, and it's information, you can do whatever you want with it, you can present it in any way you want. (...)The core information doesn't change*

The idea of information as being a fixed, but reusable artefact able to carry meanings into different contexts was echoed by Theo, who used the term in a rather precise way, in that he felt able to distinguish between information and the less generic “knowledge” on a case by case basis, even though he could not be explicit about the differences:

*it becomes information when it can be used in a more generic case then just that context of your book or your chapter I guess*

*When it becomes information it's reusable, right? (...)It's a bit grey of course, I mean, there's no formula I can use to tick off and say okay, if you score six out of then then it's information instead. So it's more a feeling, and in the long run it probably has to do with, can you re-use your information blocks to build new products?*

In another view specific to the systems informants, Curt defined information in contrast to “document”, as something more granular, “smaller fragments or pieces of information”. This idea of the fragment will be explored more fully below. Finally, following on from his assessment above of meaning, or semantics, as something that

resided beyond content, Curt spoke of information as being more semantically enriched than content:

*I really want to go towards information management. It will add a layer on top of content management to do more in line with the semantic web and relationships between information and dynamic mining of information (...) They want to be able to do data mining and define relationships, automatically interrogate meaning of information, semantics on top of content management*

The final of these top-level concepts that I want to explore is **knowledge**. Unlike the common components discussed above which were used, albeit with various meanings, by all the informant groups, knowledge was only used in this component sense by informants in the systems group. When informants from other groups used the term, they used it purely in its conventional sense, to represent an internal state of mind, similar to expertise. Systems informants, too, used it in this more conventional sense, to refer to something that exists within the minds of people:

*Chris: knowledge can be defined as information that can be set in some context of your own mind actually and it's not just data or information*

*Theo: it's quite hard, especially for publishers, to get the knowledge out of the, let's say the authors, who are really the knowledge holders, right?*

For Chris and his colleague Carl, as technology information consultants, one of the primary aims of the service they offered was “to make knowledge explicit” or “visible”, which Chris acknowledged could be an imprecise science: “each explicit making of knowledge, you forget something”. In moving knowledge from an internal, personal state to an explicit environment so that it might be shared, Chris referred to the multiplicity that might result: “when you have knowledge it is normal case that you want to see it from several viewpoints”. Once shared and explicit, Chris presented knowledge as something with tangible materiality, to be explored by users of the products: “we offer multiple options to navigate through knowledge”.

Alone among the informants, Ivan spoke of knowledge as something to be straightforwardly commoditised, describing the mission of his organisation as:

*to deliver innovative, useful, evidence-based knowledge, best practice and learning to doctors, other health professionals, researchers, and patients when and where they need it*

The singularity of this use of the term is perhaps all the more remarkable considering the fact that the department of the publisher whose products I investigated in this study had taken the term “Knowledge” as its name; in fact, the majority of instances of the term in the data were to refer to the department itself. With the exception of Ivan’s comment above, the term was not used at all by informants at the publisher to refer to the purpose or activity of their department.

On a more prosaic level, all roles discussed their products in terms of the technical formats used to encode the content to enable digital dissemination. At the charity, informants in all roles referred to PDF as a content format. For the graphic designers, the standardisation offered by PDF had greatly simplified the process of sending files to the printer. Gerry:

*just convert it to this kind of PDF and away you go. (...) we’d been going through this meticulous checklist, but in actual fact, if you convert it into a PDF, it does all that for you*

Other roles talked about PDFs as a content delivery format on the charity’s website. Eve, the educational consultant, expressed reservations about this format:

*Eve: what we’ve got at the moment on our website, is every leaflet in PDF, is that the right word, I don’t know what these words are you see, and I looked, I mean I know I looked at the (name of condition) one yesterday, and it’s really hard to read it on the screen. Really hard.*

In contrast Ian saw a place for PDFs in the delivery of a specific kind of content:

*If something is 20, 30 pages maybe it should be a PDF that’s downloadable, it shouldn’t be a big long list*

HTML as a format was discussed by graphic designers and production editors at the charity, both of whom worked hands on with this format. Both roles talked about problems they had encountered when converting data between formats. Penny:

*most of the occasions when Greek symbols have dropped off or got garbled, is it when Word goes into InDesign or when InDesign goes to HTML*

Penny also expressed her preference, when working in HTML, to work with the code itself, rather than the “what you see is what you get” or WYSIWYG interface of the charity’s website CMS which hid the detail of the underlying HTML code from the user:

*I’ve just done a tiny bit of work with HTML itself and then you know what’s there, but with Contribute you’re just sort of guessing*

David, the technical content developer at the publisher, spoke about various quality problems he had encountered with HTML, which he described as being, at times “badly formed”, “tagged with (tags) which aren’t recognised HTML elements” or containing “dodgy tagging” which he had to “strip out”.

The technical content format most discussed most, with over 100 references in the dataset, was, without question, XML. The majority of references came from business, and particularly from systems, informants, but clinical editors Elle and Emma at the publisher also displayed awareness of this format. Emma spoke largely of the limitations and practical difficulties of the implementation of XML within her product:

*At the moment, we really don’t have the tools that we would want to have in order to manage our evidence, really. It’s all stored as, there is XML, but it’s all the data, all the data that’s extracted is within paragraphs, almost always. Or it’s in a table that’s flat, so it’s not re-usable or very easy to find*

*whilst I wasn’t working on it, they changed the XML, so I went to use the tool one day and it didn’t work, because the XML that was underpinning the tool was different XML to the one that they were using*

Speaking from a business perspective, Eric demonstrated his high level understanding of the potential benefits of XML:

*this sort of prototype website, which is a redesigned version of the (charity’s) website, but it’s all set up in XML, as I understand it, so it’s set up in this more powerful sort of database setup, where you’ve got more control over the website, more central control, and more ability to change things easily.*

Also from a business perspective, but this time from within a systems vendor rather than the publisher, for Ben, XML represented the vision of the founders of his company, which was now becoming mainstream:

*It is proved that Curt and the founders of (our company) had the right vision at that time. There will be, one day, a need for this kind of environments, and I see IBM producing their own XML database, you see Oracle, which have XML-enabled variants of their products*

The bulk of discussion of XML came from systems informants. The charity was in the early stage of considering XML technologies. Ian, the information technologist, presented a view of the benefits which was similar to Eric's, if more practical and lower level:

*Things need to be defined, when they're put in, when they're entered, which is the XML side of it, I think. (...) It splits the content from the presentation*

Similarly, David, the developer who worked hands on with XML systems at the publisher, and his colleague Ivan, the information technologist involved in systems selection and implementation, outlined the broad goal of flexibility:

*David: there's a vision in the company to have...in crude terms to have a bucket of XML. Which from that bucket they can produce various products*

*Ivan: we had created this XML schema which was a very generic schema (...) – it's our own internal delivery schema which has multiple different levels which allows a user of that content to do very fine grain stuff or very high level stuff with the content depending on what their specific needs are.*

Curt, whose company was founded on the development of XML-driven systems, outlined in depth the motivation for his interest in XML, which he traced back to the solution it offered to intelligent management of the unstructured data residing within documents, bringing transparency to information unreachable by relational data management techniques:

*We liked the idea of having documented-oriented content and make that more structured. Because if you look at companies, then, I think that less than 5% of the content they have are in relational databases. And if you look at somebody's desk, then it's filled with documents and paper. Or electronic documents. And they are*

*highly unstructured. So there's a much bigger challenge in document-oriented information compared to table-oriented data.*

Curt explained the way he saw XML as being intrinsically a better match for information within documents than relational data structures:

*If you look at the document-oriented world, the document has an implicit hierarchy. So it's a hierarchical structure, and if you make it structured with XML, then you get a hierarchical data structure. Relational models are table-oriented, and it's very hard to map hierarchical structures into a table-oriented model. It's like, I don't know, like viewing a spreadsheet in Word, or viewing a Word document in Excel. So there is an inherent mismatch, and implicit mismatch, between the two data models. And that's why we decided to build (our XML database product), because we wanted to have a database that was optimised for very large volumes of hierarchical structures, based on XML.*

He contrasted this approach with the approach of relational database vendors, whose support for XML relied on constant translation between what he saw as incompatible data models:

*they have an XML layer on top of their relational model, but they actually do a mapping between the hierarchy and the table-oriented model, or binary objects. And it's because of that mismatch it's really not performing, it's not really working. You're also bound to a particular structure you choose, the structure is the schema in XML terms. And they take the schema and they create a relational data model, derived from the XML schema, and the drawback of that is if you're changing your DTD or schema, then soon your database will have to change. And from the beginning we tried with XML, and we were pretty successful in that, to have a model where changes in content and changes in the structure doesn't reflect any database schema changes. Because the XML schema or the DTD is the database schema, there's no difference any more.*

Theo, working in a context where XML was in everyday use, expressed a view that, at the time these interviews took place, XML had become so mainstream as to be invisible to users, no longer even worthy, as he put it, of being described as a technology:

*I wouldn't call (XML) a technology any more, I guess. I mean, it's not a technology, you just use it, right. I mean, again, you don't have to reinvent the wheel, the first thing you do is go out to Google and try to find a matching schema or DTD and try to join the workgroup if it needs changes according to you, and then jump on board.*



*In saying it's not a technology, what I think what I mean is there are enough tools that basically shelter the intrinsic of XML for you. So if you're an author and you're used to working in a WYSIWYG environment, you can do so, even now with XML. That's what I mean it's not a technology. It's no more effort working with an XML file than it is working on a Word file. And Word is also not a technology. How would you call Word? An application, right, or whatever. That's what I would call XML, then*

By the time of the second round of interviews, after the company had been bought by the enterprise-level content management vendor, Curt's vision of the future of XML was that it would become ubiquitous, bringing a sort of universal transparency to a range of document formats:

*they expect that every content type will get a certain degree of XML. Whether that's a pure XML form, like for instance Word is now XML, or whether there is a meta data layer in XML around that and they want to be able to do data mining and define relationships, automatically interrogate meaning of information, semantics on top of content management. That's why XML currently is so important. That's really exciting*

*No matter what the input is, it all has to go to XML, that's the idea. I like that.*

In contrast to the victorious flavour of Theo and Curt's perspectives, Dee, who worked alongside them to develop and maintain the XML systems hands on, felt that over time, XML technologies had lost some of the simplicity and elegance that had first appealed to her:

*It's easy to read and it seemed very elegant at that time (...) It's readable, you know exactly what's in it (...), it's simple. I like simple (...). Although I cannot say that now that I work with (name of company) that we have to get into all the XML specs and it's not so simple anymore so... The very elegance at that time is well, it's relative really. (...) You run into special things like name spaces and stuff that are not modelled so well and you bump into that all the time*

David, too, working with the same technologies but at the publisher, found that the reality was often somewhat messier than the ideal of the vision:

*when I started working here, the first product I worked on was (...) vaguely held in XML. Not pure XML, it was a mish mash between badly formed HTML with an XML wrapper around it. And one of my main jobs was to convert that into something more useable*

### 5.3.2 Generic low level components

The generic terms **title**, **line**, and **sentence** were used by both content and systems informants, but with different nuances. **Title** was used by both Eric and Pat at the charity as a synonym for “product” or “booklet”. Emma used it in its more conventional sense as a heading or name for a larger piece of content, but linked it also with the actual subject matter covered in the named content, creating an equivalence between the title of a piece of content and its general meaning:

*the (...) editor would decide which topic would be covered. So it would be sort of the title of it. So in this case rheumatoid arthritis. So we say say, okay we would like to cover this, because it's important*

In contrast, systems informants David and Curt used the term in a purely structural sense, in relation only to other pieces of content, and not to their real world meaning:

*Curt: if you allow total freedom at the fragment level, then suddenly a title could be used, for instance, or a para, could be used in a totally different context as well*

*David: we've got other type of content which is quite loose with you could say, titles, headings, section with HTML content*

*David: it allows you to transform it quite simply on a website because you can say 'this is a section which contains text and this is its title'*

**Line** was used by both graphic designers and production editors at the charity in relation to the time consuming and detailed collaborative work they did on the print layout of the content they worked on, while for systems informants Theo and David, the term was used to estimate the size of pieces of content, with Theo imagining a future product which might amount to “two lines on your mobile phone” and David describing a particular element of the content as being about 10 lines long.

Graphic designer Gerry was keen to downplay the importance of the grammatical entity **sentence** with regard to questions of layout, commenting pragmatically:

*The idea that a sentence starts on one page and continues on another, well people turn the page. That's how you read normally*

Eve used the term to signify the smallest unit of meaning imaginable, stressing that even such small units could change their meaning when read in different contexts:

*even the same sentence, you might read it in a different way two years down the line, because it's now relevant to you, or you've understood that better*

Elle similarly used the term to indicate the closest of detail, this time from the perspective of the final checking before publication:

*the final stages, when you go through each of the sentences, and check both for style, and also for content*

Systems informant Curt zoomed in even closer, homing in on the term “character” to illustrate the smallest possible unit, before correcting himself to zoom back out to the sentence level when he considered practicalities and usefulness:

*The main difference was really being able to store large volumes, while at the same time being able to address a single character. Well in practice it would be like a sentence or a paragraph*

The low level components discussed above all have long standing conventional meanings, rooted in style, layout, or grammar. In contrast, the terms “element” and “chunk” are more unusual, looser in meaning, and do not necessarily have any formal, commonly understood relationship to meaning or structure.

Clinical editor Emma used the term **element** in its generic sense, simply to refer to different, currently nameless parts of her product, which at the time of data collection were subsumed into a larger unit, but which might be separated in future workflows:

*we may have (...) have the people who are detail focused working on one element of the product, and other people working on other elements, as opposed to now, where one editor does everything for a particular review*

Systems informants, including Theo, Curt, David, and Dee, used the term in a much more specific way, to refer to the basic coding entity of formal markup languages such as XML and HTML. The elements in any particular variant of a markup language are defined in a master document called a schema, as referred to here by David:

*we have a schema for each product and we try to have common elements in their own schema*

*we have quite alive products in that we're always adding new content elements, so we're always changing the schemas here and there*

Once an element is formally defined within a schema it can have extra levels of meaning attached to it in the form of metadata, as David describes here for SNOMED codes which are a standardized medical terminology:

*I would hold the SNOMED code as metadata against the document and the different elements*

Metadata can be attached to elements via the formal mechanism of attributes, and content which is formally marked up as elements and attributes becomes, in a sense, self-describing. Here, Dee, the systems developer at the company which supplied the publisher's CMS, spoke of querying elements, and having them respond to identify themselves by listing their attributes, which hold extra meaning about them:

*if you have an element and it has default attributes, the default attributes are only located in the schema - you always see them those default attributes, you can ask from an element, 'what are all your attributes?' and you will see the default attributes*

In contrast to the term element, which held a precise, formal meaning for systems informants, the term **chunk** has no conventionally accepted meaning in either content or systems spheres. This was a term used with enthusiasm by systems staff at the publisher and at their systems supplier, who saw “chunking” as a way of dividing content up to support novel re-use and management scenarios. Theo stressed the importance of relating chunks to meaning as well as structure, using an example from a “frequently asked questions” section of patient topics created by the publisher:

*their chunking level is, it's question-answer, question-answer. And that's what I would call meaningful. I mean, the option would be to have a separate chunk for question and a separate one for the answer (...) Then it's not meaningful, because you sort of miss the context, and them being together, question-answer, in this particular sample, describes the meaningfulness*

This link with meaning differentiates the chunk from more conventional structural elements such as chapters. According to Theo, it could be problematic to map from conventional elements to chunks. Here, he described the problems encountered by an educational publisher client who tried to use existing chapters as chunks. Some of these problems were issues of deixis, or indexicality; as text moved around, verbal “signposts” no longer pointed in the right direction:

*So the chapter still said “As described in the previous chapter,” for example. Well, that didn’t work, because that’s not the previous chapter any more. And also, looking at the end of each chapter was like maybe three pages of questions. And a lot of those questions were also related to stuff that he or she should have studied in an earlier chapter. So we had a discussion with them, so, okay, chunking level of chapter probably doesn’t work.*

In contrast to more conventional structural elements, Theo described the chunk as essentially fluid, and likely to change over time:

*it probably still is a process of trial and error to see in the end what your chunking level should be. And that also means that you have to look for products that support that kind of evolution, right. What could be a good chunking level now is probably not enough in five years’ time*

Regardless of the perceived benefits of “chunking”, the reported difficulty of defining chunks in the most useful way might be seen as an impediment to the adoption of this unit. But Theo felt the difficulties would resolve with time, and with the development of new information literacies:

*let’s call them the Google generation that will probably bring new authors that are used to working in chunks*

David, the developer at the publisher who worked hands on to translate content into machine-processable structures, spoke of chunks in practical terms, as items against which to hold metadata such as standard terminological codes:

*it depends how low level you want to code but currently we code on chunks of XML that we’ve chunked, so the individual chunks of XML would have their own metadata attached to them. If we wanted to code to a smaller chunk within one of these chunks that might produce a challenge*

Despite this hands-on facility with chunking, he expressed some scepticism about the usefulness of the approach:

*Business about two years ago got very excited about chunking and the ability to chunk really small bits of data and then use those small bits of data to create new documents, but I mean that was a misunderstanding of capabilities, or misunderstanding of the nature of our content, that you couldn't actually chunk very low levels because most chunks existed within a context*

A similar scepticism came through in a rather more amplified form from the business and content informants at the charity, as they contemplated their first steps into structured content management. Eric, faced with a purchasing decision which could overturn the working practices of his publishing team, mused on

*the more complex question of whether we want to break it down into chunks to link it together in quite a complicated, well in the background I would imagine it would be complicated, whether it will on the surface... Beyond that I don't really know what a content management system is likely to do for us or whether we need one or not.*

Production editor Penny was even more forthright:

*Is this dividing it up into chunks just to facilitate web use, or what? (...) on the whole I wouldn't have thought, you know, sort of dragging out bits from a database to put into a booklet ain't going to work, unless I've missed the point totally*

She questioned the usefulness of the approach, even at the mundane production level:

*you know my Word documents seem to slot into the InDesign template without thinking about chunks and things*

In a lively debate in the workshop context, systems informant Ian and business informant Eric laid out the hoped-for benefits in terms of production time and effort saved, including the following exchange:

*Penny: So it's easier if things are all in chunks, even if the chunks are not that meaningful?*

*Ian: Well, we need to make it meaningful*

The term chunk, while intuitive to those who worked hands on with content, carries with it an air of informality, and, in more formal settings, the systems vendors and those who work with their systems opted for the more business-friendly term **component**, differentiating their main systems product from competitors by describing it as a “component content management system”. Chris, the implementation consultant:

*What (this system) supports better than other content management systems is it supports not only on document level but also on information component level, that's the difference*

Theo discussed the way the flexibility born from the generic nature of the component required customers to make fundamental decisions about the nature of their content up front:

*in principle, anything within (this system) can be a component, right? Even a single character could be, but that wouldn't be very practical. So what I always say when I go out to customers is, try to identify that level, that could be in your case a paragraph, in someone else's case it could be a chapter or what used to be a chapter, that can be used as a solo unit, maybe with links to other solo units, but still, by itself, be meaningful*

In contrast, and in service to the ideal of genericism, Curt took pains to distinguish components, which he defined as structural items, from their usage or meaning, describing the choice of components as “arbitrary”:

*we soon discovered that something that might be a component is not necessarily useful for content reuse. So we always say that what a component is is something completely different than the level of reuse. Because you choose a component level which is sort of a management level, right? In our terms, the version history is maintained of that, and you check it out, and you know the changes. But no matter what choice you make in what a component is, a certain day someone will come up and “Well I want to reuse only a fragment of that” or “I want to reuse multiple components into an assembly”. So there are two arbitrary choices, and that's how we set it up in (this system), allowing you to reuse fragments anywhere. You're not bound to a previous decision of what a component is*

For Ivan, at the publisher, a component was potentially a commodity that could be sold:

*this is what (this system) is all about. It's componentising our content and to the minimum reusable or resaleable unit, plus anything which is reusable within this*

*there's a systematic review relating to every condition (...) so each one of those is, in itself, a saleable component. Potentially.*

For Ben, business development director at the systems vendor, the saleable proposition was the concept of component content management itself, embodied in the system his company had produced:

*We just said, there are so many vendors in this space, we must be different. And the product is different, because we're a component content management system, not a content management system, focusing on managing these information components, and linking them together, assemble them for publication*

In a statement somewhat contradictory to the above, he also described how the concept of component content management had come about to fulfil a customer need:

*the whole idea a couple of years ago of component content management was also customer driven. It's not something we found out "hey we need to be different", no, (a client) needed that. And then (another client) needed that. And then we figured out there are a whole lot more companies needing that.*

Theo, Curt and Ben all looked forward to a future when the skills and practices involved in publishing would better support componentised content, without being, to use Ben's phrase "overwhelmed by all these components":

*Theo: There is and there will be more a need for information managers, right, is that a correct term? People who lay out a structure without it being the structure of a book, but let's say the structure of information components. And then have experts, ask them to fill in those components.*

*Curt: you could tell them well this component is for instance reused in 3 other contexts, then when you're writing that particular piece of text, you have to be aware that it's going to be reused in three contexts*

*Ben: if you're (a client), you don't have all those reusable components yet. You start with a huge amount of information of data, and over time, you can say, now I want to take this piece out, normalise it, and put a link to that from different sources*



Other, more idiosyncratic synonyms for component were **fragment** (used only by Curt) and **information block** (used only by Theo). Using the term fragment, Curt discussed the detachment of pieces of information from their context, and the some of the practical limitations of that approach:

*if you allow total freedom at the fragment level, then suddenly a title could be used, for instance, or a para, could be used in a totally different context as well. And sometimes that's overwhelming for authors*

*if you take any author and ask him to write a context independent fragment, well you only have to look at the content and at some point the fragment becomes so small that it's not context independent anymore*

Theo, using the term information block, also spoke of the fluid relationship between such components and their context:

*What could be a good chunking level now is probably not enough in five years' time when you have to find new products when I don't know, when you set up new liaisons with other companies that might have something else that information blocks need to tie into*

*context will be more fluid, it will be more dynamic, it will require more words or tags or whatever to describe your context, and thus the information blocks, you have the same tags and metadata attached to them, to be able to find them*

### 5.3.3 Generic high level components

Of course, there is more to an information product than a loose bag of low-level components, and informants used a range of terms for the higher level components of products. Some of these, such as **chapter**, were adopted from traditional terminology for books. Of the content informants, only Elle used this term; the product she applied it to had started life as a regular print publication, before transferring to be an online product. The use of the term by systems informants Theo and Curt was slightly different; they used the term to describe a part of a larger product that might be combined with parts of other products to create novel products for a particular market, such as study materials to support a particular course design. Curt:

*if you look at the study material, they sort of pick pieces of content from other studies, and they combine, because otherwise it's not do-able. So within some of*

*these studies, they are encountering that they need a chapter of this book, and a paragraph of that one*

Theo used the term in a similar way, to describe the same usage, but also stressed the inadequacy of the traditional chapter to support this kind of pick-and-mix approach to product design:

*their idea was to sort of allow the teachers, or maybe the students, to select out of their whole collection exactly those chapters that they needed. So they started out by chunking out all the chapters out of the books, and make a simple list of that, and then try to describe the chapters. Made a simple interface, you know, people could basically take off which chapters they needed. But it turned out that that's a way too high level of granularity.*

The history of content development at the charity was different, and here the term **booklet** was used to refer to components covering a single topic or condition, harking back to the genesis, and continuing use, of this content as self-standing booklets, as well as the basis of an online product. This history led to some blurring between the use of the term to signify piece of information, or complete product.

Graphic designer Gill described booklets as something to be “assembled”, rather mechanically, from “information” supplied by production editors:

*We have our templates on the computer that we use for the booklets (...) we'll take all the information from (the production editors) and then we will assemble it in InDesign, so we've actually got the booklet on screen, as it should be*

She went on to describe how her painstakingly assembled work was then re-assembled by an information technologist for use on the web:

*(Isaac) has been inheriting all of my information from the booklets, all the text and everything else, to put onto the web, and then he's been having to sit and go through and reformat it all*

For Ian, another information technologist at the charity, “booklet” was best considered an output format, rather than a meaningful unit of organisation:

*Instead of spending two weeks creating a booklet, and then another two weeks creating a website, you would just create text, and then it would be very simple to create a booklet and a website from that original text*

The term **topic**, though most often used in its conventional sense to mean “subject matter”, was also used to describe a structural element within publications. Systems informants Ivan, Theo, and David all used the term in this way to refer to the condition-specific sections of the patient information produced by the publisher.

*Theo: If you look at how they chunk their information, for example that patient topic, then you can really tell that they started to get things out of their original context*

*David: we have quite well structured content for (our patient product) and I wrote a schema from that so I developed it by taking the 200 plus (product) topics, then reverse engineered a schema from it*

David spoke of his use of the topic component as a hanger for metadata, highlighting the ambiguity of mapping standardised medical terminologies to pieces of content of this size:

*you can code a topic in so many different ways to mean the same thing and I envisage that if we're ever going to use this successfully we need to stick to the same rules all the time and try to stick to them*

Louis, from an information specialist perspective, distinguished the term “topic”, which he used broadly to refer to the conditions on which he regularly searched for newly published research, and the “review” which was created by the publisher, and which term I discuss in section 5.3.4:

*every 12 months we come back to each topic and we look at the checklist and we look at the topic plan and we look at the review itself*

In contrast, clinical editors, who were not closely involved in the literature search, used the term topic synonymously with review. Elle:

*this is what we use as a topic plan, and this is used (...) by editors, in order to define the topic, the review*

*the structure, we follow a template there. And it's also now in content management system. This is the document that we start off with and that gets transformed into the topic later*

In addition to the conventional terms discussed above, systems informants Chris, Curt, and Ivan also used the term **configuration** to refer to higher level components. The connotation was rather different; a configuration was explicitly a compilation of smaller components. Chris, the implementation consultant:

*you get some point where you make connection, you make a configuration, you make a combination of the information components and they need some glue text, some context related text to glue together*

For all of those who used the term in this way, there was a strong element of enabling personalisation of product by customers.

*Chris: the ideal situation is that customers are able to configure their own products*

*Ivan: it was just a question of setting up a new rendition, a new instance of that pipeline to suit specifically (our client's) requirement so as far as I'm aware it was an incredibly simple delivery or configuration to suit the requirement and actually it was just very minor fine tuning of that pipeline delivery to cater for the changes which they'd identified.*

*Curt: what we expect is that content on the web will be personalised to a very high degree where a very simple example is hey, you have a particular configuration of, let's say, a product now you're looking at a user menu or you see all sorts of options that don't apply to you. And if you were able to personalise that then you exactly see a manual that is tailor made for you – for your particular preferences, personal preferences and configuration.*

Systems informants also used a range of more idiosyncratic terms for higher level components which provide an insight into individual understandings of content structure.

David, working daily with content in a hands-on way, used the term **bucket** to describe the generic container for reusable smaller content components which was, in effect, the content management system:

*there's a vision in the company to have...in crude terms to have a bucket of XML. Which from that bucket they can produce various products and that's the vision*

*the vision is that you can componentise it quite well and use it as a big bucket and interlink between the different components and publish with freedom*

Both graphic designer Gill, as already reported, and business development director Ben used the term “assemble” to describe the creation of information products. Ben:

*we’re a component content management system, not a content management system, focusing on managing these information components, and linking them together, assemble them for publication*

Despite this use of the related verb, of all the informants, only Curt used the noun **assembly** to describe a higher level component of information products. It was a term he used often to describe a highly automated product creation process:

*the whole consequence of a component approach is that you have to do an assembly again to make it somehow in a readable form*

*the whole idea is to have a degree of flexibility to do content aggregation, and especially the linking model is one choice, but then you have to predefine links as well, so you have to apply links to build an active assembly*

*the database is very suitable to do dynamic delivery of content based on XML or you have all sorts of conditions and preferences of end user, and you do dynamic assemblies and dynamic rendering of content to end users*

Similarly, only Curt used the term **composition**, suggestive of more creative human input than the mechanical term “assembly”, to describe the user-driven selection of components to make novel products:

*he wanted to let teachers build their own compositions out of reusable fragments*

Having raised the term, Curt mused on the implications of layering creative processes in this way:

*I never thought of things like, if you’re building a composition out of components, how do I trust the composition?*

Two more terms for higher level components were uniquely used by Ivan. The first was **amalgamation**, applied to a product made from blending the publisher's own content with content from third party suppliers or partners:

*we very much recognise that third party content amalgamations are actually more beneficial and we have to acknowledge that we can't provide all of the information pertinent to a clinician but we could certainly manage the process by which it's amalgamated and delivered.*

*we have services where we receive feeds of peer-reviewed journal articles from other publishers, where they're rated for newsworthiness, and importance. So again peer review validation of that content, which is being amalgamated and integrated into our own*

The second term used uniquely by Ivan, at least in the sense of a higher level information component, was **category**. Here, he explains why he feels that categorisation of reviews is potentially of more commercial value than the reviews themselves:

*(reviews are) only saleable components when you start to categorise them. So then you start to categorise by various things, it might be user categories, or it might be specialist interests, or it might be market sectors, or it might be diagnostic tests or conditions or whatever. So when you actually start to apply that categorisation, then you can start to create feeds which are pertinent to a category. And once you've made it pertinent to a category, you can also start to then build up the personalisation such that you can allow an individual to say, well actually, my unique interests are this, this, this, this, and this. And as a direct result of those unique interests then you can actually serve content or content access based on that. So you either serve content as a set menu, or you serve it as an a la carte menu, and obviously the way we sell stuff is set menu as it stands at the moment. It will increase the number of set menus we can offer, through the categorisation, but ultimately we want to get to a la carte*

#### **5.3.4 Domain-specific components**

As already mentioned above, at the time of data collection, the publisher was engaged in an experimental project to append SNOMED codes to its content, in order to facilitate information retrieval when content from the publisher was integrated into healthcare systems. These codes were created and maintained by an external body, and mapping the codes to the publisher's content was not straightforward. Both Elle and Emma cited the provenance of SNOMED coding within different fields as one reason for the difficulty in implementing it within their own context:

Elle: *it has come out of the pathology and insurance systems, so for example there's a code where you can say okay, someone who has, you know, breaks a leg after being hit by a fridge falling from a ship, or something like that. So really sort of very distinct things*

Elle: *the problem is that because you can come in from so different angles to the codes, it's very difficult to make sure that what the clinician is looking for and what we've created, that that code is actually listed*

Emma: *you can get the same thing coded different ways, and it can be quite difficult to marry those together. They can do it quite well if it's in the same ontology, but if it's in a completely different one it's not working quite so well for them. Because SNOMED has been, it's basically been generated by insurance companies and ICD-9, so people can put in a code for anything at all. So you get this bizarre thing where there is actually literally a code for "man run over by bus whilst on pedestrian crossing" but there's no code for non-Hodgkin's lymphoma. Because presumably, at the time when the coding was done, non-Hodgkin's lymphoma was a very specialised illness, and rare, no-one happened to have it. So they haven't got a code for that. But they have got a code for the man who got run over. Which is sadly macabre but funny. The poor man who got run over by the bus on a pedestrian crossing. Gone down in indexing history.*

David, despite being personally tasked with building the applications which were used to apply and manage the SNOMED coding, was sceptical about its usefulness:

*ideally everybody's coded their stuff up in SNOMED or Read or whatever and we all do this amazing computer talking to each other. So the concept's powerful. It's very nice, very Star Trek-y but reality in terms of business, no-one's ever come up to us and said 'supply us content with more SNOMED codes in, we're ready to use it.' And I, after looking at SNOMED quite a lot, I can understand why it's never happened because it's really complex and involves a lot of time investment and understanding*

Staff at the publisher also favoured domain-specific terms for higher level components. The most commonly used was **review**, shorthand for **systematic review**, used by content informants Elle and Emma, the clinical editors, Louis, the information specialist, and systems informant Ivan. Far from being a simple technical or structural aggregation, the systematic review must be prepared in accordance with a strictly defined, standard methodology determining the inclusion and exclusion of references, and the ways in which the content of those references is presented and interpreted. In addition, at the publisher, where many systematic reviews were created and regularly updated, process

efficiency required a high degree of specialisation in tasks, so that the work of compiling a systematic review was not only methodologically rigorous, but also socially complex, involving the timely engagement of a range of actors, both internal and external.

Elle described the planning process that she and other editors carried out in conjunction with clinical experts to define the scope of the review:

*this is what we use as a topic plan, and this is used (...) by editors, in order to define the topic, the review. So which condition we are dealing with, the population we are dealing with, what are the relevant outcomes, what are the relevant interventions*

A strict methodology of evidence identification and selection was employed to ensure that, as Elle put it, “what is actually part of the review is not influenced by beliefs or preferences of the authors.” Louis described the painstaking specialist work carried out by his team, the information specialists, to first locate and assess the relevant literature:

*you do a literature search and we have an inclusion criteria which is set beforehand and written up in a protocol and within that protocol we appraise the results of the literature search and we’d review it, we’d literally systematically review it*

With work on this scale, economic concerns came into play, but as Louis described, these could trigger complex negotiations with the authors of the reviews, in the light of the methodological rigour required:

*we’ve a limit to the time and the resources that we can spend on each review so we limit the content at this update, at this search period, but we will include it at the next one. But then you might get something back...the end review from the author might include information that we didn’t agree, and if that’s the case – sometimes it’s happened that the consequences of that is that it gives us extra work because we then have to go and do additional searches to make sure that we’ve captured what they’ve already included. Because if it’s left alone and we don’t do a back search, then we will have excluded maybe other relevant studies.*



In addition to interactions with economic factors, specialist clinical expertise, and the rigour of standardised methodology, Louis also described how reviews were further shaped by the characteristics of the particular conditions they covered:

*You may get some reviews which are more complicated than others. Cancer reviews for instance tend to be quite complicated because of the different stages of cancer.*

Speaking from an editorial perspective, Elle described the work of making the reviews readable and relevant for the clinicians who were their audience. Paradoxically, this involved hiding from the reader much of the painstaking rigour which provided an assurance of quality, and hence much of the value of the review:

*we are usually not that explicit within the review, within the chapter, within the definition and so on, or even in the methods section, as we are with our information specialists, because they have to make sure that they include everything that is relevant and exclude everything that is irrelevant, in order to reduce the workload for editors and authors. So I think at this point in time, they want that clarity and they want that explicit coverage. Whereas we then, when we go towards publication, we just take that away, filter it out again.*

Yet another factor in shaping reviews was the needs of particular audiences, as perceived by the content workers. Elle described the different focus of reviews designed for patients:

*(The patient editors) look at a wider range of interventions than (our clinical product), because they think, and I think they are right, that patients will expect to find all relevant treatment options discussed in a patient review, not just the ones that we've already covered with our authors on (our clinical product).*

And finally, when the complex methodology, team relations, and editorial craftsmanship were all completed, the review, like so many of the components described above, existed as a structural element, against which metadata could be appended, with the process described by Elle as “we assign one code per review, one code per intervention.”

Finally, I would like to look at terminology for components which has its roots, not in the structural forms of the content, but in the meanings they carry. The two terms of note used by informants in the study were **condition** and **intervention**.

The term condition was used widely by informants from all groups, across both organisations, in its literal meaning of disease, or disorder. In this sense, conditions were a key aspect of the external context of the information product.

*Eve: the charity is to help people with this condition live their lives more easily*

*Louis: at the end of the day you're producing something that...ultimately you're hoping it's helping people out there with a condition*

Although Eve took pains to point out that the condition covered by the charity “isn’t one thing, it’s a huge continuum of conditions”, this tight focus meant that the term “condition” was not used to describe a structural content component by informants from the charity. In contrast, at the publisher, which routinely covered hundreds of diverse conditions, the term was very often used as a synonym for chapter or review, to cover a structural element dealing with a specific condition. Ivan used it to describe an element that could be used to drive navigation:

*If you select a condition like anxiety, then it will take you off to the (product) site, but also if you select the same thing from the patient site, a very clear breakdown, what treatments, what is it, what are the symptoms, how is it diagnosed, how common is it?*

In similar vein, Elle and Emma described the use of “conditions” as search terms, by clinicians seeking particular pieces of content within a system:

*Elle: if your clinician is looking for this condition, please put this into your system, and that will link to our content*

*Emma: a clinician may be working within an electronic patient record system, and would be looking for a condition or an intervention, and would search that*

Ivan also used the term in a more abstract and strictly structural sense, to mean a piece of content:

*If you go down very much to the lower level and you look at a specific condition, then we have integrated into that condition articles which have been rated for relevance and newsworthiness and also associated guidelines which are coming in from third party organisations*

And again, like so many of the components, conditions were something to which metadata could be appended:

Elle: *we are SNOMED coding our conditions and interventions now*

Emma: *SNOMED CT? Right, this is a coding system where you assign certain number codes to conditions or interventions*

David worked alongside Elle and Emma, and created the tool they used to apply codes on the SNOMED project. He was clearly still learning the terminology for these specialist components:

*Options are question and answer...I'm not very good at (clinical product) terminology. You have a treatment which is basically an option to an intervention which is...is that right? Or is intervention a treatment...I don't know. \*laughs\* I would have to look at the (clinical product) book*

Like condition, intervention was used in its literal sense, to mean a particular treatment. Louis used it in this literal sense, but also as a specific analytical measure used within the standardised methodology of evidence search and appraisal:

*it doesn't really make any difference to us what topic we're doing, because we apply our inclusion criteria and we use what's called PICO: Population Intervention Comparison Outcome, and study design, so it's like PICO, and if you apply that to your appraisal, you keep those things in mind – that's what you're looking for – then you can make the decision*

For Chris, the implementation consultant, interventions were one example of an information “facet” which could be used to aid meaning-driven navigation of an information product:

*see for example you can select the audience type, you can select the intervention type, you can select the disease, actually, the section where it's belonging to, and the age of that. A user is able to select and navigate any of these things, and say okay, I want to have only the interventions for surgeries, I want to have the Men's Health section, the audience type is 35 years old, actually the age group, then give me the interventions which are suitable.*

According to Chris's account, "facets" could be used in combination, so that quite complex filtration techniques could be used to home in on the most relevant information:

*here you see a relation between two facets. For example infants, when you have selected infants, maybe there is a medical doctor who says okay, chemotherapy is not suitable for infants. And when that's always the case, or you can say please apply this rule, that's knowledge, and will result in, when you're selecting infants, you don't see the intervention types or chemotherapy as selectable. And so this is just a way, the word-intelligent faceted search, that you add more knowledge to the system*

Elle talked about the process of adding more meaning to the structural element, to increase the relevance of system-based retrieval:

*how to weight certain interventions, so that when you get the output at the end, it makes sense to the clinician*

Finally, in a loop back to the literal meaning of the term, Elle described how the work of creating systematic reviews, and researching interventions, is then fed back to those commissioning clinical research, to inform research priorities:

*there's one initiative that we do with (our clinical product), is that we work together with the HTA, the Health Technology Agency of the NHS. So we would give them a publication, and they go through the new interventions and conditions, and look at those interventions that have been categorised as unknown effectiveness, and let us know that they would be interested in looking at that area in detail, because they're also research funders. So they feed that back to us, and we submit that intervention, as a research suggestion, back to them, to their website, giving the information that we have gathered through the review, with that submission*

## 5.4 Conclusion

In section 2.8 of Chapter 2, I posed the questions *How are **information artefacts** mobilised in the digital mediation of healthcare meanings?* and *How are they characterised?* In this chapter, I have explored informant perspectives on information artefacts, working within the conceptual framework also set out in section 2.8 of Chapter 2, in particular the concepts of *interlocutor models of communication*, and *digital materiality*. In sections 5.1 and 5.2 of this chapter I presented my findings firstly on perceived intent and communicative action with respect to information artefacts, while in

section 5.3 I presented findings on the perceived materiality of digital artefacts. My findings showed wide variation in informant perceptions across these dimensions, suggesting disparity in interlocutor models of communication, particularly between particular expertise groups, within which thematic patterns were observed to emerge consistently. This suggests that achieving mutual understanding and communicative transparency might be particularly challenging between these different expertise groups within the digitally mediated healthcare discourse.

In Chapter 6, I will bring together the themes from Chapters 4 and 5 to explore the ways in which expertise and digital artefacts can be seen to work in combination in digitally mediated healthcare to promote or hinder communicative transparency, a research objective which informed the third of the empirical questions I introduced in section 2.8 of Chapter 2.

## CHAPTER SIX

### Mediation and transparency in the digital healthcare discourse

#### Introduction

In Chapters 4 and 5, I presented empirical data on a range of expertises and information artefacts brought to bear on the digital mediation of healthcare information. In this chapter, I build on that presentation, and further consider the implications of that data for *communicative transparency* in the digitally mediated healthcare discourse.

Communicative transparency was introduced in section 2.8 of Chapter 2 as a key element in the conceptual framework for this study, and explicitly related, in section 2.1 of Chapter 2, to the Habermasian notion of idealised discourse in the service of mutual understanding. As discussed in that section, communicative transparency depends on the raising and resolution, within a discourse, of validity claims to propositional truth, to expressive truthfulness, or sincerity, and to normative rightness. When such validity claims cannot be resolved, or when they cannot even be raised, transparency is challenged.

The analysis presented in this chapter will inform answers to the third and fourth sets of my empirical research questions, also introduced in section 2.8 of Chapter 2:

*How do specialist expertise and digital artefacts work in combination in digitally mediated healthcare to promote or hinder communicative transparency?*

*What factors exacerbate challenges to communicative transparency in the digital mediation of healthcare meanings, and what factors mitigate them?*

In the course of this chapter, I will consider all aspects of the conceptual framework introduced in section 2.8 of Chapter 2, which are italicised in this introduction. The chapter begins with a consideration of the mediating processes of standardisation as they emerged from the empirical data in connection with information artefacts, with expertise, and with combinations of the two. I then consider expertise as a mediator, and the ways in which it shapes the structure of the *digitally mediated healthcare discourse*. I present

this diagrammatically as it emerged from the data. Next, I present a detailed consideration of *interlocutor models of communication* enacted through information artefacts as these models emerged from the empirical data, including models of *digital materiality*. Finally, a consideration of challenges to *communicative transparency* as revealed in the empirical work is presented.

### **6.1 Dimensions of mediation: standardisation**

When meanings are subject to mediation, a gap often emerges between the contexts of “production” and the contexts of “consumption” and, consequently, in the terminology used in this study, between interlocutors. With healthcare meanings, this gulf takes on particular shape and dimensions, crossing as it does between healthcare contexts, which are simultaneously highly formalised on the clinical, professional side, and deeply subjective on the experiential, patient side, and non-healthcare contexts such as the content and systems environments in which information products are created. Additionally, when healthcare meanings are digitally mediated, the differing modes by which meanings are transported across contexts take particular forms and impact in particular ways. Transparency across contexts is challenged by the material limitations of mediating artefacts such as systems and formats, by the different expertises held by the wide range of mediating interlocutors, and by the way these two factors interact.

One of the mechanisms by which the gap between contexts is bridged is *standardisation*, which emerged in several forms from the empirical data as a means of addressing the shift in focus from a single clinical case or patient, as is found in the classic healthcare encounter which forms the communicative baseline for this study, to generalised statements, applicable to many cases. Meanings shared in this way were generic, rather than specific, and formal standards were often employed to enable continuity and ensure that the meanings had as broad an applicability as is possible. Creating these generic meanings required multiple layers of interpretation and translation in order to promote relevance at both generic and specific levels. In the course of those processes of

interpretation and translation, and the consequent layering of contributions from multiple interlocutors, challenges to transparency arose.

In the interview data, three types of standards were referenced as being brought to bear on the sharing of healthcare meanings. These were standards of healthcare practice, material standards, and *blended standards* that contained aspects of both practice and material standardisation.

### **6.1.1 Standards of healthcare practice**

Both the charity and the publisher were explicitly committed to the advancement of medical knowledge through clinical research, with the charity's primary function being to fund such research, and the publisher's primary function being to interpret and disseminate the results of such research. As discussed in section 2.3 of Chapter 2, the evidence-based medicine (EBM) movement, which champions scientific findings as the basis of clinical practice, aims to identify and standardise best practice, to maximise beneficial outcomes for the highest possible number of patients. There is, of course, a gap between standardised best practice, calculated for maximum efficiency at the level of a population rather than an individual, and the most appropriate clinical approach for an individual patient. In the EBM model, negotiation of the gap from generic best practice into relevance for individual patients is left to the professional discretion of the presiding clinician. In the mediated sharing of healthcare meanings, the presiding clinician at a case level is not generally present as the meanings are captured, encoded, and circulated, and so this gap must be considered and negotiated especially carefully by those involved with the creation and circulation of such information.

One of the communicative challenges faced by the charity, which, alongside its primary activity of funding research into improvements in clinical care, also had the task of providing patient- and clinician-facing information on a currently incurable chronic condition, was to bridge the gap between the present, generic reality of incurability, and the personal experience of patients living their everyday lives. Content informants Eve and Gerry presented their information as bridging this gap by using the tactic of helping



patients to cope with an unpalatable reality (pp.174-175). While still addressing an audience at a generic, rather than an individual level, they sought to ensure that the communication addressed aspects of patient experience, as well as the scientifically sanctioned clinical angle, bridging the gap between the two.

For the publisher, focused on distilling lessons from scientific research to inform clinical practice, the communicative challenge was different. Here, the gap was between the abstract world of scientific research and, for clinical products on the one hand, the needs of the individual clinician treating individual patients, and, for patient products on the other, the needs of the patient when making sense of treatment alternatives. Informant Elle described the tactic of structuring publications around realistic clinical questions, for which answers were then sought in the research literature, rather than adopting a research-led approach to defining publication scope and structure (p. 114). Approaching the task from the angle of the imagined needs of user-interlocutors bridged a gap between generic information and its applicability to specific cases.

### **6.1.2 Material standards**

Material standards manifested in the research data in two variants; healthcare standards, and systems standards, both of which were discussed in section 2.7 of Chapter 2.

Material healthcare standards were represented in the data by the standard terminologies MeSH (Medical Subject Headings, maintained by the US National Library of Medicine) and SNOMED CT (Systematized Nomenclature Of Medicine Clinical Terms, maintained by the International Health Terminology Standards Development Organisation). These terminologies were in active use at the publisher, and were discussed by both systems and content informants.

- MeSH was used by information specialists in their literature searching, as a means of locating research relevant to the topics they covered. Literature searches were performed in third party databases of abstracts, some of which were MeSH coded to aid discoverability. But according to informant Louis, even when MeSH coding was available, a degree of flexibility, interpretation, and judgment on the part of the

information specialist was often required to locate the desired information which was not always straightforwardly evident from the MeSH coding (p. 142). Typical problems in this MeSH coding, solved by the ingenuity of the information specialists, were incorrect assignment of codes; variation in the “level” or specificity of coding; and institutional variation in the ways codes were applied and used.

- SNOMED-CT codes were applied to pieces of content by clinical editors, using applications created by internal developers. In theory, the purpose of this coding was to aid systems integration and help clinicians answer clinical questions by surfacing the most relevant of the publisher’s content in the appropriate context. Both systems and content informants expressed scepticism and frustration at the difficulties they had encountered in implementing SNOMED coding, pointing to the muddled origination of the codes across different fields, the inherent complexity of the coding structure, and uneven institutional adoption of the SNOMED standard as reasons for its lack of success in delivering the cross-context transparency it was intended to provide (p. 207).

Material systems standards were represented in the data firstly by standard formats for the digital encoding of information for distribution via systems, such as PDF, HTML, and XML, and secondly by the de facto standards imposed by applications used to create and edit content, such as Microsoft Word and Adobe Indesign.

Graphic designers Gill and Gerry talked about the ways the use of the standard PDF format had eased their communication with printers. By hiding the complex configurations that designers had previously had to supply, the PDF format enabled automatic transfer of information for print. But though it provided a successfully “transparent” format for communicating layout specifications for printers, the shortcomings of the PDF format in another context, as an on-screen delivery method, were highlighted by other informants (p. 189). The transparency offered by this format was optimised only for interpretation in specific contexts, namely, for defining print layouts. In other contexts, the format fell short, being too unwieldy to provide easy access

to the desired information. HTML, too, though a more flexible format, was discussed in terms of the problems it caused, as well as the more straightforward transparency it offered to the sharing of information (p. 190). In contrast, the technological format most often discussed, XML, was presented specifically in terms of the flexibility it offered to carry information into different contexts; but, here too, as with the other two technical formats mentioned, XML was spoken of in terms of the practical problems that its usage created (pp. 190-193; pp. 197-199).

Flexibility and control came at the expense of an explicitness that had to be added technologically, in ways that were not always easily achieved. The outcome was that the goal of transparency, though theoretically within reach, was still not necessarily straightforward to realise in practical terms. Although systems informants highlighted XML as a better match than relational data modelling techniques for the unstructured information typically found in textual content, they also highlighted the issues the authors of such material had in grasping the complexity of the technical rules which had to be followed in order that transparency be achieved (pp. 128-130). Technical content developer David spoke of the way that XML's requirement for explicitness, via the assigning of defined codes beyond the natural language meaning of the text, imposed constraints on authors and editors which they struggled to overcome. While XML as a vehicle might indeed provide the potential for a more transparent mechanism for transporting encoded meanings across contexts, the difficulties associated with working in the format meant that the range of meanings that authors and editors could convey was itself limited by the difficulties of encoding.

The implication was that, due to the complexities of encoding, there were meanings that could not be easily expressed in this medium at all, or at least, not by those specialist healthcare interlocutors, clinical authors and editors, with whom those meanings originated, if they were working without assistance and support from third parties with data encoding skills. Working within the constraints of XML, there were things that could be said, and said exceptionally clearly, but there were other things that could not be said at all. The "transparency" offered by XML was therefore presented as highly

mediated; mediated firstly by the material constraints of the format, and secondly by the technical expertise required to encode meanings.

There was a sense in the contributions of the systems informants that, at the time of the interviews, XML was moving from being the preserve of technologists to becoming a mainstream tool (pp. 192-193). For Theo, whose company's success had arrived on the back of the success of XML as a format, this transition to mainstream acceptance was already complete, and he no longer considered XML a technology, but rather, an application. His description of the adoption of XML by companies was social in nature; he described companies as "jumping aboard" as they aligned themselves with data design work done by others. Dee, the systems developer who had worked with XML from the beginning, mourned the loss of the purity and elegance that had first attracted her to the technology. She felt that what had once been clear and straightforwardly transparent (if limited in use to technologists) was, as its constituency grew, becoming messier and losing clarity.

In addition to standardised content output and management formats, such as PDF, HTML, and XML, informants spoke about the applications and tools they used to create information. These tools imposed their own de facto standardisation. The use of content applications or tools was determined by role and by institution. Information specialists used databases of abstracts to locate evidence, and reference management software to filter and appraise; editors and authors commonly used Microsoft Word to write and modify text; graphic designers used Adobe InDesign to create layouts; information technologists used various web applications to build websites. Informants described the movement of healthcare meanings through these different proprietary technological contexts, and the glitches and breaks in meaning which they had to use personal ingenuity and expertise to identify and fix. The introduction of centralized content management systems, based on open standards such as XML, was proposed by systems and business informants as a way to improve the smooth transfer of meanings between technical environments (p. 182, p. 193, p.196, p. 200). In contrast, content informants, struggling with the complexity of the proposed solutions in use, simultaneously

questioned the need for such intermediary applications, and lamented the work involved in migrating content across environments; a task of safeguarding meaning which, in itself, seemed meaningless (p. 198; pp. 182-183). Systems informants, particularly Curt, criticised approaches to the manipulation of content which required translation between incompatible technical models (p. 192). As I will discuss below, far from being limited to transfer across technical standards, such acts of translation across conflicting models seemed common on many levels in the digital mediation of healthcare meanings.

### **6.1.3 Blended standards**

Blended standards, encompassing aspects of both practice and materiality, were described as being employed by content interlocutors in the processes they used to create healthcare information. The least specialised of these were editorial standards, used by both the charity and the publisher. Much of the editorial work described by the clinical editors at the publisher, and by production editors at the charity, concerned manipulating the contributions of clinical authors into standardised forms for circulation. This editorial standardisation happened at many different levels. Both organisations made use of style guides in the creation of their products, manuals created in-house which defined preferred standards for items including naming conventions for conditions and treatments, grammatical style preferences such as active over passive voice, preferred spelling conventions (US, UK, or a blend of both), and citation styles. These styles were imposed in-house on work submitted by authors. This was a level of translation which, while it might improve clarity for the reader, by enforcing consistency, was not intended to alter meaning. More impactful was the commitment both organisations shared to readability and accessibility, with editors taking pains to aim patient-facing content at low reading levels so that literacy would not be a barrier to access for patients. At the publisher this commitment to accessibility was formalised via accreditation by an external standards body.

The most specialised area of content standardisation was the standardised methodology for systematic review of clinical research evidence, used by the publisher to underpin its products. Here, again, standardisation was a blend of artefact and practice. The

standardised artefacts of systematic review included the different styles of research study to which the technique was applied, such as systematic review (SR), randomised control trial (RCT), or observational study. Each of these study types was allocated a different weight depending on the scientific rigour of the method behind it, and the association of that rigour with reproducibility of results. This created a sliding scale of standardisation, against which information specialists, clinical editors, and authors measured individual studies to assess the weight that should be given to the findings of those studies in the final presentation of reviewed evidence. The final product was intended to educate clinicians towards making more scientifically informed decisions in their own individual clinical contexts with live, individual patients. The journey between scientific findings and the clinical approach for an individual patient was apparently a long one, and presented in the interview data as both heavily populated with contributing interlocutors, and beset with confounding factors. Long and winding though it might be, it was nonetheless a mappable journey, and a traceable line, albeit not a very straight one, emerged from scientific findings to the individual patient.

The contributing roles involved in this long and convoluted journey from scientific research to patient were not all held by clinical specialists, but rather by a chain of diverse experts, each of whose own specialisations played some part in the preservation of healthcare meanings as they wound their way towards patients. Louis the information specialist spoke of his use of standard analytical frameworks such as PICO (population; intervention; comparison; outcome) employed by those in roles like his own to enable non-clinicians to make decisions on the clinical relevance of particular papers in areas they were not familiar with; the intention was that by the correct use of standardised, criteria-driven frameworks and methodology, all topics could be treated in the same way, by specialists in assessment methodology rather than specialists in clinical specifics (p.211). In this way, standardisation, of both practice and artefacts, was used to allow a variety of actors to negotiate an unfamiliar knowledge landscape.

## 6.2 Dimensions of mediation: expertise

In Chapter 4, I presented themes from informant views of the range of specialist expertises which come into play in the creation and sharing of digitally mediated healthcare meanings; expertises which collide, combine, and overlap through the practices of shaping and circulating digital healthcare information artefacts. The presentation of these expertises was broken down into three broad “communities of expertise” as follows:

- healthcare expertise (both professional and lay/patient)
- content expertise (author, editor, information specialist, graphic designer, educational consultant)
- systems expertise (systems developer, technical content developer, information technologist)

I presented these expertise groups in concentric layers of mediation, with the kernel being the “classic healthcare encounter” introduced in Chapter 2 as the communicative baseline for this study.

Figure 6.1 (below, first presented in Chapter 2 as Figure 2.2) represents the clinical variant of the classic healthcare encounter. The lines between the participants represent the two-way contextual expertise which mediates clinical communication, with the pink line representing the experiential expertise of the patient – personal and subjective – and the purple line the generic, standardised clinical expertise of the clinician. The patient has subjective knowledge of how he or she is affected by symptoms, while the clinician is able to relate the reported symptoms to his or her abstract knowledge of disease.



**Fig. 6.1: The classic clinical encounter**

Even in this basic healthcare encounter, the different expertises of the participants, and the expectations conferred by those expertises, act as mediators. Expertise here does not necessarily influence what *can* be said by each participant, but it certainly influences what is *likely* to be said, and, more importantly, it influences what is *likely to be understood* by the second interlocutor from what is said by the first. For example, the sentence “I’m afraid it’s cancer”, uttered by a patient, is most likely to be understood as an expression of a subjective state of anxiety about a potential diagnosis. The same sentence uttered by a clinician is more likely to be understood as confirmation of a diagnosis, softened by an expression of regret. In this way, the mediating expertise of the speaker, both as it is, and as it is perceived, has implications for the meaning of the utterance.

The interactions between different expertises which are explored in this study lie distant from real-life healthcare encounters. This distance, along with the variety of expertises brought to bear on a single shared artefact, means that the mediating implications of the various expertises involved are less straightforward to distinguish than in the example above. But however layered, complex, and distant their relationship with the communicative baseline of the classic healthcare encounter, these expertises play a key part in the sharing of meaning and, therefore, have implications for meaning, which are nonetheless inescapable for being difficult to isolate and to trace. Throughout this section, I expand on Figure 6.1, adding mediating content and systems expertises to the picture to support and illuminate the discussion.

### **6.2.1 Healthcare expertise: the first layer of mediation of healthcare meanings**

In this study, the representation of clinicians and patients was filtered through the perceptions of the information workers who acted as informants, and it is, of course, highly likely that clinicians and patients would have presented themselves differently from the way they were drawn by the study informants. But the perspectives of information workers on the healthcare interlocutors who provide both their subject matter and their audience carries particular weight for an understanding of the mediation of healthcare meanings, in that it provides insight into the models held by information



workers of their mediated interlocutors, and the contexts in which their products are used. The information workers interviewed for this study had made a deliberate choice to work with medical meanings, and expressed personal commitment to achieving positive outcomes in support of healthcare professionals and patients, who they generally presented in the interviews with a high degree of respect and sympathy. Even so, there was variation in the detail of their understanding of these core healthcare roles.

None of the informants in the study had direct contact with patients in the course of their work, but at least one informant from each informant expertise group (content, business, systems) expressed views of patients as interlocutors. All of those who spoke about patients presented a view of patients as actively engaged in information seeking, in learning about their conditions, and as makers of informed decisions. Members across all informant groups demonstrated a belief in the capability of healthcare information to effect real-world change for the better on patient wellbeing. To be informed about healthcare, all informants agreed, was beneficial to patients, with examples of cited benefits including improved communication with medical professionals, or, more directly, if more vaguely, “feeling better”.

One specific aspect of the model of patient as interlocutor, referred to by informants from all groups, was the informational expertise held by patients. Patient literacy forms a gateway through which all mediated patient-facing communication must pass in order to connect with its intended interlocutors. Information workers’ perceptions of levels of textual literacy, computer literacy, and medical knowledge have a role in shaping information products designed for patients, because these perceptions have implications for what can be expected to be understood by patients, and, therefore, for beliefs about what should be said, and how it should be said.

Informants from all expertise groups estimated the level of informational expertise in patients as low (pp. 121-122). The most commonly proposed solution to this problem was to standardise information for a low reading ability, achieving maximum clarity for the widest possible group. Indeed, the publisher had gone to some lengths to have the

readability level of its publications accredited by an organisation committed to simplicity and clarity of written expression. There is a risk, of course, in standardising to support across-the-board low literacy, and that risk is that the complexity of the messages that can be conveyed is limited, so that only a partial, simplified view of healthcare issues can be presented. The choice to speak clearly and unambiguously requires that some ideas are not expressed, and that some things are not said. This caused frustration for some informants, who mused on ways to enable readers to select their own level of appropriate complexity (pp. 163-164). Even these informants, uncomfortable with the degree of control they needed to exert over meanings on behalf of patients in their current modes of working, had to accept that, paradoxically, to ensure clarity of expression, they had to compromise on full transparency of communication, so that, in effect, complex meanings were obscured by omission (p. 171).

Another aspect demonstrated by informants of the models they held of the patient as interlocutor was their understanding of the experiential expertise of their patient interlocutors. This was described by business and content informants at the charity, in their nuanced presentation of the experiential trajectory in chronic illness. Informants described the highly-informed chronic patient and the newly diagnosed patient as living in a different experiential context, with different hopes, fears, desires, and practical needs, and noted that the same statements might mean very different things to patients in these different groups, depending on the contextual filter of experience (p. 116). It was this understanding that led to the ambition to somehow achieve digitally-mediated patient communication that could be personalised to adapt to individual needs (pp. 163-164). The ambition was to enable the dynamic adaptation of digitally mediated communication, to context and to interlocutor, emulating the communicative flexibility of the classic face-to-face healthcare encounter. The map of expertises drawn in the sections that follow will demonstrate one of the challenges in achieving this flexible dynamism, in the number of mediating expertises which would need to work in alignment to achieve this goal.

In the classic clinical encounter, the clinician is often considered to be in a powerful position, as the master both of abstract domain knowledge, and of the translation of this

knowledge into a course of action for the individual patient. This familiar view was reinforced in the interview data; content, systems, and business informants presented clinicians as specialist domain experts (p. 111). Clinical editors also spoke at length about the role of the clinician in bridging the gap between specialist, generic domain knowledge and the needs of the individual patient, acting as master of the particular contexts in which abstract knowledge was applied, as well as master of the abstract knowledge itself (p. 111-112). This mastery of the contextual application of generic knowledge would put the clinician in a uniquely powerful position with regard to the sharing of healthcare meanings in the classic clinical encounter. It is hard to imagine how the final translation of knowledge to action in the classic clinical encounter could ever be made fully, generically, transparent, demanding, as it would, a level of interpretation which would not be accessible to anyone but the presiding clinician in a particular case, an interpretation based on a combination of specialist knowledge with analysis of contextual particulars based on accumulated personal clinical experience.

At times informants presented clinicians as less than expert in the clinical domain. When this was the case, for the most part clinicians were positioned on a learning journey, generally via their interaction with published information, which was presented as improving clinical expertise in its users (p. 111). A lack of clinical expertise, when this could be remedied with information, was not in itself portrayed as a negative by the informants in the study, but rather, as the very problem their organisations had been set up to solve. Informants from different groups presented different models of the way in which clinicians interacted with information to improve their clinical knowledge.

Content informants presented clinicians as playing an active role, seeking answers to real-life clinical dilemmas (p. 114). These informants had a strong sense of a primacy of context and practice over the information which fed into decision-making. This sense was shared by Eric, the business informant, as he reflected on the difference between the experience of learning from a media artefact such as a DVD, and learning face-to-face from a senior clinician in traditional medical school style (p. 115). In medical education, face-to-face learning from senior colleagues traditionally provides a social context by

which the process of learning can be extended to a process of acculturation; a richness of context difficult to replicate in a fully mediated environment.

While content and business informants demonstrated a nuanced understanding of the complex social processes by which clinicians develop their domain knowledge, systems informants described a more mechanical model, speaking of the “delivery” of information, and of “equipping” clinicians with knowledge (p. 114-15), with little sense of either the active engagement required on the part of the clinician to develop domain expertise, or of the social context provided by the community of clinical expertise of which all clinicians are part.

If different collaborating groups hold different models of learning, there are implications for communicative transparency. For example, content and business interlocutors who sought to emulate social models of learning might find themselves hampered by systems which had been built to support a more mechanical delivery model that might not accommodate the kind of social interaction content and business interlocutors had in mind.

These differences between informant groups’ presentation of the processes by which clinicians interacted with information to develop domain expertise did not detract from the general acceptance across all expertise groups of the clinical, domain expertise of clinicians. In contrast to this universal acknowledgement of clinical expertise, informants presented clinicians as decidedly inexpert in informational terms (p. 118-119). To be more specific, clinicians were presented as failing to understand the informational needs of patients, and as a result, as failing to successfully share meanings with them. Some clinicians were characterized as creative in terms of their approach to information, but lacking the practical informational ability to realise their creative ideas, the implication being that clinicians were dependent on non-clinicians to supply the informational expertise that they lacked, and to share healthcare meanings originating with clinicians with the wider world.

This dependency on other expertises introduced, by necessity, further layers of mediation. Clinical editor Elle mentioned two areas where she considered clinicians to be informationally inexpert. The first was in the area of clinical coding. She presented clinicians as unaware of the “behind the scenes” informational work of coding, which involved the application of standardised codes to patient data to enable its smooth transition through systems (p. 119). The reported lack of familiarity of clinicians with the detail of this work raised a question of transparency; if clinicians were to be unaware of this work, which supported and informed clinical work, they could not be sure that the meanings it assigned to items of data adequately captured or matched their own understanding of that data.

Secondly, Elle referred to the lack of informational expertise held by clinicians in interpreting clinical research (p. 119). Here, again, a lack of familiarity with the standardised practice of evidence appraisal put clinicians at risk of a loss of transparency around the significance of reported research findings. This loss of transparency, if not addressed, could put clinicians at risk of basing clinical choices on opinion, or on skewed research, with a resulting negative impact on their understanding of the likely efficacy of treatments, and, eventually, a negative impact on patient outcomes. To mitigate this risk, content informants described initiatives to improve informational expertise in healthcare professionals (p. 118-120), for example by training them in critical appraisal skills, so that they could more easily spot false claims and misinterpretations. The intention of these initiatives was to develop informational sophistication in healthcare professionals to support greater transparency in their own interpretation of meanings via the standardised methodology used in critical appraisal. This second example, in particular, illustrated the understanding held by some informants of the highly active and direct force of the communicative artefacts they produced; an understanding of the capacity of information artefacts to enact real-world change.

While all informants agreed that clinicians held domain expertise, the question of clinical power was not so straightforwardly presented. Eric, from a business perspective, presented the power of the clinician as constrained within an informational context, when

he explicitly limited the clinician's input into informational discussions to the provision of specialist clinical expertise (p. 113). In doing this, Eric situated clinical expertise within a wider context of informational expertise, within which the mastery exercised by the clinician was shared with other expertise groups, and therefore was necessarily collaborative in nature.

Systems informants presented a unique perspective on the expertise of clinicians, a perspective which had its own implications in terms of power. While they agreed with content and business informants that clinicians were holders of clinical expertise, systems informants defined this expertise in relation to the systems that they, as systems workers, developed and implemented (p. 113). To systems informants, clinicians were, in the first instance, providers of expertise to be captured within systems, and, secondarily, escalation points in case of systems failure. In this model, with clinical expertise decanted into a system for dissemination, the context in which the clinician operated was determined, and to an extent limited, by the systems through which the clinical information circulated. This systematically constrained view of the sharing of clinical expertise stood in stark contrast to the highly social model of the sharing of clinical expertise in medical education presented by Eric (p. 115), though it had much in common with his view of the contribution of clinicians to the development of information artefacts.

It seems evident that the clinicians *providing* "expertise" in the form of knowledge to populate systems would be distanced from the classic clinical encounter, because these clinicians would be unlikely to even meet the patients who were helped by their expertise. Perhaps less obviously, I would also suggest that those clinicians *using* healthcare information systems to inform their treatment of patients are likely to have lost some of their mastery of context. In the case of users, this loss of mastery is likely to be due to the expansion of the *informational* context in which these clinicians are working beyond their own personal expertise and experience. I note this not as a criticism of the use of information systems by clinicians, or to highlight any weakness in the practice of system-supported clinical decision making, but merely to observe that the perspective of

those building and implementing systems to circulate healthcare meanings may differ from the perspective of those more familiar with the communicative dynamics of the classic healthcare encounter. In a system-mediated context, it should not be taken for granted that clinicians would be able to straightforwardly exercise the power they might expect, or be expected, to demonstrate.

### 6.2.2 Content expertise: the second layer of mediation of healthcare meanings

I turn now to informant perspectives on the second layer of mediating expertise in the digitally mediated sharing of healthcare meanings; the expertise of content professionals. Figure 6.2, below, illustrates a distillation of the views expressed in the interviews of how these different expertises were progressively layered into content artefacts as they were developed. By the time content reached its clinical and patient audiences, it had been shaped, according to the study informants, by up to six distinct content expertises, each with a different perspective on the nature of the communicative action they were facilitating.

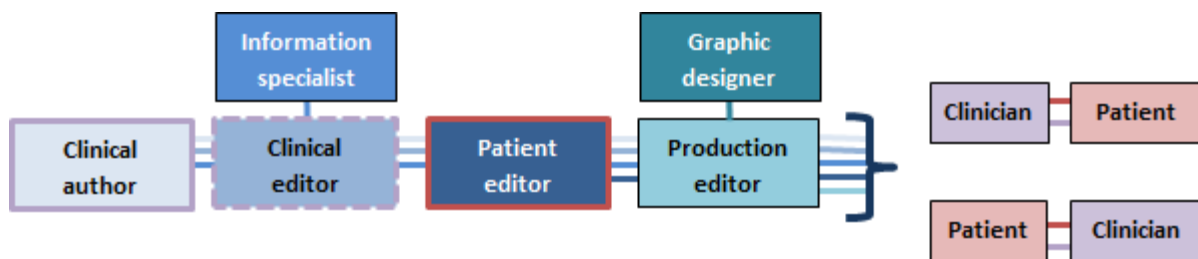


Fig. 6.2: The mediation of healthcare meanings by content expertise

Content expertise was the first of the layers of expertise looked at in this study not to be directly touched by the direct experience of the communicative baseline of the classic healthcare encounter. Of the content interlocutors examined in this study, some were clinically qualified, though most were not. Of course, all at some point would have been patients themselves, and would have had patients among their friends and family. This personal contact with healthcare aside, although they were all deeply involved in the process of capturing and sharing healthcare meanings, and all, with the exception of the clinical author, engaged full time in the creation of those meanings, they were also all,

again with the exception of the clinical author, disconnected from any real word context for the particular meanings they worked to share.

Figure 6.2 illustrates the crowded nature of the route that informants described meanings as having to take from clinical authors to their intended audiences. The number and diversity of expertises layered into healthcare content artefacts along this route has implications for communicative transparency. As already discussed above, perception of interlocutor expertise plays an important role in the mutual understanding of meaning. It is unlikely that either the clinicians or the patients identified in Figure 6.2 as the target interlocutors of mediated healthcare meanings could accurately describe the progressive layering of expertises between the originating authors and themselves; in effect, these mediating expertises form part of a hidden informational infrastructure. It is likely that the clinical authors to the left of the diagram would have more awareness than their target interlocutors of the types of expertise that separated them, but it is also likely that they, too, would struggle to fully and accurately describe all of the contributing expertises, still less the roles they played in the sharing of meaning. The views held by these hidden informational interlocutors of the nature of the communicative action in which they were engaged might differ substantially from the views of the healthcare interlocutors who originated the meanings they mediated, and yet their role in shaping healthcare meanings was so central that, without their involvement, meanings could not circulate in this mediated arena at all.

The authors discussed by informants in this study were all clinical specialists, and accordingly both content and business informants presented a united view of the authorship of healthcare meanings as an extension of the clinical role (pp. 123-126). According to informants in the study, these were highly experienced clinicians extending their clinical reach, via the medium of information products, to speak to a wider audience of fellow clinicians and patients. For content informants, the main strength the author brought to the creation of healthcare meanings was an understanding of the clinical context.



The generic, content-centric view of authorship put forward by systems informants sat at odds with this highly domain-specific view of “mediated healthcare”. The link to the communicative baseline of the classic healthcare encounter was harder to identify based on the generic view of authorship favoured by systems informants. Those factors which set apart the sharing of healthcare meanings, including the nuances of clinician/patient power relations, could not be fully accounted for. Systems informants, taking a content-centric view of authorship, set the communicative baseline not in the classic healthcare encounter, but in a pre-digital vision of mediation, with their baseline being the idea that in the pre-digital world, authors would “simply write something they have in their mind” (p. 129).

In the content-centric view proposed by systems informants, authors were not particularly powerful actors. Rather than extending their clinical reach beyond the classic healthcare encounter, they were portrayed as struggling to align their communicative processes with the formal restrictions of authoring systems (pp. 128-129). The move to digital mediation in this model was not a move away from face-to-face interaction with patients, but a move from a pen-and-paper communication which, in the healthcare context, was, in fact, unlikely to ever have been a commonplace reality for many. The lack of alignment between the model held by systems informants and the historical lived experience of sharing meaning held by the clinical authors considerably depleted the power of this model as an alternative communicative baseline.

Two types of expertise were attributed to authors in the sharing of digitally mediated healthcare meanings, and the second, process expertise, highlighted weakness in both of the models of authorship discussed above. The collaborative creation of digital healthcare meanings emerged from the interviews as neither a straightforward move from analogue to digital media, nor a transparent rendering of the classic healthcare encounter in mediated form, but rather a specific blend of healthcare and informational expertise-mediated practices, with unique complexities and challenges. As figure 6.2 above illustrates, the processes of creating information artefacts were described by informants as highly social, involving many interlocutors with different expertises. The process

expertise demonstrated by authors acted as a means to align them with the broader social and cultural group upon whose successful collaboration the successful communication of mediated healthcare meanings rested.

Chronologically speaking, the first of these process expertises to be exercised by the author lay in the scoping of content. Informants spoke of authors drawing on their knowledge of the external clinical context in order to define topic scope. Crucially, this was described as a negotiation with editors, rather than as a one way setting of a fixed message for onward transmission; authors advised, and discussed, as much as they decided (p. 126). Louis, the information specialist, spoke about the risk of authors failing to respect the scopes they had agreed to (p. 128). Such transgressive actions might jeopardise the integrity of the entire work. Selecting and appraising research evidence to decide what to include, based on the lists put forward by information specialists, was similarly a highly interactive piece of work, a validation of the work of researchers in order to set parameters of truth within which the content creation process would operate. Context here was twofold, encompassing both the broader healthcare context and the social context of content creation. When both contexts were taken into account, the raw communicative practice of “writing” assumed a relatively small part in the work of the author. The final stage, authorial approval, was necessary as a final clinical validation of the meanings which had been continually shaped throughout the process. By its necessity, this validation highlighted the non-mechanical and unpredictable nature of the contributions of the host of mediating interlocutors between author and audience.

The dominant perspective on the role of the clinical editor came from content informants, and particularly from clinical editors themselves. Perspectives on this role from systems and business informants were rather limited, focusing heavily on the validation aspects of the work. Like authors, clinical editors were recognised, by both systems and content informants, as supplying context, as well as working on content; they provided an important link between the content being produced and the contexts of its use by determining relevance (pp. 131-134). This might occur in the formulation of links between clinical practice and the research literature, for example, with the clinical editor

acting as a proxy for the clinician as user, modelling the user perspective and the context of use of the information product, in relation to the scientific knowledge base which informed it. Here, the role of the clinical editor was to render content active by transforming it into decision support, combining the specialist domain knowledge provided by authors with, firstly, an understanding of the context of use, and, secondly, a practical knowledge of what was achievable within the specifics of a particular product format. As a final step in closing the loop between information artefact and real world action, Elle described the way she fed back to research commissioning bodies on the gaps in the research literature that she uncovered during the process of summarising research. This feedback marked the last transformation from action, in the form of clinical research, through informational artefact packaged for use in a different context, and then finally back to action again, in the potential commissioning of new research.

Above all, the clinical editor role was portrayed as an intermediary. It provided an intersection between expertises, and a point of translation from one context to another. This translation might be, for example, between research literature and clinical practice, as already described above; or it might be between the detailed precision required by the information specialist, and the higher level interpretation required by the practising clinician. While often this translation happened between two different expertise groups, or between a real-life context and the product artefact designed to inform that context, the translation could also happen internally, between two conflicting analytical viewpoints which the clinical editor would have to align within themselves. Emma illustrated this with her identification of the contrast between detail orientation and clinical flair and bravery (p. 135), both of which were perspectives the clinical editor must be able to adopt. In Emma's dilemma on splitting the team in order to more comfortably provide both perspectives, we saw, in microcosm, the process of disciplinary divergence within the team, as a tension between perspectives which could not easily be reconciled within a single individual was externalised in the creation of new, more specialised roles, with formal, social relationships proposed to facilitate the dialogue between different expertise perspectives.

Regardless of whether the dialogue between these nascent disciplines was internal or external, there was the possibility that moving from the text-centred, interpretive approach previously followed to the data management approach which was being proposed at the time of the interviews might change the nature of what could and could not be said within the clinical information product concerned. Any decision on the appropriateness of such a shift would sit firmly with the clinical editors. All informant groups agreed that control was an important aspect of the clinical editor role. Clinical editors acted as gatekeepers to publication, in that the communicative action of publication could not be completed without their approval. But the thread of editorial control could, in fact, be seen throughout the process of the creation of healthcare meanings, from scoping onwards, as the clinical editor took ultimate responsibility for deciding what should and should not be said, what was important and what was not, in a context extending beyond the immediacy of content creation, beyond the requirements of the individual practising clinician, to take into account the needs of commercial clients and providers of healthcare at national level from around the world. The means by which clinical editors processed and prioritised these wildly diverse inputs was hidden from the clinical end user, who was as a result rather blindly dependent on the decision making of the clinical editor. Such invisibility is the opposite of the communicative transparency which is the focus of this study.

The remaining four content roles mentioned in the interview data differed from the clinical editors in that, though they were fully engaged in the creation of healthcare meanings, the role holders themselves had no specific healthcare expertise. Lack of clinical training notwithstanding, their perspectives were layered into the content they collaborated to create.

Two types of non-clinical editors were mentioned in the interview data; these were patient editors (p. 138), and production editors (pp. 138-139). Both were engaged, in their different ways, in work of translating clinical meanings into standardised forms. Patient editors performed this work of translation on behalf of patients, for whom they acted as advocates, representing patient interests in an otherwise clinically-oriented setting. With

backgrounds in journalism rather than healthcare, their work to support patients required interpretive effort, to imagine the informational needs of the patient, and how those needs might be best fulfilled. In contrast to the scientific basis of much clinical knowledge, patient knowledge leans towards the experiential and the subjective. Appropriate patient language was harder to define than the standard medical terminology adopted for clinical products; hence the use of standardisation in the form of accreditation which defined guidelines for patient editors to follow. Systems perspectives on this role focused on the technical mechanics of the way the work was carried out, differentiating between the systems which had been mastered, and those which had not. Lack of mastery of the content management system, as for all roles identified as struggling with this technology, had the potential to impact on what could and could not be easily said by patient editors.

Both systems and business informants presented a rather simplistic view of the contribution of the production editor to the content creation process, characterising their checking work as “dotting is and crossing ts” and “spotting commas out of place”. The production editors themselves reported their contribution differently, characterising it as the policing of accuracy at all levels, checking facts as well as commas, locating statements that they felt needed to be reassessed and escalating appropriately within the broader content team. Their work could be seen as the interpretation of a series of inputs into a standardised, technical output, and it was the unstandardised nature of the inputs that made this a work of true interpretation rather than a straightforward mechanical task. In their own view, the production editors held responsibility for policing the entire content creation process, not just checking the output. Systems informants also appreciated the wider process role of the production editors in keeping things moving in a practical sense, in other words, in making things happen. In this sense, and in their work of engaging with and briefing contributors, their work had direct implications for what was said. One particular aspect of this was their commitment to timely delivery via their administration of schedules, since there is an unavoidable connection between what can be said, and how long the speaker has to say it.

Two further, non-editorial content roles were discussed in the interview data. These were information specialists (the specialist librarians who identified recent clinical research literature to inform the publisher's products) (pp. 139-143), and graphic designers (pp. 143-144), who worked on layout and graphical aspects of the charity's print and online publications.

In locating and appraising research literature, information specialists took the first step in the chain to build the publisher's evidence-based products, determining the evidential base of content by translating scopes into search strategies which they then applied to the available research evidence before selecting or rejecting papers based on strict criteria. Their decision making was based on strict criteria, following a methodological rigour intended to promote transparency by imposing explicitness on the principles by which truth was established. The detail of this rigour was reportedly often hidden from end users, in the name of ease of use, by the clinical editors (p. 133), so that this transparency, in the final product, was displaced by trust.

The information specialists' work was presented as process oriented, with speed of decision making a priority, due to the high volume of work. Louis described the way in which the rigour of the methods permitted information specialists to appraise research in areas they were not familiar with (pp. 142-143), which, in turn, meant that specialist clinical input needed to be sought on the inclusion or exclusion of particular papers. But despite this rigour of method, and the separation it enabled from the contextual interpretation of findings, the work of the information specialist was not fully automatable. This was because it required a degree of interpretation, due to the nonstandard input provided by abstracts, and by variances in reporting of results in research papers (p. 143). In their highlighting of deviance from standardised practices, and their enforcement of methodological rigour, the information specialists too played a policing role in content creation, and exercised a form of control over the healthcare meanings that emerged from the content creation process.

The information specialist role was little discussed by systems informants, whose perspective on content had been gleaned largely via interaction with business and editorial interlocutors. As part of the work of the content interlocutors involved reducing the detailed and rigorous transparency enforced by the information specialists, there was a risk here that systems might be developed without a full understanding of the contribution of the information specialist, with potential negative implications for a close fit between the work of the information specialists and the systems that supported it.

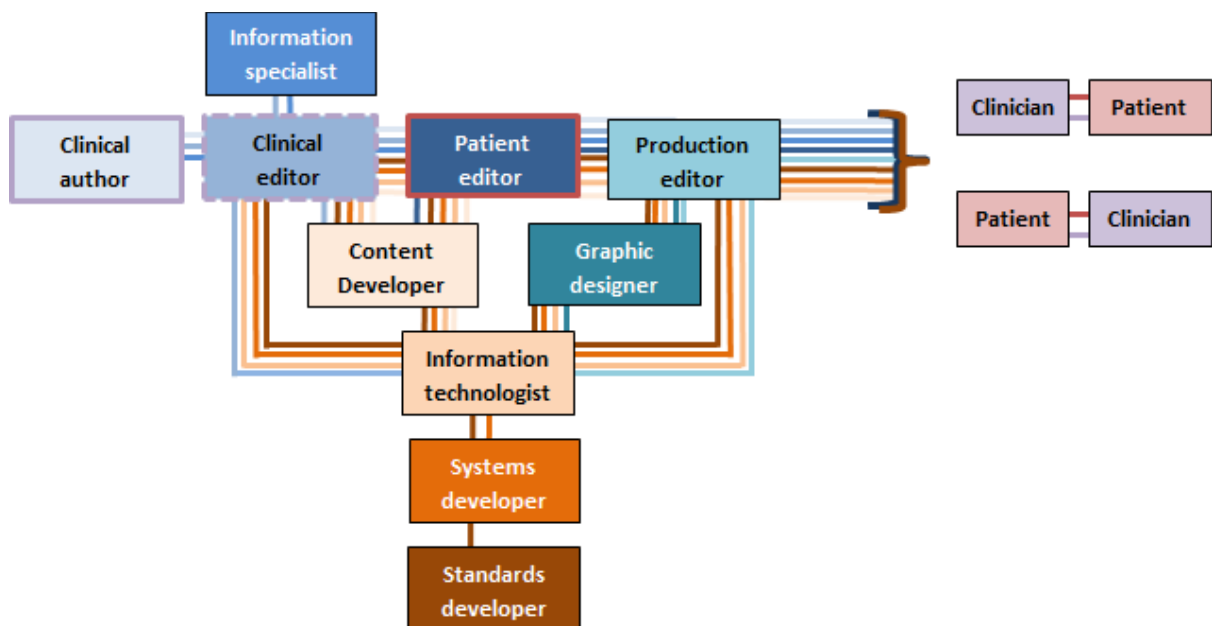
As figure 6.2 illustrates, graphic designers, who in this research were largely discussed by informants at the charity, made their contribution at the opposite end of the content process to the information specialists, in the final stages before publication. The technical aspects of graphic design were those most widely cited, with the designers at the charity supporting a transition between content and technology, albeit one that was filtered through a visually inclined lens. As we saw with the production editor and information specialist roles above, the work of the graphic designer, though it might have seemed to be a straightforward and mechanical task, translating from print to web, or between technical formats, was presented as requiring a degree of interpretation. The designers themselves described their work as creative and fast moving, with an aim to entice and appeal to the reader, albeit in the service of education or information. Once again, this was a role presented by its holders as having an element of policing, often requiring subtlety of negotiation with editors who seemed not to fully understand the material constraints imposed by page layout. And, like other content roles, this was a role which supported the crafting of unstandardised inputs into a standard, technical format.

### **6.2.3 Systems expertise: the third layer of mediation of healthcare meanings**

In Figure 6.3, below, I add a third layer to the mediation of healthcare meanings, a layer provided by the expertise of those who worked on the technical systems through which those meanings were shaped and shared. Like the work of the content interlocutors discussed above, this was work with implications for the formation and sharing of healthcare meanings. Systems workers were one or more steps further from the communicative baseline of the classic healthcare encounter than the content workers.

None of the systems workers interviewed had any formal training in healthcare, and only those directly employed by the charity and the publisher worked exclusively on healthcare information. Those who worked for supplier organisations worked across a range of industries, from aerospace to insurance.

If the route from author to audience looked crowded after the content interlocutors were added to the diagram in figure 6.2, it is even more crowded in figure 6.3, with a range of systems interlocutors weighing in from early in the process to enable, shape, and also to constrain the material forms that could be shared in the creation of healthcare meanings.



**Fig. 6.3: The mediation of healthcare meanings by systems expertise**

A paradoxical relationship emerged from the data on systems expertise, between, on the one hand, the commitment to principles of clarity, logic, and explicitness expressed by systems informants such as Dee (p. 150, p.193) and Curt (p. 185, p. 188), and, on the other, the complexity of the systems implemented to promote this clarity. Although systems respondents were comfortable with highly abstract analysis, the clarity which they perceived, and sought to promote, was not always reported as evident by content informants (p. 137, p. 146, p. 158, p. 172, p. 190, p. 198, p. 207).



There are implications for transparency in the sharing of meanings via cross-expertise collaborations, when not all expertise groups share the same level of abstract understanding. What might seem clear to systems interlocutors might seem anything but to content and healthcare interlocutors. When this was the case, communication could not arrive at true mutual understanding, but instead had to rely on trust. As described by David, who held the systems role most closely involved with content interlocutors, that of technical content developer, this trust was based on factors such as personal relationships and an established track record of delivery (p. 154). At the publisher the role of technical content developer was an internal role, and David described how he worked both to maintain and develop content systems, and to manipulate and shape XML-encoded content. At the charity, in contrast, the technical content developer role was generally an external role, in which personal relationships and shared experience would be harder to establish (p. 146-147).

Informants from all groups acknowledged technical content development as a highly practical discipline, concerned with making things happen, and with making things work (p. 146-147). The actions of the technical content developer had real communicative force both within the collaborative environment of content creation, and beyond on the content meanings shared with customers and users. This active communicative force sat a little uncomfortably with the mysterious aspect that development work held for some content informants, who did not seem confident that the mediation this work effected on healthcare meanings was either transparent or predictable (p. 146).

Like the work of editors, graphic designers, and information specialists, technical content development involved making material changes to content, to impose standardisation on non-standard inputs, and could therefore be considered a work of interpretation. Uniquely, the focus in technical content development was on the automation of content change (p. 146-147). In order to enable this automation, the rules for change had to be made explicit, and then would be applied, repeatedly, without the opportunity to exercise human judgment. This kind of automated change layered meanings into content at one remove, without a clear originator for those changes. The editors who had to take

responsibility for what the content said on release might not be fully aware of the ways in which changes might have happened (the “how”), while the content developer who made the changes happen might not be fully aware of the implications for meaning (the “why”). The ownership of the change therefore was shared, in a de facto collaboration between interlocutors from these two expertises.

On a similar topic, both David the technical developer and Gerry the graphic designer lamented the failure of editors to grasp the limitations imposed on meaning by technical constraints (pp.153-154). Here, again, only those with systems expertise demonstrated confident understanding about the ways in which these constraints played out, while only those with healthcare or content expertise were in a position to assess their significance. Successful negotiation of these constraints would again require effective collaboration and shared ownership of meanings.

One more step further from content interlocutors was the work of systems integration and adaptation, described by the systems informants as a collaborative process, and as being laborious, even painful, as well as being a specialist skill in its own right. While the technical content developer acted as an intermediary between the systems and the content worlds, in systems integration and adaptation, the systems world and the content world converged, and as they did so, their various models of communication collided. Wrestling the reality of systems built to serve a generic purpose of information exchange into alignment with the communicative goals of healthcare information providers was not only hard work, it was work that was inaccessible to content users, and carried out by a specialist intermediary function of information technologists, whose focus was making a system designed to work generically work in a specific context. This was work that required an abstract understanding of the way systems were built, coupled with sufficient sense of the meanings to be shared to identify successful alignment. In addition, it was often work to be carried out within a tight implementation time frame, by external workers who would then move quickly on to the next project, in another domain, the next alignment between system and context.

The terms used by content informants to describe system selection (“tell us”, “determine” “this is what needs to be”) were terms of control rather than support or advice. Content informants spoke of their reliance on the information technology function to protect them from unscrupulous systems developers, who might be motivated by profit rather than improved healthcare outcomes (p. 148). At the same time, they presented the informational technology function as controlling, albeit in a benevolent way, as well as protective. There was a sense that this was a function happily and fully delegated by content and business interlocutors, due to an inability, or perhaps even an unwillingness, to engage with technology at the required level of complexity. Once again, the ownership of the choice, and of responsibility for the communicative implications of that choice, was the product of a rather ambiguous and murky collaboration.

One step further still from content interlocutors, Dee, the systems developer, described the convoluted process of translating client requirements into systems (p. 150). This, too, was presented as work of interpretation, with layers of analysis to be carried out before foundations could be defined, followed by further layers of development work, before the clients were finally presented with their system via the user interface, without seeing or understanding the interpretative steps which led there from their initial statement of requirements. Systems development, as described by Dee, involved more than a straightforward translation from blueprint to build. There was also an element of evaluation, demonstrated in her depiction of developers as unwilling to implement requirements if they felt they did not make sense (p. 152). There is an element of control here, of course, but also a more nuanced challenge to transparency caused by the questioning by developers of the truth validity of a client’s assessment of need. Whether this questioning is the product of misunderstanding or, less likely, a genuine desire for control, it carries implications for trust, already identified above as the basis, in lieu of true transparency, for interdisciplinary collaboration.

Staff at the CMS developer chafed against the restrictions of working closely with clients on requirements, preferring to use implementation partners for this task to free developers up for pure development work (p. 152, p. 155). Curt spoke of isolation in positive terms,

in two specific ways; once of the benefits of isolating a research and development team away from commercial and administrative distractions, and once in terms of using remote teams to carry out “clear” development tasks that could be delegated with little communication (p. 150). In both cases, though this isolation might increase focus and efficiency, it was easy to imagine how the separation of developers from the contexts of use of their systems might lead to a loss of insight into perspectives held by the other expertise groups who would make up the users of the systems. Such separation had the potential to diminish the capacity for collaboration in the creation of shared meanings, making it less likely that the generic systems constructed by systems interlocutors would prove a good fit for the specific use cases of the clients. Coupled with a low level of systems expertise and understanding on the part of the content interlocutors, this placed a great deal of interpretative pressure on the intermediary expertise of information technologists (pp. 154-156). The role came across as occupying a middle ground, without the benefit of either the developers’ in depth knowledge of systems, or the content interlocutors’ in depth knowledge of context.

Systems and content interlocutors reached out to each other via the concept of requirements, but this communication was not always straightforward. On the content side, Eve expressed her hope of finding a systems interlocutor who would help her and other content interlocutors to see possibilities, to extend their perception so that they could make informed choices (p. 151). This illustrates that Eve’s goal was deepened mutual understanding, rather than control. On the systems side, for Ben, business development manager for the systems vendor, his colleague Curt’s gift was as a visionary, someone who could make sense of the complexity of the client’s lifeworld and relate it to a systems frame (p. 151). For Ben, the interpretation of the messy complexity of the lifeworld into the structured, standardised models of systems was a one-way transaction.

While content informants expressed scepticism about some of the claimed benefits of systems-streamlined processes, and questioned systems interlocutors’ understanding of high-level communicative aims, systems informants expressed scepticism about the

ability of content interlocutors to utilise systems correctly, identifying content users of systems as the source of problems, as disrupters of the systemic flow. The response of systems informants was to hide complexity from users, resulting in a collaboration which, whilst undoubtedly intended as supportive of content interlocutors, was far from transparent (p. 154). Systems expertise was possibly mysterious to content interlocutors in part because so much of its detail was hidden from them. The systems implementation informants in particular spoke at length about their mission to make the knowledge of users explicit and, therefore, visible and shareable (pp. 155-156). This drive to make content knowledge visible seemed to stand in contrast to their approach to their own systems knowledge, which remained hidden and mysterious. This contrast raises the question of how complete any transparency of knowledge could be considered to be when the means by which it was made transparent were in themselves hidden.

Systems informants acknowledged the lack of domain expertise on the part of systems interlocutors (pp. 156-157). In the eyes of systems informants, this lack was compensated for by their belief that the relationship between content and context was generic and modellable using techniques that could be applied across a range of domains (pp. 154-156). Implementation consultants Carl and Chris spoke at length about their work of modelling specialist knowledge, while acknowledging the limitations of this type of representation along with its usefulness. They felt that exactly what was lost in modelling knowledge could not be made explicit, because, if it could be made explicit, then it could be modelled. But though resistant to capture, the presence of the undefinable could be felt, at least by these systems informants, as they recognised that they had somehow failed to capture it.

An aspect of expertise that was ascribed to healthcare and systems interlocutors in common, but limited in content interlocutors to systems perspectives on the author role, was the positioning of their expertise on a learning journey (healthcare interlocutors: pp. 111-112, pp. 114-115, pp. 116-117, pp. 118-120, p. 121; authors: p 124; systems interlocutors: pp. 157-158). Although this shared focus on learning might seem promising in the interests of enabling transparent collaboration, a review of the way that systems

informants presented their growing expertise reveals a loose, exploratory, experimental approach to finding new techniques that might sit rather uneasily in today's safety-conscious healthcare contexts, if not tempered by the content interlocutors' focus on fixing, and checking, established facts (clinical editors: p. 131; production editors: p.139; information specialists: p. 141-143).

One of the softer skills attributed to systems interlocutors was the conveying of technical constraints to content and business interlocutors; of "saying no" (pp. 152-154). There was a sense in which systems interlocutors became gatekeepers to the feasible, their expertise at capturing and representing knowledge acting as ultimate arbiter of what could and could not be said. Although content sign off and accountability resided with the clinical editors, battles on the shape of what could be said were lost and won before the clinical editor, or author, or any content interlocutor even entered into the fray. Limitations were built into the systems they relied upon long before those systems were matched to the products they would be used to support. By shaping the environments in which meanings were created and shared according to their own models of communication, systems developers and standards setters exercised a fundamental, though distant, influence, an influence which was, moreover, blind to the specific requirements of the healthcare context.

This distance on the part of systems and standards developers is made clear in Figure 6.3, where the mediating expertise of these two types of interlocutor is drawn as circulating around all of the other interlocutors contributing to the sharing of healthcare meanings, while the two roles themselves sit alone, isolated from the hectic layering of mediating expertise playing out in the centre of the diagram. Those working in the centre of the diagram could not help but be aware, via their regular collaboration, of the complex layering of both systems and content expertise that went into the sharing of healthcare meanings. Those towards the edges of the diagram – systems and standards developers towards the bottom, authors and information specialists to the left and top, worked with a much narrower visible frame of collaboration.

This study did not examine the perspectives of either the “originators” of healthcare meanings, the authors, or of the “users” of information products, clinicians and patients, who in this model were only exposed to healthcare meanings once these had been fully mediated by interlocutors from all contributing expertise groups. It would be interesting to examine, in further research, just how many of those mediating expertises they could characterise, or even name. The richness of layered expertise was in this way hidden from some of the key interlocutors in this sharing of meanings, introducing a serious challenge to the transparent sharing of meaning.

In their work to share healthcare meanings, interlocutors from the expertise groups examined above worked collaboratively to produce information artefacts; websites and other forms of digital and print information, distributed in different formats, via various routes to their clinical and patient user-interlocutors. In the creation of these externally shared artefacts, the expertise groups employed other types of information artefacts, including systems, particularly content management systems, and standards, including technical standards such as XML and methodological standards such as systematic review. Although interlocutors from the different expertise groups came into contact with all of the artefacts, they often demonstrated different understandings of those artefacts. The interview data revealed differences in informant understandings of the purpose, usage, and material components of information artefacts.

### **6.3 Dimensions of mediation: interlocutor models of communication**

Differences between the models of information held by interlocutors in the study were reflexively recognised, and often actively debated both within and across expertise groups. An example was provided by clinical editor Emma when she talked about the two different ways of presenting research information in the product she worked on; one textual and one graphical (p. 135). The two approaches illustrated two different models of the nature of the communication enacted via the product. Underpinning the data-driven graphical format was a belief that the purpose of the product was to represent, as clearly and transparently as possible, a scientific truth contained within the research papers on

which the content was based. Underpinning the textual format was a belief that simple representation, be it numerical or graphical, was insufficient to direct the reader toward important nuances of meaning, and that a degree of explanation had to be wrapped around the data in order to cultivate the reader's understanding of its significance. The difference between the models was not in their view of the validity claim of propositional truth, as the underlying scientific facts were the same in both approaches. The difference lay in the understanding of the validity claims of "truthfulness" and "rightness".

The textual model favoured subtle interpretation as a means to achieve full transparency of meaning; the success of this model had a greater reliance than the graphical model did on meeting the validity claim of "truthfulness", in that the interpretation provided by author and editor needed to be sincere to achieve transparency. The underlying data were not made fully available for the reader to check the interpretation, so the claim for transparency relied on trust (p. 133). The biggest contrast was in the views of "rightness" across the two models, with the textual model identifying textual explication as the most appropriate means of achieving communication, and the graphical model favouring graphical representation. In terms of the validity claim of "rightness", most appropriate here meant most in tune with the cultural expectations of the interlocutors which, in this case, were strongly shaped by their expertise. In weighing up the relative merits of the formats, Emma took into account the expertise and preferences of her team, as well as those of their intended interlocutors, in an attempt to select the most effective approach to sharing these complex meanings.

The information artefacts examined in this study play a central role in the enactment of complex, multi-interlocutor communication. The nature of the communication, including the contributions of both interlocutors and artefacts, was presented in different ways by different informants in the study. These different perspectives are considered in this study to represent different models of communicative action. Intrinsic to the concept of models of communicative action is the concept of purpose, or communicative intent. The fact that informants ascribed communicative intent to information artefacts (pp. 162-166), and then assigned value judgements based on how well that intent was conveyed (p. 163),



underlines the role of healthcare information artefacts as proxies for human interlocutors. Recognition of a proxy role for artefacts highlights the derivative relationship of mediated healthcare communication to the communicative baseline of the classic healthcare encounter. This derivation, though evident, is not straightforward, with artefact-mediated communication being complicated by factors including interlocutor expertise and artefact materiality.

Even in the simplest acts of communication, face-to-face between two interlocutors, communicative intent is not straightforwardly conveyed into communicative action. A host of material and contextual factors come into play during the sharing of meaning, including the individual understanding of communicative action itself which is held by each interlocutor. In the digitally mediated sharing of healthcare meanings, each of the contributing expertise holders depicted in Figure 6.3 above plays an interlocutor role. Both their expertise and their model of communicative action have implications for the sharing of meaning.

### **6.3.1 Interlocutor models of intent in artefacts**

In this section, I look in more detail at a range of communicative intents enacted via information products, as reported by the informants in this study. Although I have grouped the models according to the expertise groups which reported them, the analysis does not claim to represent a definitive statement of any generalised correspondence between particular models of communicative intent and the expertise groups in this study. The relationship between the two was neither straightforward nor fixed. In these highly informationally literate groups, debates on aspects of communication were common both within and between expertise groups, and collaboration between expertise groups led to new, shared understandings which bridged groups. It is possible that a different study, with different informants, might reverse any association between models of communicative intent and expertise groups, or uncover different models. It is the fact that variation exists between models, and the presence of forms of interplay between the different models, that are of interest here, rather than the associations uncovered between particular groups and particular models.

### **6.3.1.1 To inform, to educate, to interact (systems / business: pp. 162-164)**

The most basic of communicative intentions appearing in the data, “to inform”, seems a straightforward locutionary act, implying a simple transfer of information from one interlocutor to another. It was little referenced in the interview data. Content and business informants, at least, favoured richer models of communicative action, incorporating vividly drawn contexts and interlocutors. These richer models carried specific pragmatic implications. The intention “to educate” implied that one interlocutor was the educator, and the other the educated; that the instigating interlocutor, from a position of greater knowledge, was actively shepherding their interlocutor into changing their knowledge state. In this model, in the context of healthcare publishing, the creators of information can be seen as instigators of the communicative act. Rather than putting representations of fact into the world for people to take or leave, they were engaging the informational artefact as a proxy to go out and change people’s minds.

There is an element, if not quite of control, at least of direction, in the concept of education; an inherent power balance which places power in the hands of those instigating the act of education which, in this example, would be those engaged in the creation of communicative artefacts. Since one of the interlocutor roles depicted in the creation of healthcare information artefacts was the role of the author, and in this study the author was also a clinician, there was a strong chance that in this model educative power would overlap with clinical power. But although potentially aligned with clinical power, the source and manifestation of the power associated with the instigating interlocutor was different. Rather than being confined to the clinician, or author, it was shared across the contributing expertises engaged in the creation of healthcare information artefacts, creating a moderating layer with the potential to both amplify and dilute clinical power, disrupting the power balance found in the classic healthcare encounter.

The intention “to interact” suggests a model of multiple strands of action; a perception of what interlocutors did with interactive media artefacts, and, reciprocally, what those

artefacts themselves did with interlocutors. Informants used the term differently, to refer to different strands of action; these strands included multimodal cognitive engagement of brain, eye and hand, prompted by artefacts, as well as social engagement between fellow healthcare professionals, and the complex indexing of content against context to create context-sensitive information artefacts, personalised to match the experiential expertise of individual users. Here, again, the derivation of mediated communication from the classic healthcare encounter was clear, with informants expressing scepticism about the ability of mediated interaction to deliver equivalent benefits to face-to-face social interaction. Nonetheless, in the concept of mediated interactivity, informants demonstrated a belief in the perlocutionary force<sup>22</sup> of artefacts; that is, their capacity to act, and to enact real world change.

#### **6.3.1.2 To deliver and contain content (systems: p. 162, p. 166)**

While content and business informants presented sophisticated communicative models in relation to artefacts, incorporating aspects of context and power via the concepts of intent (illocution<sup>23</sup>) and action (perlocution), systems informants implied a simpler, more mechanical model in the intentions they referenced, “to deliver” and “to contain” content. Based on a concept of simple provisioning, content in this model was presented as generic and passive, speaking little to the idea of context, or to the intentions, experience, or understanding of interlocutors. This is not to say that systems informants did not present sophisticated models of activity and context. It is simply that, as will be discussed below, they assigned the action of artefacts differently.

#### **6.3.1.3 To make explicit, summarise, disseminate and update scientific truth (content: p. 162, p. 165, p. 166)**

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<sup>22</sup> The concept of perlocution is introduced in section 2.1 of Chapter 2, where it is defined as “real world effects, beyond the simple understanding of the intended meaning, brought about by (an) utterance”.

<sup>23</sup> Likewise, the concept of illocution is introduced in section 2.1, Chapter 2, and defined as “the intention to communicate something via an utterance”.

Content informants expressed a range of related intentions around the theme of scientific truth. Under this theme, information products were presented as having an implicit duty to be explicit about their sources and rationale in the interests of achieving transparency. The emphasis was on methodological rigour and scientific accuracy, with a goal of minimising personal or political bias; on matching truth with truthfulness. This insistence on transparency placed limitations on the personal or political power which might otherwise accrue to the creators of the information artefacts, if only along the narrow dimension of scientific fact. The intention “to update” underlined the timeliness factor in truth: today’s scientific fact is, after all, tomorrow’s outdated belief. Transparency in this arena was not a static property, but rather one that shifted with changing research and developing clinical practice.

#### **6.3.1.4 To facilitate the clinical relationship (business / systems: p. 162, p. 165)**

Business and systems informants both spoke of the role of healthcare information artefacts as facilitators within the clinical relationship, once more defining mediated communication in relation to the classic healthcare encounter. The model of the clinical relationship held by the creators of healthcare information artefacts is surely of interest in relation to the effective facilitation of that relationship; for example, whether the clinical relationship was characterised by clinical control, or was rather considered the locus of shared responsibility and joint decision making. The models demonstrated in the interview data were shown to waver even within a single individual.

#### **6.3.2 Models of action in artefacts**

Having outlined above some of the variances in models of intent presented by informants, I now consider variance in models of action. The models of action expressed by informants fell into the two categories, of action on the part of users, and action on the part of artefacts.

##### **6.3.2.1 Interlocutor models of interlocutor action (pp. 169-173)**

In Chapter 4, I discussed informants’ views of the expertise held by the patients and clinicians who used their information products. The models of interlocutor expertise they

were found to present were part of a broader informant model of the interlocutor. A range of informants expressed their understanding of the tension between the generic nature of the content they created within a central context, and the intrinsically personal nature of its use by individual interlocutors within specific local contexts (p. 116, p. 129, pp. 170-173). This tension also surfaced in the “everyman” view of patient users expressed by content informants, for example, in Eve’s paradoxical notion of a highly specific “everyman” which prompted her desire for information artefacts intelligent, or interactive, enough to speak appropriately to different users in different contexts (p. 168).

To complicate the model still further, systems informants also referenced the concept of the organisational level user, introducing another layer between the generic model of the user and the individual interlocutor (p. 168). This extra mediating layer brought with it institutional priorities and needs that might differ from those of the individual users, raising questions in the mind of the producers as to which, between the institutional purchaser of their products and the individual user, was the more appropriate communicative target. These questions have implications for transparency, in that different approaches might be more appropriate, and therefore more effective, for one or other of the different user types. Adopting such approaches might increase transparency for one user type, while reducing it for the other.

Some systems informants were found to hold models of users which extended beyond healthcare into other industries which used their systems, notably aerospace (p. 171). This gave those informants a far broader concept of “generic” information use which for them stretched to encompass mechanics working in hangars, far removed from the classic healthcare encounter. For these informants, the gap between generic and specific was much wider than it was for those who focused specifically on healthcare.

Informants from all groups acknowledged that their interlocutors often subverted the envisaged pattern of communication, by using information products in unexpected ways (p. 169, p. 171). Users might choose to skip challenging pieces of text, or struggle with navigational design and abandon the product altogether; these were, after all,

interlocutors with free choice of whether to engage in this communication. By highlighting these examples of subversion, informants expressed awareness that their interlocutors were not under their control, and needed to be seduced, or coaxed, into pursuing the communication. Informants from all groups also acknowledged that their interlocutors could and did speak back to them, providing feedback on the products, communicating their own needs and expectations (p. 169, p. 171). Unlike the information products themselves, this second strand of communication was generally hidden, accessible only by the commenting interlocutor and the information creators. Although genuine two way communication could, and did, occur, such exchanges, by excluding some of the interlocutors who were party to the initial communication enacted via the product, was not fully transparent.

Informants in all categories recognised users as active interlocutors, coming to healthcare information products from particular real world contexts with real world questions to be answered, seeking to fit information into their lives, rather than to accommodate their lives to the needs of the information. There was recognition across the board, too, that information products were embedded into the fabric of users' daily lives. From the booklet in the bedside table to the coded intervention information in the electronic record system, informants in all groups presented their products as being "domesticated" into social contexts (pp. 169-170, pp. 172-173). Some of these social contexts – the bedside table, the classic healthcare encounter between patient and nurse – were well established, and for these, informants were in a position to present strong models of the eventual contexts in which their information products would be used, creating a link between the context of production and the context of use, and therefore lessening contextual barriers to transparency.

In other cases, information was being developed for contexts of use, such as electronic decision support systems, that were still in the early stages of development. In these cases, the best that those involved with the creation of healthcare information could do was to imagine the eventual context of use, for it did not yet exist. From a systems perspective, Ivan tried to imagine ways of creating and managing content so that it could

be used in any future context, while Chris presented a view of delivery in which contextual need could directly, dynamically drive content supply (pp. 172-173).

Any content delivered via such systems would still, of course, have a defined context of production, and, at the point of production, an imagined interlocutor and context(s) of use. In such situations, the implications for transparency become harder to assess, in line with the unpredictability of the eventual context of use. Transparency is particularly at risk when the users of the information have no view of their communicative connection with the creators of the information, as would be the case in the “black box” decision support tool described by Elle (p. 172). With creators blind to the context of use, and users equally blind to the provenance of the information, transparency between the two sets of interlocutors would be particularly hard to establish. Meanings would circulate detached from interlocutors and since an understanding of the interlocutor is a key component of the sharing of meaning this would pose a significant barrier to transparency.

#### **6.3.2.2 Interlocutor models of artefact action (pp. 173-176)**

Beyond models of interlocutor action, which were presented by informants in all groups, content and business informants also referred to the information products themselves as active. One aspect of this action on the part of information artefacts was the power of information artefacts to enact tangible benefits for users; to help them in ways that extended beyond the provisioning of information. For Louis, the information specialist, working to support this perceived benevolent agency was an important motivational factor in his work (p. 174). Whenever an artefact was presented as having agency, it was important, for the purposes of this study, to seek the human source for which the artefact was acting as proxy, in order to assess the validity claims for the communication and the implications for transparency. It would be simplistic to ascribe the source of this benevolent agency to the clinicians who authored the information artefacts, as commitment to benevolence was expressed by content and business workers all along the chain, including not only the information specialist, but also the educational consultant,

the graphic designers, and the education and publications manager (pp. 174-175). The benevolence enacted by healthcare information artefacts should therefore not be considered as simply an extension of the clinical role, but as a more complex and multi-layered compilation of intentions, hard to decipher from the outside, and, therefore, not transparent.

Information products were also portrayed by content and business workers as interacting with users, for example, in prompting users to ask questions, or establishing the expertise level of users (p. 175). Again, the source of the agency here was hard to assign, and so the meaning of the interaction hard to establish. Unlike the vaguer sense of benevolent action described above, these more specific actions carried a sense of surveillance and control. However well-meant the underlying intention, when neither the originating interlocutor, nor the intention itself, was identifiable to interlocutors, there were negative implications for transparency. Penny, the production editor, expressed scepticism about the drive to create active products when the communicative intention was unclear. Ivan, the information technologist, presented a view of products interpreting context to redirect users, behind the scenes, so that whatever their entry point, they were served up similar content. Again, the underlying intention was benevolent, but the result far from transparent; an impression of context-sensitivity that was not, in fact, followed through by any contextual variation in the information it uncovered.

On the whole, systems informants were almost silent on the capability of information products to act. Where they ascribed agency, it was, as with the example from Ivan in the paragraph above, to systems rather than to content. Where content informants saw their content as active proxies in communicative action derived from the baseline of the classic healthcare encounter, for systems informants it was systems which acted, while content was passive. The model of meaning expressed by systems informants was markedly different from that expressed by content informants, as will be explored in the next section, on models of materiality.



### **6.3.3 Interlocutor models of materiality in artefacts (pp. 176-212)**

There was little direct agreement in the ways informants spoke about the material aspects of information products. There were differences both in the presentation of materiality and in the underlying models of the ways in which materiality related to the sharing of meaning. Bearing in mind the illustration in figure 6.3 of the way that expertises were presented as combining and overlapping to layer intent into information artefacts, these differences in understanding of materiality and meaning, and associated variances in practice, have implications for transparency.

Informants from all groups agreed that content had material aspects. Its creation and maintenance required effort, and this effort was costly (p. 182). Some systems informants, aware of the high costs associated with the creation and maintenance of content, expressed enthusiasm for reuse and streamlining (p. 129, p. 153), to reduce the effort required, while those informants from all groups who had been in the front line of messy implementations were more questioning of techniques promising to reduce the material impact of content work (p. 153, p. 183, p. 189, p. 190, p. 198). For those on this front line, the materiality of content could not be abstracted away, and the impact of snarl ups was only too tangible, soaking up the time and effort of skilled workers to correct. Content, for these front line workers, was far from being an abstract concept, although to those who viewed it from a greater distance, it might at times appear as such, or, at least, have the potential to become as such. It seemed significant that no content informants applied the rather abstract term “knowledge” (p. 177, p.188) to the material reality of the content they worked on, perhaps because this buzzword, beloved of management and systems enthusiasts keen to reduce the material drag of content work, bore little relation to their lived reality of effortful, weighty content work.

There was perhaps more consensus between informants on what content was not, than on what it was. Informants from all groups agreed that content was distinct from presentation (p. 180); that there was a nub of meaning within the term content which should be distinguished from the ways in which that meaning was presented to interlocutors. Equally, informants from all groups agreed that content was distinct from

systems (p. 180), though the informants from each expertise group presented this distinction differently. Systems and business informants focused on the flexibility arising from the distinction, with benefits arising when content and systems were able to be manipulated independently of one another (p. 180, p. 182, p. 184, p. 185). In contrast, content informants voiced concern about the gap in big picture understanding which arose when content expertise resided separately to systems expertise (pp. 146-147). The implication of this division of expertise was that no single individual's view could encompass both aspects, or fully appreciate the consequences for meaning of interactions between systems and content. According to this model of the split in expertise, the combination of content and systems could only be fully understood and managed via a collaboration between different expertise groups. The need for transparent communication between collaborating expertise groups thus became a central factor in the transparent sharing of healthcare meanings.

Contrary to Habermas's semantic presupposition of consistency of meaning in successful communicative action (Cooke 1994:30), informants often used the same terms to mean different things, or different terms to refer to the same thing. Content informants tended to choose the term "data" to describe an underlying truth inscribed within content, a truth which could be extracted from within the looser, more ambiguous framing of text. In contrast, "data" was a word that systems informants rarely used to talk about the content of information products, perhaps not recognising within these essentially text-driven artefacts the mathematical purity they associated with the term (pp. 179-180).

Even editors presented text as a format prone to obscure as well as reveal, inadequate for fully transparent exposition of fact. The technical content developer, David, whose role involved the technical encoding of text, barely engaged with the subtleties of textual meaning, instead choosing to encode simple structural elements (p. 178. p. 194, p. 197). Chris, the implementation consultant, saw text as a poor conveyor of meaning in computer-based searching, in comparison to other, more sophisticated searching techniques (p. 179). The sense that "databased" text could form a useful resource was reported as attractive to business and systems informants (p. 179, p. 182, p. 190, p. 205) ,

but contested by content informants, with tangible benefits resisting definition, due to the subtle variations in the relationship between meaning and text (p. 198). Across the board, text was presented as a rather imprecise and troublesome means of conveying fact, but it was also seen as an ingredient which was at times necessary to hold together factual aggregations (p. 179), as though text, though tending to obscure transparency, was, at the same time, required for the socialisation of plain data, in order to meet the “rightness” criterion for transparency.

Ideas relating to the makeup of information products varied between expertise groups. Even where the same terms were used, the meaning of those terms often differed between groups. The term “element” was one example of this, used non-specifically by content informants to denote any identifiable part of a product which did not have a name, and highly specifically by systems informants to describe a structural element defined within the XML protocol (pp. 195-196). Such well-defined, highly specific differences in usage were straightforward to identify and describe. More complex were the different models implied by the use of looser, more informal, even idiosyncratic terms, such as those used to describe higher level components.

For higher level components, content informants favoured either terms carrying the cultural weight of the historical forms of print publishing, such as booklet or chapter (pp. 201-202), or terms which blurred the boundaries between form and meaning, such as review and intervention (pp. 207-212). This contrasted strongly with the aggregation-based terminology favoured by systems informants (pp. 204-206). The bottom-up, structural approach described by systems informants moved the focus away from both the broader context of the information, and the communicative intent it served, focusing instead on the active processes of compilation. The process of active user configuration described by systems informants depicted users as being in control of the meanings they shared which, of course, had implications for the nature of the communication enacted via the information products. In this model, the communicative action resided in post-creation compilation, with the primary interaction taking place between system and user.

In the model of mediated discourse proposed in this thesis, when an artefact takes part in communicative action, it is as a proxy, enacting the agency of human interlocutors. In user-led product compilation, the system could not simply be acting as a proxy for the content producers, or at least, not transparently so, unless they were explicitly aware of the logic within the system which interpreted perceived user need into content compilations. Therefore, the user-driven aggregation model of content de-emphasised the communicative agency of the content producers, placing a systems-inspired barrier between human interlocutors. In its shaping of communicative action, the system acted as proxy as much for systems developers as it did for content producers. Transparency of healthcare information, when mediated by this type of system, therefore relied on a three-way understanding between systems developers, content producers, and the final interlocutors of patients and clinicians.

The ambition to drive communication from interlocutor need, rather than authorial intention, turned the concept of transparency on its head. Rather than transparently resolving a layered intention as it passed through a complex journey to a final interlocutor, the requirement became to transparently resolve the communicative need of the final interlocutor – but with whom? Since the meanings held within the systems described were fixed in advance, and there could therefore be no dynamic response from human interlocutors to an unexpected request, this transparent resolution was with the system alone; the communication stopped short of direct interplay with human interlocutors.

At first glance, this model might appear to empower users, equalising the power balance of mediated healthcare meanings which might otherwise appear to favour clinical and producer perspectives. Closer consideration reveals the implications to be more complex. Automation of the interface with the end user, as proposed by the systems informants in the study, with their aims of products which could dynamically assemble themselves in response to perceived user need (p. 173, p.184, p. 188, p. 205) , carried implications for the communicative act between the interlocutor types of creator(s) and user(s). The

presentation of the systems informants suggested that it was that the system itself which selected, based on a combination of explicit internal rules, and user context.

Given the assumption that when artefacts act they do so as proxies, I would argue the intervention here of human actors, namely, the designers, developers and implementers of the system. It is only at this point, that of dynamic configuration and delivery, that the communicative intent of the systems interlocutors is fully enacted, and combined with the communicative intent of the content interlocutors. The communicative intent of systems interlocutors, shaped by their understanding of communicative intent, both in the abstract and in the particular models held by content and user interlocutors, their understanding of the relationship between content and context, their understanding of the clinical and human consequences of error, and their understanding of ownership and accountability, come fully into play only at the point when neither content nor systems interlocutors are present to assess the communicative implications. At the point at which all interlocutors finally engage fully, the users are alone, with content and systems interlocutors represented only by their proxies.

The neutral, business-friendly term “component” stood out in its promise of harnessing generic efficiency to reduce the material drag of content creation and maintenance (p. 199). Unfortunately, attempts to streamline the material impacts of content had the potential to incur other kinds of cost. In reusing information in multiple contexts, with the aim of reducing the material cost of creating information, the dynamic range of content might be lost; the more generic the solution, the harder to accommodate outliers and anomalies. In addition, the work of “normalising” content into components to support this model was itself identified as onerous; a work of dematerialisation which itself consumed material effort (p. 129, p. 200). All of these factors weighed against the intended economic advantage of generically efficient content. Flexibility was an aim commonly cited by systems and business informants, defined as the ability to create products and meanings that could be adapted for use in a range of contexts. As a property, it was difficult to reconcile with the validity criteria of truth, truthfulness, and rightness, and so sat in uneasy relation to transparency.

The relationships between content and meaning presented in the study were varied and complex. One of the ways in which the term information was used by informants in the study was to signify an underlying “meaning” encoded within products, a “meaning” which formed the basis of communicative action between interlocutors (pp. 185-186). At the same time another, more mechanical use of the term positioned information merely as a technical format (p. 187). These usages varied within expertise groups, and even within the contributions of single individuals, underlining both the ambiguity of commonly used terms, and the shifting models of meaning they pointed to.

At one extreme, systems informant Curt presented meaning as something that sat entirely separately from content, needing to be added in an act of explicit encoding which he considered to be more transparent than the capture of meaning via the natural language text of the products (p. 185, p. 193). While this explicit encoding might satisfy the validity claim of truth, its appeal to rightness was at a systems, rather than a social, level. This divorcing of content from its meaning sat in contrast to the commitment of content informants to embedding critical, real-world meanings directly into content via the range of complex social processes they employed in the course of their work. In their socially-inspired, meaning-rich model, content was able to achieve a form of truth transparency via the validation afforded by methodological scientific rigour, and of truthfulness validation via expert endorsement. At the same time, content could also achieve rightness validation by being shaped to chime with expectations of its target interlocutors, in particular, with imagined contexts of use.

Meaning emerges from content in context, so any division of content from its context of use has implications for meaning. Content and systems informants presented the relationship between content and context differently. While some systems informants in this study presented particular content workers as focusing principally on the material content before them, with little or no awareness of its context of use (p. 181), content informants themselves demonstrated keen awareness of an imagined context of use of the information products they created, an awareness which informed and directed their content work (p. 132, pp. 133-134, pp. 164-165, p. 170) . This disjunction in

understanding between the two groups has implications for their ability to collaborate effectively in the transparent sharing of meaning.

If systems informants did not acknowledge the subtle understanding of context that content informants expressed in the interviews, symmetrically, content informants did not report any need for systems developers and implementers to recognise this understanding of context, in order, for example, that they might take advantage of any insight it might provide when designing their systems. Rather than seeking to identify the models held by content interlocutors, those information technologists involved in the implementation of systems relied on their own methods of analysis to make explicit the tacit knowledge underpinning the work of content interlocutors (pp. 155-156) The direct contact between systems and content interlocutors was limited, and the vitally important link between content and context appeared to have been lost in the gap between the roles. There was work to be done on both sides in order to share this information effectively, so that the contextual insight of content interlocutors might inform systems development. Informants from all groups appeared hampered in effective collaboration by their lack of insight into the perspectives of other roles.

The mediation of healthcare meanings carries single locutionary acts into multiple contexts, where their illocutionary and perlocutionary force will be enacted in various ways according to those contexts. If content use can be thought of as contextualisation, then *reuse* can be thought of as *recontextualisation*. As already discussed in this chapter (p. 257), reuse, as a goal, was viewed with scepticism by content informants in this study, while systems informants spoke of it enthusiastically as a way of reducing the material drag exerted by the effort involved in content creation. The association of reuse, or recontextualisation, with economic goals in itself has implications on the truthfulness validity of communication, as the consideration of cost issues may in itself have mediating implications. These implications for truthfulness have the potential to be amplified if the proponents of cost-effective content working have a model of context which does not match the model of either their collaborators or their co-interlocutors.

The goal of creating context-independent meanings is an attractive one from a cost effectiveness perspective. The adaptation of meanings to align with particular contexts is costly, and one of the key drivers towards digital mediation in the sharing of healthcare meanings is cost effectiveness, since it would simply not be affordable for every patient to have a clinician on hand whenever required to educate, explain, and inform as well as to diagnose and to treat. However attractive the prospect of context-free meanings, the importance of context in the sharing of meaning cannot be overestimated. The analysis in this study shows different groups conceptualising this issue of context in different ways. These approaches might work symbiotically, but equally, they might conflict. David, the technical content developer bridging systems and content, spoke of the need to come up with new rules, and to stick to them (p. 203). Without a clear and explicit mapping of those rules to the models of communicative action held by the various interlocutors, the outcome in terms of transparency would be left to chance.

When mediated forms exhaust their limited material flexibility, the resulting torque<sup>24</sup> between intention and form has the potential to constrain the transparent enactment of communicative intent. In this way, the materiality of media artefacts can provide barriers to communicative transparency. The attempts discussed by the informants at reducing the material drag of media artefacts were driven by a mixture of motivations. While there was undoubtedly a communicative drive to achieve greater flexibility of material in order to achieve greater relevance to individual user needs, there was also an economic drive. Material artefacts are costly to build, costly to maintain, and costly to change, and ways of reducing this cost are understandably attractive. But the material drag which results in economic cost, and the torque between material forms and their communicative intent which can result in communicative constraints, are not necessarily the same, and reducing one may increase the other. Creating cost effective methods for sharing information

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<sup>24</sup> I use the term torque in the sense introduced in section 2.7 of Chapter 2, to describe “the wrenching force that is brought to bear when the rigidity of a system does not quite accommodate the shape of the lifeworld experience to be encoded within it” following Bowker and Star (1999).



might provide fresh challenges to the transparency of that information, just as creating methods for sharing information which ensure the transparency of that information might increase the associated economic costs.

#### **6.4 Challenges to transparency arising from mediation in the healthcare discourse**

The data analysed in this study suggest that the biggest risk to transparency in the digitally mediated sharing of healthcare meanings is the lack of a mutual validity framework between the collaborating expertises of those who contribute to the creating and dissemination of healthcare information artefacts. Reconciling the highly crafted, highly social models described by content informants with the automation promised by systems informants was not simple for the participants in the study, despite the commonality of the artefacts they shared. The systems focus on structural elements and the dual content focus on interlocutors and on meaning were applied to the same artefacts, but there was little overlap in the terminology they used, and the models this terminology was used to describe. The resulting collaborations, lacking a shared frame of reference, could have no other basis than trust, and yet were characterised by a wariness born of unfamiliarity.

With such divergent models, it was difficult to achieve transparency even between collaborators, and all the more difficult under such circumstances to preserve transparency of communicative action with the target interlocutors of clinicians and patients. Misunderstanding of communicative models has the potential to hamper the transparent specification, design, and acceptance of systems. In a model of collaborative communication as complex as that drawn in figure 6.3, if the collaborators could not understand how their different contributions interacted, then the ways in which meanings generated by their collaboration would be shared would not only be highly unpredictable but also fundamentally unknowable.

When concepts first emerge, and are informally named, without the weight of cultural adoption behind them, they are fluid, yet to be fixed and standardised. As an example, the terminology by systems informants used for content components was a combination of

the highly defined (element / metadata / tag) and the highly emergent (chunk / bucket / block) (pp. 195-198). The reconciliation that must occur for transparent collaboration was therefore not only between divergent models, but between models which, at least in parts, were developing and changing. It was perhaps in the fluidity of emerging models that the greatest hope of transparency lay. Far more than established models with defined terminology, models that are not yet fixed have the ability to adapt and to accommodate other perspectives.

There were aspects of the development of digital healthcare content which required close collaboration across technical and content disciplines. These included the iterative, side-by-side development of structural schemas and content (p. 159, p. 184) and the application of semantic metadata to textual content, (p. 196, pp. 206-207) as well as broader issues of website design and digital content management. Such endeavours had the potential, if enacted socially with the active involvement of the different expertise groups, to provide a site for the negotiation of meaning between the community of systems, the community of content, and the community of healthcare, in which all participants could gain insight as they co-constructed what needed to be said, what could be said, and how best to say it. Within the interview data, business, content, and systems informants were shown using the terminology and concepts favoured by other groups, sometimes rather haltingly, in what seemed to be a move towards mutual understanding (content informants: p. 175, p. 189, p. 190, p. 198, p. 207; business informants: p. 179, p. 190, p. 198; systems informants: pp. 211-212). This cross-fertilisation of terminology and concepts occurred at points where the cultures had to engage closely on an individual level, suggesting that, once again, in the service of transparency, the face-to-face encounter set a communicative baseline.

## **6.5 Conclusion**

In section 2.8 of Chapter 2, I posed the questions

*How do specialist expertise and digital artefacts work in combination in digitally mediated healthcare to promote or hinder communicative transparency?*

*What factors exacerbate challenges to communicative transparency in the digital mediation of healthcare meanings, and what factors mitigate them?*

In this chapter, I have explored interactions between expertise and information artefacts in the digitally mediated healthcare discourse, and considered the implications of aspects of this complex discourse for communicative transparency.

In this chapter, I have shown interlocutors in the healthcare discourse negotiating the complex landscape of digitally mediated meanings. I have elaborated the challenges to transparency which emerge from the different validity frameworks adopted by different interlocutors, and in particular differences in validity frameworks which emerged from the different expertise groups engaged in the digitally mediated healthcare discourse.

The challenges that emerged were many. This is a complex area, due to the diversity it demands in its contributing interlocutors, the specialised expertises which must collaborate in order to make digitally mediated healthcare discourse function in the real world, and the stubborn materiality of the digital artefacts employed as proxies in the discourse. Such complexity was shown to introduce challenges to communicative transparency which, I argue, if left unexamined, might compromise the integrity of the healthcare discourse itself, influencing what we can and cannot say on the topic of healthcare in the digitally mediated discourse. In addition to highlighting challenges, informants also demonstrated some ways in which they negotiate complexity to support the continuity and development of the digitally mediated healthcare discourse. I suggest that these discursively negotiated solutions to novel informational problems provide a way forward in terms of indicating useful norms for the further development of the digitally mediated healthcare discourse.

In the next and final chapter, I review my findings in relation to the research agenda I set out in Chapter 2. I reflect on the mobilisation of the conceptual framework I developed, summarise the answers to the empirical questions defined in section 2.8 of Chapter 2, and present my answer to the core research question driving this study: *Can digital mediation increase the transparency of healthcare communication?*

## CHAPTER SEVEN

### Conclusions

#### Introduction

In this thesis, I have sought to provide empirically-informed answers to the central question informing the thesis: *Can digital mediation increase the transparency of healthcare communication?* This question was operationalised to facilitate an examination of some of the particular challenges to communicative transparency which arise from the digital mediation of healthcare meanings. “Communicative transparency”, for the purposes of this study, refers to the idealised achievement of mutual understanding through discourse which was defined by Habermas as “communicative action” (Habermas 1984, Cooke 1994); “digital mediation” refers to the creation and dissemination of information artefacts such as websites, on healthcare topics, using digital technologies.

This final chapter sets out the main theoretical insights arising from this project, along with the central empirical findings. In section 7.1 of this chapter I elaborate on the theoretical insights, organizing this discussion around the four components of my conceptual framework, as set out in section 2.8 of Chapter 2, and I reflect on the contribution each component makes to an improved understanding of the question of transparency in digitally mediated healthcare communication. In section 7.2, I revisit the four empirical research questions, and summarise the key findings. In section 7.3, I consider the strengths and weakness of the study, before reflecting in section 7.4 on the implications of my study for further work in this area. In section 7.5, I summarise the overall conclusions.

#### 7.1 Theoretical synthesis and discussion

In this section, I elaborate on the theoretical contribution of this thesis and provide a synthesis of the main insights. Following a recap of the theoretical positioning of my study and a summary of the key insights, I structure the discussion around the

components of the conceptual framework that guided the study, as set out in Chapter 2, section 2.8.

In accordance with the conceptual model I developed, which was based on theories concerning the pragmatic analysis of communication, *meaning* in this study was conceptualised as co-created by participating interlocutors, who work discursively to achieve shared understanding. It is this discursive work towards mutual understanding that I describe as “the sharing of meaning”, following the theoretical approach set out by proponents of linguistic pragmatics such as Levinson (1983), Sperber and Wilson (1995), Mey (2001), and Cummings (2005), inspired by philosophers of languages such as Grice (1989), Austin (1962), and Searle (1969), and adopted, with broader and more critical social implications, by Habermas, in his theoretical programme of formal pragmatics (Habermas, 1984; Cooke, 1994; Habermas, 1999). For the purposes of the study, theoretically, the digital sharing of healthcare meanings, via digital information products for clinicians and patients, was conceptualised as a single complex *discourse*. I have explicitly linked my use of the term “discourse” to the normative, idealised, context-transcendent, Habermasian notion of discourse. This is a deliberately narrow definition of the term, as I suggest that it is that narrowness which offers opportunities for analytical precision. In this sense, my use of the term contrasts with both the familiar, generic use of the term to signify any type of communication or dialogue, and with Foucault’s concept of discourse as both historically situated and constitutive of society (Foucault 1972 chs. 1-2). My use contrasts, too, with the use of the term within Fairclough’s methodological programme of Critical Discourse Analysis (CDA) which uses the analysis of language as a tool in the service of a larger socio-cultural research programme, seeking linguistic evidence within media texts for the power structures implied by social theory, while highlighting the role of texts in shaping social and cultural factors (Fairclough 1995: 54-55).

The patients and clinicians who are the intended users of healthcare information products, together with the holders of content and of systems roles involved in the creation of digital healthcare information artefacts, were all conceived of as *interlocutors* in this

complex discourse. An *interlocutor* was defined as an active participant in a conversation or discourse, who seeks to build an intersubjective connection with other interlocutors in order to reach mutual understanding. In section 2.1 of Chapter 2, I introduced the term by referencing Mey's (2001) definition as "conversational partner". In this study, my contribution has been to expand the concept of "conversation" to encompass specific aspects of communication, such as those occurring during the processes of systems design and development that are normally considered peripheral in the analysis of healthcare discourse. Still working with the relatively narrow theoretical definition of discourse discussed above, empirically I placed the boundaries of the digitally mediated healthcare discourse broadly, encompassing not only the straightforwardly recognizable healthcare statements made by clinicians and patients, but also the many actions through which these statements are brought into being in the digital media environment. This was essential and fruitful as a means of attracting attention to the need to surface aspects of meaning that might otherwise go unnoticed in an empirical analysis of healthcare discourse. In this study, the communicative actions making up systems design and development, systems implementation, editorial work, graphic design, and critical research appraisal, are all considered, following the terminology of pragmatics, to be *locutionary acts*, defined by Levinson (1983: 236) as "the utterance of a sentence with determinate sense and reference". In pragmatic analysis generally, such "utterances" are taken as the basic units of communication. For this study, the locutionary act, more broadly defined as the performance of *any action* of determinate sense and reference *with communicative intent*, is assumed to have the same function. Speech act theory, as initially set out by Austin (1962) and Searle (1969) suggests that in *saying* something, we *do* something. Conversely, in this research I was interested in demonstrating that when holders of content systems *do* something to progress communication, they also *say* something and hence participate in the broader discourse.

By granting systems and content workers the same interlocutor status theoretically within the healthcare discourse as I give to clinicians and patients, I was able to apply this theoretical approach to explore the particular influence that holders of systems and

content roles bring to bear on healthcare meanings. In the literature in this area, systems and content workers are often considered as performing simple administrative functions, straightforwardly supporting the public discourse they enable. My theoretical framing of these roles as interlocutors, or active participants in the healthcare discourse, enabled a critical examination of their contribution. I suggest that such critical readings of healthcare discourse are essential to ensure that healthcare meanings are not subject to unnoticed distortion. The need is particularly acute in healthcare communication, since anything that impacts on transparency in this area, particularly anything that might potentially distort that communication, has the potential to bring harm to health at an individual or a population level. The analysis in this study surfaces modes of interlocutor influence that might indeed challenge transparency, but it also surfaces modes of interlocutor influence which offer potential mitigations for those challenges.

Cooke (2001) clarifies the critical and transformative ambitions of the social theory Habermas built from his idealised theory of communicative action:

A central aim of the theory is to explicate standards for critically assessing, and if necessary transforming, existing social institutions and structures in the light of the normative conceptions yielded by these investigations. (Cooke, 2001: 1)

It is the tension between the normative ideal of communicative transparency and the complex, messy distortions that occur in real life communication that drives this research, with the notion of communicative transparency offering, as a framework for the empirical research, “a demanding ‘ought’ that faces the sobering ‘is’” (Habermas, 2006: 411). It is important to recall, as I noted in section 2.1 of Chapter 2, that Habermas himself identifies rational discourses as “*improbable* forms of communication”. (Habermas (1982), as quoted in Cooke (1994: 32): my emphasis). That challenges to transparency exist in the arena of digitally mediated healthcare is not in itself noteworthy. The focus of this research has been to explore the precise mechanisms and processes of distortion arising from the structure of this particular communicative context. Accordingly, this research did *not* set out with the expectation of finding instances of perfectly transparent

communication, but instead to delineate the nature of the almost inevitable distortion of meaning which occurs in this type of real world communication with the ultimate aim to provide insights that might point towards ways of reducing, though probably never wholly removing, such distortion.

The intersubjective understanding which is explored in this study is achieved through the employment of a mutually comprehensible mediating framework. Many challenges to transparency arise from the various modes of mediation in this framework and these challenges can lead to what Habermas refers to as *systematically distorted communication*, a concept first introduced into this thesis in section 2.2 of Chapter 2. Systematically distorted communication disrupts “the internal organization of speech”, defined as “a connection between meaning and validity, a connection between meaning and intention, and a connection between speaking and acting”. (Cooke 1994: 148). Within the terminology adopted in this thesis, systematically distorted communication occurs when communication suffers from a loss of *transparency*. Commentators such as Cooke (1994: 148) and Crossley (2004) have indicated that Habermas does not fully develop the concept of systematic distortion. Bohman (2002) develops Habermas’s rather abstract concept into one with practical application, mainly in the arena of deliberative politics, but with an acknowledgement of potential use in science. Bohman’s exploration, noting that “restrictions on communication undermine implicit conditions of communicative success”, focuses on the power of reflection to “unblock communication by making distortions explicit”.

For the purposes of this study, mediation was understood across three dimensions, all relating to the different ways in which interlocutor intention is enacted in the world. The first dimension of this mediation is the linguistic and para-linguistic mediation by which intersubjective sharing of meaning is achieved in spoken, written, or digitally encoded communication, as discussed in section 2.1, Chapter 2 of this thesis. The second dimension of mediation applies to the contexts in which communication takes place, making particular reference to the mediating aspects of expertise, and is discussed in section 2.5 of Chapter 2 of this thesis. Experts themselves act as mediators, passing on



their particular knowledge to the less expert (Stehr and Grundman 2011: 39), but more importantly, the possession of expertise by an interlocutor is understood to alter the context of their utterances, or locutionary acts, as illustrated in section 2.2, Chapter 2, in particular in Figures 2.1 - 2.3 and their explanatory text. Aspects of context are key to pragmatic analyses of communication and are explored by the same theorists listed above in relation to linguistic and paralinguistic mediation. As a more specific counterpoint to the pragmatic account, relating to expertise in particular, Knorr Cetina (1999) theorises particular types of expertise as enacted in social settings as “epistemic cultures”, emphasising the importance of differences in expertise by relating them to differences in the ways knowledge itself is conceived:

culture (...) implies ruptures in any uniformities of practice; these ruptures are important because they suggest the existence of different technologies of knowing serving different substantive, technological, and economic ends. (Knorr Cetina 1999: 10)

The third dimension of mediation applies to the information artefacts through which healthcare meanings are captured and disseminated and the technological processes by which such capture and dissemination are achieved. I discussed aspects of mediation via artefact in section 2.6 of Chapter 2, framing mediation via information artefacts in relation to the account given by Thompson (1995), the “logic of remediation” (Bolter and Grusin 2000), the concept of design set out by Mansell and Silverstone (1996) and the parallel notion of domestication (Silverstone and Haddon 1996). In section 2.7 of Chapter 2, I conceptualised the artefacts employed in digitally mediated communication as *material*, and explored such specifics of digital materiality as *malleability* (Quintas 1996), *weight* (Winner 1999, Garnham 2000, Mansell 2004), and *texture* (Bowker and Star 1999).

If distortions to healthcare communication can bring harm, it follows that increased transparency in healthcare communication may enhance health and wellbeing. It is therefore important, in analyses of digitally mediated communication mediation in

healthcare, to be aware of modes of mediation that might enhance health and wellbeing and to be able to contrast these with modes of mediation that might bring harm. The analytical framing used in this study enables such distinctions to be made with greater precision than is afforded by other, less normative approaches.

The empirical study examined discursive modes of collaborative working between holders of content and systems roles. Within these modes of working, *validity claims* were raised and resolved by interlocutors from different intellectual traditions, such as clinical editors and technical developers. The meeting of the validity claims of intelligibility, truth, truthfulness (or sincerity), and normative rightness was set out theoretically by Habermas in his programme of formal pragmatics (Habermas, 1984; Cooke, 1994; Habermas, 1999) as the prerequisite for successful communicative action. In this study, the raising and meeting of such validity claims was particularly observed in the collaborative, cross-disciplinary discursive resolution of novel informational concepts which arose from the application of digital media technologies within healthcare contexts, as described particularly in section 2.3 of Chapter 5. Such discursive collaboration was shown to have facilitated the construction of a more transparent healthcare discourse. The key insight of the research was that communicative transparency in the cross-disciplinary collaborations required by digital mediation was a necessary foundation for achieving a greater degree of transparency in the wider healthcare discourse. By implication, distortions to transparency in the collaborations around digital mediation, indicated by unresolved challenges to the validity claims of truth, truthfulness, or rightness, facilitated distortion of meaning in the wider healthcare discourse.

The theoretical conceptualisation of digitally mediated healthcare meanings as a single discourse and, in particular, the granting of interlocutor status to holders of systems and content roles, enabled the bringing together of a diversity of roles and activities into a comprehensive analytical framework. The study covered a wider range of expertises and contexts than is customarily covered in healthcare communication research. Some of these expertises and contexts, such as those of clinical and patient actors, were enacted at

times and places that were not accessible to me as a researcher in this study. My conceptualisation of these more distant actors, which emerge in the study as “imagined interlocutors”, differs from both the approaches to imaginary audiences summarised by Litt (2012), and from Massanari’s concept of imaginary users (Massanari, 2010). Both Litt and Massanari conceptualise the role of the imagined audience, or user, as *fundamentally different* from the role of the performer (Litt), or designer (Massanari). Within the conceptual framework for understanding discourse that I developed, the concept of *interlocutorship*, that is, of participation in a discourse, is considered as being fundamentally similar across diverse functional roles and expertises, whether the nature of participation is as audience, user, producer, or designer. This concept of equality of interlocutorship is central to this research, which deals with many varying types of participation in discourse, including reading, writing, and editing text, but also laying out that text, producing graphics, carrying out research to inform products, and the development and use of the digital systems through which information products are created and disseminated. For the purpose of this research, all those engaged in the exchange of digital healthcare meanings, whatever the detail of their role or the nature of their participation, are considered to be engaged, on an equal basis, as interlocutors in a single complex discourse.

When, in this study, I use the terms “originating interlocutor” for the person performing the locutionary act, or “target interlocutor” for the person towards whom the act is directed, I am attributing these roles conceptually on the level of the *locutionary act only*, and not on the level of the discourse. Interlocutors are understood to play both roles within a discourse and to switch dynamically between them. That is the nature of discourse as understood in the theoretical framing for this study. In this respect, my concept of the “imagined interlocutor” has perhaps more in common with the idealised “model interlocutor” described by Blair and Johnson (1987) as exhibiting “certain traits of reasonableness” – including that they are knowledgeable, reflective, open, and dialectically astute. The idealised rationality of classical argumentation chimes well with the idealisation inherent in the Habermasian concept of discursive rationality. Originating

an utterance in a discourse does not define a participant as a “producer”, any more than interpreting an utterance defines a participant as an “audience”.

Clinicians and patients did not contribute directly to the empirical work informing this study, and yet were referenced heavily in contributions by all other informants, lending shape and purpose, even in their absence, to the emerging understanding of mediated healthcare discourse. Affording them the status of interlocutors, or participants in a shared discourse, enabled the mobilisation of the intersubjective orientation of pragmatics, so that even in their absence as informants in the empirical work, the subjective status of clinicians and patients could be recognised, alongside that of fellow interlocutors such as holders of content and systems roles who acted as empirical informants. Cooke (1994: 21) sums up the co-dependency between interlocutors identified by Habermas as “the need for intersubjective recognition of the criticizable validity claims that they raise.” Analysis of the broad sweep of digitally mediated healthcare discourse was made possible by the framing of these very different, if connected, practices as part of a single discursive activity.

Another borrowing from the pragmatic theory of communication, the use of the concepts of locution, illocution, and perlocution from the speech act theory of Austin (1962) and Searle (1969), as summarised by Levinson (1983: 236); Mey (2001: 95-97) and Cummings (2005: 6-9), enabled precise distinctions to be made between the nature and implications of particular aspects of the communicative events enacted through digital media artefacts.

In particular, the notion of *illocution*, which in speech act theory conveys the intention of an interlocutor in making an utterance, provided a formal framework for the discussion of the various intentions of diverse actors. This was a helpful strategy because it worked to support an analysis of the differences in communicative intentions found between different expertise groups. In parallel, the notion of *perlocution*, which in speech act theory conveys the consequences or effects set in motion through utterances, provided a means of enabling real world actions to be brought into the theoretical framework,

thereby enabling an analytical engagement with the belief expressed by many informants in the capacity of digital media artefacts to bring about real world changes in healthcare.

Finally, my focus on context as an important component within my theoretical framework in relation to the sharing of meaning was also taken from the field of pragmatics:

“Context is more than just reference. Context is action. Context is about understanding what things are for; it is also what gives our utterances their true pragmatic meaning” Mey (2001: 41)

The concept of context within this study was used to support an analysis of a variety of issues, from the implications of modes of information access within healthcare contexts, to the implications of particular technical contexts, as introduced in section 2.4 of Chapter 2.

Drawing upon formal pragmatics theory to inspire my conceptual framework, particularly with respect to the role of the interlocutor, and through the deployment of the concept of locutionary, illocutionary, and perlocutionary acts, the notion of validity claims and the distinctions between them, and the ways in which these concepts appeared to operate to support, or distort, communicative action oriented towards mutual understanding, provided a basis for a systematic and normative analysis of the digital mediation of healthcare meanings. Cooke’s summary of Habermas’s argument for a formal pragmatics to support empirical pragmatics is apt:

only formal pragmatics has at its disposal the *conceptual instruments* that are necessary if the rational bases of linguistic communication are to be discerned amidst the confusing complexity of everyday linguistic activity (Cooke 1994: 123; my emphasis)

The first component of the conceptual framework developed in the light of the broad theoretical framing for this study discussed above was *communicative transparency*, defined in relation to Habermas’s idealised notion of discourse as communicative action.

Adopting Habermas's notion of transparency supplied the analytical parameters of truth, truthfulness, and rightness which are, in Habermas's model, the validity claims which must be satisfied in order for transparent communication to take place, and so enabled the evaluation of the varied communicative configurations examined in the study. Early analysis of key terms used across the organisations was oriented towards surfacing contrasting truth validity claims. No such contrasting claims were found, at this or any other point in the study, and the only challenge to transparency arising from truth validity claims was found in the unfamiliarity of some interlocutors with the highly formal mechanisms by which parameters of truth were established.

Contested claims to truthfulness were more common in the empirical data than contested claims to truth, occurring, for example, when economic aims conflicted with the communicative aim of mutual understanding, and between expertise groups unfamiliar with the contexts in which their interlocutors worked. In addition, claims to truthfulness would be difficult to maintain in the face of obscured interlocutor identity. The trickiest validity claims to maintain in this complex arena were those to rightness. Validity claims to rightness are by their nature tightly bound up with social context and, with such a complex context, with many different types of interlocutor holding many different perspectives on that context, most challenges to transparency were found to be concentrated around this particular validity claim.

The notion of validity claims provided a useful framework for the categorisation of challenges to transparency. In an arena populated by expert actors, articulate on the nature of truth and expressing a keen commitment to the growth of mutual understanding, this framework supported a nuanced investigation into the challenges to transparency that nonetheless arose, and provided insight into the ways in which particular categorised challenges played out.

The second component of the conceptual framework was the particular framing of the *structure of digitally mediated healthcare discourse* as a layered discourse, with the

classic face-to-face healthcare encounter at its kernel providing a communicative baseline.

Establishing a communicative baseline against which various types of mediated discourse could be measured maintained a constant connection with the healthcare context, even when informant discussion turned on technical or production process issues. For many informants, particularly content informants, the healthcare context appeared prominent among their concerns as they grappled with the detail of healthcare meanings, at only one remove from their clinical and patient interlocutors. Though the specifics of the healthcare context appeared less prominent in the concerns of systems informants, taking this layered approach to the digitally mediated healthcare discourse, as introduced in sections 2.5, 2.6, and 2.8 of Chapter 2, and further developed in section 6.3 of Chapter 6, meant that the different concerns of systems informants could be accommodated within the healthcare discourse frame, albeit inhabiting the outermost layer to signal their greater distance from the communicative baseline.

One of the principles of the study was the identification of holders of diverse roles as active interlocutors in the healthcare discourse, even when those interlocutors, such as systems developers, might seem only distantly connected to healthcare contexts. The specific roles considered in this study, including clinicians, patients, editors, systems developers, and all of the other content and systems roles I discussed, emerged from the empirical data, and were initially categorised along the lines of “functional” roles, according to “what the actor does in his relations with others seen in the context of its functional significance for the social system” (Parsons, 1951: 25). Once the roles had been categorised along these functional lines, the intimate relationship of the roles to expertise became apparent and the roles were further categorised into the broad groupings of healthcare roles, content roles, and systems roles. These groupings were explored in detail in Chapter 4, and utilised as an organizing principle in Chapter 5.

Analysis of themes against these broad groupings highlighted similarities in themes within expertise groups, across organisational barriers, in that themes were spread

symmetrically between the publisher and charity, but that this spread was noticeably different between the expertise groups, as evidenced in the data tables throughout Chapters 4 and 5. The consistent, yet dispersed “expertise groups” identified in this study sit in contrast to the co-situated, specific “epistemic cultures” identified by Knorr Cetina (1999), and highlight the contrast between Knorr Cetina’s model and the discursive mechanisms I have identified as operating within what Knorr Cetina (1999: 8) might term the “epistemic settings” of the charity and the publisher. Members of “expertise groups” in this study do undoubtedly enact their expertise in the course of performing functional roles, but also, in parallel, play the role of interlocutors in the broad healthcare discourse. Their discursive interlocutor roles are not necessarily aligned with traditional healthcare functional roles in terms of their influence on the development of the healthcare discourse. In contrast to Talcott Parson’s depiction of functional roles which, as I mentioned in section 2.2 of Chapter 2, places the functional role of the clinician in the powerful position of affording legitimacy to the socially deviant role of the sick (Parsons 1951: 428-479), in the expertise-based assignment of roles adopted in this study, in the particular digitally-mediated environment under examination, the customary discursive playing field of healthcare is, if perhaps not quite *levelled*, at least *disrupted* by considering those in all roles as active *interlocutors* as well as functional performers.

There is a contrast, too, between the context-specificity of Knorr Cetina’s model of “epistemic machinery” (1999: 3) and the context-transcendence of the Habermasian model of communicative action which underpins this study. The context-transcendence of the Habermasian approach enables the research to follow a normative rather than a descriptive thread, providing an analytical framework which supports distinctions between knowledge-producing organisations based not on the “disunity” of their specific epistemic cultures but rather on the degree of transparency inherent in their discourse; on whether they open and resolve validity claims discursively, leading to an ever-deepening discourse, or whether alternatively, and less transparently, they close down potential avenues of discursive exploration, perhaps by dividing expertise groups from one another, or overly formalising their engagement to preclude explorative discourse.



The notion of the communicative baseline helped to highlight the distance of systems developers from healthcare contexts, as illustrated when one systems informant identified the communicative baseline for his own work as a pre-digital, paper-and-pen based vision of “authorship,” which was far removed from the presentation of authorial healthcare expertise and practice presented by those content informants who worked closely with authors. The relationship of mediated communication to the classic face-to-face healthcare encounter as communicative baseline was also helpful in defining the role information artefacts played as *proxy interlocutors*. The information artefacts presented in the study were understood as proxies not for authors, editors and systems developers in their functional roles, but rather in their interlocutor roles, as healthcare actors sharing healthcare meanings; an important distinction often overlooked, indeed overlooked by the systems informants themselves, but a crucial one in determining transparency in healthcare discourse.

The identification of information artefacts as proxy interlocutors appeared to bind them to the communicative intent of their creators, and, by implication, brought them into the service of the intersubjective sharing of meaning. This approach highlighted another point of contrast with Knorr Cetina’s 1999 account, in which she wrote of the “collective epistemic agency” which she identified in the organisation of scientific work in the field of theoretical physics and the associated “erasure of the epistemic subject.” (Knorr Cetina 1999: 171). While the knowledge-creating work carried out by holders of healthcare, content and systems roles investigated in this study shares some of the characteristics elaborated in Knorr Cetina’s account, in that the work is essentially co-operative, without an individual author, the positioning of the work in this study as a discourse in which diverse individuals participate allows agency to remain firmly with the interlocutors in this discourse, rather than being attributed to any larger structure. This is an important factor for the assignment of communicative intent which, in turn, drives the resolution of validity claims, and again, in turn, allows us to assess communicative instances and environments against the normative framework of transparency.

The analysis indicates that while systems informants and content informants both showed awareness of the face-to-face healthcare encounter as a communicative baseline for their own mode of informational work, systems informants did not recognise the relationship of content artefacts to this communicative baseline, instead relating those artefacts to prior modes of mediation, while giving systems artefacts prime position as apparently active interlocutors in the wider healthcare discourse. The lack of recognition in these interlocutors of a shared communicative baseline points to a lack of a validity framework common to all interlocutors. This lack was particularly manifested around validity claims to rightness. The lack of such a shared validity framework indicated a risk of systematically distorted communication, with content and systems interlocutors failing to resolve validity claims, and, therefore, failing to create a transparent discourse, because of their lack of a shared understanding of rightness.

The notion of a shared validity framework for communication brings me to the third component of the conceptual framework, which was the notion of *interlocutor models of communication*. This notion, introduced in section 2.6 of Chapter 2, was important because of the challenges to transparency arising from interlocutors engaging in discourse while holding different understandings of the parameters of validity. The concept was elaborated drawing on theoretical perspectives on intersubjectivity, as mobilised by proponents of pragmatics, including Habermas, and on the design and domestication of media artefacts, as set out by Mansell and Silverstone (1996) and Silverstone and Hirsch (1992). This supported the consideration of informants' reflexive understandings of their own intentions and actions as interlocutors and the ways in which these interacted with the intentions and actions of others, and with information artefacts.

Models of different types emerged from the data as analysed in Chapter 4 and, particularly, in Chapter 5. Informants presented various models of their interlocutors, of communicative intent, of the acts of communication in which interlocutors engaged, and of the information artefacts which, I suggest, acted as their proxies in the mediated healthcare discourse. Interlocutors that featured in the interview data included both the “target” interlocutors of clinicians and patients, as well as the “collaborating”

interlocutors of content and systems workers. Models of aspects of “target” interlocutors, such as their levels of healthcare and informational expertise, were reported as having implications for the way information workers developed information products. Models of interlocutors were seen to differ between collaborating expertise groups, raising implications for the success of collaborations, where these involved holders of conflicting interlocutor models. This was discussed in section 6.3.1 of Chapter 6, where the concept of differences between models held by interlocutors of other interlocutors was used to pinpoint this particular challenge to transparency.

Under the Habermasian framework used in this study, if the imagined interlocutor were understood differently by other contributing interlocutors in a discourse, it would become difficult, if not impossible, to establish a shared validity framework between those contributing interlocutors, especially around the dimension of rightness, which is dependent on a joint understanding of social norms. Cooke (1994) develops Habermas’s distinction between violation of a validity claim to relevance and violation of a validity claim to rightness, suggesting that because claims to rightness involve an “attempt to establish an interpersonal relationship” (Cooke 1994: 89), violation of such claims, rather than leading to simple error, leads to “damaged intersubjectivity”, because “where irrelevance is a mistake, inappropriateness is a moral transgression.” According to this account, attempts at communicative action which fail to meet validity claims to rightness do not increase mutual understanding, but neither are they neutral in regard to intersubjectivity. Instead, they cause moral breaches and damage to intersubjective relationships. In other words, working towards a goal of increased mutual understanding in healthcare in the absence of a rightness validity framework shared by all interlocutors in the discourse is likely to cause more harm than good and damage the intersubjective relationships between healthcare interlocutors.

Models of communicative intent, or purpose, and of interlocutor and artefact action, were also shown to differ between informants, as discussed in section 6.4 of Chapter 6. The variety of purposes, or intents, which informants ascribed to the information artefacts on which they worked demonstrated the complexity of digitally mediated healthcare

discourse. There was no indication of a single, universally accepted “meaning” to be encoded into artefacts. Rather, a multiplicity of overlapping, and sometimes even conflicting, meanings was ascribed to the information products created by informants in the study. Different communicative intents raise different validity claims, particularly in the areas of truthfulness and rightness, both of which rely on aspects of the social setting for their acceptance. The analysis and classification of these different intents enabled the identification of particular contrasts between interlocutor perspectives.

The fourth, and final, component of the conceptual framework was provided by the concept of *digital materiality*, introduced in section 2.7 of Chapter 2. Materiality was understood theoretically across three dimensions. The first of these I termed the dimension of *weight*, used to signify the effort and materials consumed by the processes of digital mediation. This dimension was theorised according to the view proposed by Garnham, that “the media are systems for the production, distribution, and consumption of symbolic forms which necessarily require the mobilisation of scarce social resources” (Garnham 2000: 39), and the mobilisation of this perspective enabled this research to investigate “how the mode of production structures the field of social communication” (ibid.: 43). The second dimension of materiality was the dimension of *malleability*, used to signify the ease with which changes could be made to media artefacts. This concept was based on the tension identified by Quintas (1996) between the theoretical flexibility of software and the limiting factors which, in practice, constrain ongoing freedom of development. These dimensions proved useful in theorising, for example, the discussion in section 6.4.3 of Chapter 6 of the conflicting drives toward economic efficiency and transparency in the digitally mediated healthcare discourse, where some decisions around digital mediation were seen to be driven by the desire to preserve resources, for example by increasing reuse of media artefacts or components of media artefacts. Here, the study presented the material dimensions of weight and malleability influencing what could and could not be said within the healthcare discourse. The third and final dimension of digital materiality, in my account, was the dimension of *texture*, with the term used, following

Bowker and Star (1999), to describe the ways in which information is experienced by people.

The concept of materiality brought with it an acknowledgement that digitally mediated communication, while powerful in its extensive reach, lacked the context-agility of face-to-face communication. The discursive processes of challenge, correction, and adaptation were slowed in digitally mediated communication by the weight, limited malleability, and varying textures of the complex technical infrastructures that provided the distributive power of digital mediation. Since these discursive processes are utilised by interlocutors in the achievement of mutual understanding, such material blocks to these processes in themselves introduce potential challenges to the achievement of discursive transparency, consistent with the concept of colonization of the lifeworld which underpins Habermas's theory of communicative action.

All informants recognised the challenges brought by weight and by limited malleability, though perspectives on addressing these challenges differed. The factor of texture showed a greater variation, with different informants perceiving the material make-up of the information products on which they worked very differently, with systems informants favouring aggregative bottom-up models of composition while content informants favoured top-down meaning-driven models. A detailed examination of these differences in section 6.4.3 of Chapter 6 pointed towards the implications for collaboration of these different perceptions of digital materiality in terms of the lack of a shared validity framework, which then had broader implications for transparency in the broader, digitally mediated healthcare discourse. This insight was generated from the combination of the subjective, situated, experiential perspective inspired by Bowker and Star's (1999) consideration of the experiential aspects of information infrastructures, and the normativity of Habermas's (1984) idealised discourse. This analysis demonstrated that the combination of highly descriptive accounts with normative frameworks was a fruitful approach.

In section 6.2 of Chapter 6, I noted a balance between the potential of digital media to contribute to emancipatory change, and its potential to propagate further inequalities. The importance of developing a model of digitally mediated communication able to account for its specific materialities in conjunction with, and in interaction with, their social context was highlighted. To return to the concept of *communicative transparency*, one theme that emerged many times from my analysis in Chapter 6 was the silencing impact of challenges to transparency. It seemed that at times the complex configurations which combined stubbornly material digital artefacts such as systems and standards with diverse specialist expertise led to the exclusion of certain topics and certain ways of saying from the digitally mediated healthcare discourse. In section 6.3.3 of Chapter 6, I referred to systems interlocutors acting as “gatekeepers to the feasible”. Bohman (2000: 385) links such “asymmetric power” in discourse with Habermas’s concept of distorted communication, noting that “asymmetries generate ideology when they are sufficient to block reflexive communication.”

Asymmetries of power are prone to emerge in discourse, particularly in healthcare and particularly in systems-mediated environments, characterised as both these arenas are as domains of specialist expertise. The key insight offered by Bohman is the importance of maintaining reflexive communication in order to reveal distortion in communication as a means of potentially righting such asymmetries:

“The speech of social critics attempts to unblock communication by making distortions explicit, thus initiating acts of reflection that aim at restoring the conditions of genuine communicative success” (Bohman 2000: 385)

It is here that the stubborn materiality of digital artefacts becomes particularly problematic, lacking, as these artefacts do, the reflexive agility of face-to-face discourse which can quickly reconfigure to potentially correct distorted communication. All the more reason, then to focus on building mechanisms and processes into the digitally mediated healthcare discourse to enable the initiation of critical acts of reflection, since, according to Bohman, “such reflection produces gains in freedom by permitting speakers

to become aware of the way in which implicit violations of norms limit public functioning and inhibit those very transformative performances that might change the conditions of communication” (Bohman 2000: 389). In this way, Habermas’s normative notion of communicative action, combined with Bohman’s more developed notions of means to counteract distorted communication, provide insights to support the digitally mediated healthcare discourse to achieve its communicative promise, which I characterised in section 2.5 of Chapter 2 as the potential to support a *balanced, growing, and consensual understanding, by lay and expert actors, of the place and meaning of sickness in our world.*

The theoretical contribution of this thesis is to apply to the study of digitally mediated healthcare the enhanced analytical precision offered by communication theories drawn from pragmatic studies of communication, and in particular from the formal pragmatics which form the basis of Habermas’s normative theory of communicative action, and to augment these theories with insights from the subjective, experiential approach of theorists such as Bowker and Star (1999), Knorr Cetina (1999), and Mol (2002), who apply a Foucauldian tradition to studies of science, information, and knowledge creation. This blend of perspectives enables the central analytical proposition of the thesis, that digitally mediated healthcare information can profitably be considered as a single complex discourse, with the various contributing actors, both “producers” and “consumers”, treated as interlocutors in the discourse and information artefacts serving as their proxy interlocutors. This proposition supported insights into the surprisingly close connections diverse actors such as systems developers and editors have with healthcare actors such as clinicians and patients and the ways in which aspects of the collaborative discourse between systems and content workers can ripple out to shape the communication between clinicians and patients.

The approach, which strikes to the heart of issues of meaning, truth, and transparency, stands as a counterpoint to outcomes-based analyses of healthcare information based on a clinical efficacy, to enable a new conceptualisation of what empowerment and disempowerment might mean in digitally mediated healthcare, alongside a normative

framework for the assessment of communicative transparency. It also offers some suggestions for particular discursive behaviours, which, applied to the mediated healthcare discourse and, in particular, to the processes by which media artefacts are created to serve that discourse, might maximise communicative transparency in this complex, difficult, yet vitally important arena.

## **7.2 Summary of empirical findings**

In Chapter 3, I presented the ways in which this theoretical framework was operationalised into a set of core empirical questions. In this section, I present a synthesis of the empirical results organised around the four empirical research sub questions I defined in section 2.8 of Chapter 2.

### **7.2.1 What kinds of specialist expertise are involved in the digital mediation of healthcare meanings? How are these forms of expertise characterised, and how do they interact?**

The study looked beyond simplistic lay/expert dichotomies to examine expertise across three broad categories (healthcare, content, and systems), and across three dimensions (expert, becoming expert, and inexperienced). Empirical data on these types of expertise was presented in Chapter 4, and further analysed in section 6.2 of Chapter 6. The approach of cutting across both types and levels of expertise enabled a detailed consideration of the interplay between the expertises that drive activity in the area of digitally mediated healthcare meanings. The coverage of expertise makes no claim to being exhaustive; in addition to the three broad categories of health, content, and systems expertise which were examined in depth, there are undoubtedly other expertises which play a role in the creation and circulation of digitally mediated healthcare meanings. For example, at the scale at which the organisations involved in the study operated, successful creation of healthcare meanings required significant financial investment, while their circulation depended on extensive and sophisticated networks of procurement and distribution on the part of customers. Both the financial investment required by production and investment in procurement of the products depended on business expertise. While two business



informants were included in the study, as conversations unfolded around the knotty everyday realities of the creation and circulation of media artefacts, business expertise was little discussed, either by holders of business roles, or by any of the other participants. I therefore chose to focus the study on the core expertise realms of healthcare, content, and systems, presenting these as concentric layers of expertise, arranged in order of distance from the face-to-face healthcare encounter.

Healthcare expertise, which lay closest to the face-to-face healthcare encounter, was examined in terms of both lay and professional expertises. Lay expertise was attributed by informants mostly to patients and their carers, while professional expertise was attributed to physicians and other healthcare professionals such as nurses. Healthcare expertise held a unique position in the study, in that it was viewed and presented entirely from outside healthcare by participants who held neither clinical nor patient expertise in the condition areas on which they worked. Nonetheless, for those holding content roles, especially, but also to some extent for those in systems roles, healthcare expertise was a central focus in the sharing of healthcare meanings, both in the creation of mediated artefacts and in the imagined context of use of those artefacts. Informants presented two main subtypes of healthcare expertise, both of which were attributed to lay and professional actors, and both of which occurred at various points on the continuum of expertise (inexpert/becoming expert/expert). These two subtypes of expertise were healthcare domain expertise, both clinical and experiential, and, just as key for the information workers in the study, informational expertise, relating to the ways in which information was accessed, conceptualised, and used.

Content expertise was in evidence across a wide range of roles and was most notably characterised by its flavour of interpretation. Perhaps most familiar of the content roles to the outside eye was that of the author. In the organisations studied here, authors were invariably healthcare professionals and so their expertise was a blend of healthcare domain expertise and specialised expertise in the processes underpinning content creation. Authorial domain expertise was not limited to abstract clinical knowledge but also, crucially, included an understanding of the context of use of the information

products to which authors contributed. The insight of authors into the healthcare concerns of the clinicians and patients who were their eventual “audience”, or, in the terms of this study, their target interlocutors, coupled with the process knowledge they brought of methods of shaping meanings to engage these interlocutors, lent their expertise its flavour of translation or interpretation. This was a translation between three aspects which comprised: 1) abstract knowledge, 2) healthcare contexts, and 3) interlocutor interests. The flavour of translation was even more marked in the adjudicatory expertise of the clinical editors, which was mobilised to determine the relevance of authorial proposals to the needs of clinical and patient interlocutors.

Yet another type of specialised translation expertise was used by patient editors as they went about their work of rendering clinical meanings relevant and accessible to patients and other lay interlocutors. Finally, two non-editorial content roles were considered in terms of their expertise. The aptly-named information specialists translated editorial requirements for appraised scientific research into lists of research abstracts for consideration by authors. They carried out this translation using highly formal search strategies which they applied to online databases of research papers. This was a translation heavily reliant on rigour and formality, requiring a high degree of technical expertise. Graphic designers, meanwhile, exercised quite different forms of technical expertise to wrangle editorial outputs into publishable artefacts in both digital and print media. The second unifying characteristic of content expertise was that of validation. Editors, information specialists, and graphic designers alike engaged in work of assessment, adjudication, and appraisal, scrutinising various aspects of the work of others to ensure that quality criteria were adhered to.

Systems expertise was presented in two broad categories. The first, not surprisingly, included the hard technical expertise which those in systems roles applied to the problem of creating, managing and disseminating digital content. These were highly practical skills of building, automating, converting, implementing, and integrating. The three core roles of technical content developer, information technologist, and systems developer each had a different focus and brought their specific technical expertise to bear at a

different point in the sharing of meanings. Technical content developers wrestled to formalise instances of content destined for use in information products such as websites or DVDs; information technologists put infrastructures in place to support the broader creation and dissemination of information artefacts within particular contexts; and systems developers designed and built systems to support content creation and dissemination across a broad range of unrelated contexts. The detail of the technical expertise held by each role varied in accordance with this difference in focus.

In contrast to this inward, technically focused expertise, the second category of systems expertise was outward or socially facing, and concerned the ways in which holders of technical roles interacted with the non-technical world outside the systems which were their primary focus. As with the content roles, above, this second category of expertise was an expertise of translation, focused on forming an understanding of the communicative intention of the proposed digital content and its context of use, from the reports of those in non-systems roles, and translating these requirements into the technical design and development that would enable the desired communication to take place. The softer forms of expertise brought to bear on this translation activity included collaboration, problem solving, and, above all, analysis. Expertise in analysis was expressed in terms of visualising, building, and modelling; this, in particular, was an expertise of representation which might be aligned to a greater or lesser extent with the work of representation carried out by those in content roles in the creation of information products.

The three dimensions of expertise that emerged from the interview data, those of *inexpert*, *becoming expert*, and *expert*, illustrate the dynamic nature of expertise as portrayed by the study informants. The idea of the expertise trajectory, or journey, was applied equally to healthcare and to systems expertise, but to a much lesser extent to content expertise. The changing nature of healthcare expertise varied between lay and professional healthcare actors, with lay actors (patients and their carers) portrayed as gaining an increasingly deep understanding of their condition as it progressed, and professional actors gaining both breadth and depth of clinical expertise over the course of

their careers, as well as keeping up to date with the changing face of clinical research. Both of these trajectories were explicitly addressed by those in content roles as contextual factors informing the scope and shape of healthcare meanings. The expertise trajectories of those in systems roles likewise provided a constantly shifting dynamic, as developers and information technologists bridged changing requirements and changing technical environments, taking an explorative approach as they sought to establish stability in the relationship between these two shifting factors.

In my summary of content expertise, in the third paragraph in this section, above, I mentioned the blending of expertise attributed to authors which encompassed, firstly, abstract clinical knowledge, secondly, an understanding of the needs of their clinician and patient interlocutors, and thirdly, capability in the processes of content creation. Complex though the resulting blend was, this blending was only the first step in the broader cumulative layering of expertise that emerged from the interview data. While the blending of expertise within the author role was internal, lodged within individuals, and not subject to the social process of discourse, subsequent layering of expertise typically happened between holders of different roles and could, therefore, be negotiated discursively. The discursive interaction between diverse expertises was not neutral, with new forms and variants of expertise emerging through the discursive encounters which sprang up in the course of collaboration. Technical skills were presented as mysterious by those in content and business roles, but as the interviews deepened, instances emerged of content and systems expertises developing and being reshaped through the increased mutual understanding brought about by joint exposure to novel situations. In the course of problem solving, terminology and concepts were seen to be exchanged across expertises, enriching the nature of the individual expertises involved. This dynamic movement of expertise worked in both directions. As well as examples of expertise convergence, the interview data contained a clear example of an emergent expertise divergence in the editorial consideration of dividing the work of systematic research appraisal between those who had detailed numerical expertise, and those who had a broader editorial expertise. Here, we saw what had previously been considered,

problematically, as a single expertise, being divided into two distinct branches, in order to promote alignment with individual skillsets.

Interaction between those who held different expertises, though it might lead to deepened understanding, was not always straightforward. The perspectives of the various expertise groups on the types of expertise they did not hold provided a rich portrayal of difference and lack of understanding, even as the informants sought, via collaboration, to bridge their expertise divergences. As an example, systems informants tended to limit their presentation of the expertise of authors to the abstract clinical knowledge the authors contributed, missing their expertise in the area of clinical context, in interlocutor needs, and in the processes of content creation. Conversely, content informants repeatedly presented systems expertise as mysterious, even magical. A lack of understanding of the full range of expertises mobilised in the digital mediation of healthcare information presents a challenge to transparency, even as the holders of expertise strive to understand one another. There was a sense in this study that the expertise of the different groups had not been fully “socialised” in open dialogues between the groups, leaving the tantalising suggestion that, if these expertises were to interact more closely, the perspectives of both would develop and change, and the discourse deepen.

With the exception of authors and clinical editors, healthcare domain expertise lay outside the skills of the informants in the study. Informational expertise, in contrast, was very much the home territory of both content and systems workers, and acted as a touch point for the full range of expertise brought to bear on the digitally mediated sharing of healthcare meanings. This focus on informational expertise could perhaps be seen to sideline or disadvantage healthcare expertise, but it must not be forgotten that healthcare expertise was central to the work of both the organisations that contributed to the study and both informed and motivated the work of sharing healthcare meanings. Healthcare expertise informed the work via contributions from clinical authors and lay reader panels, and it motivated the work via vivid understandings of the types and levels of expertise held by the clinicians and patients who made up the users of healthcare information. The analysis of digital mediation of healthcare meanings in this study did not reveal a one

way channel along which clinical expertise flowed towards patients, a view commonly taken by research that focuses inordinately on technological constraints, but instead a complex discursive environment made up of many expertises, of different types and at different levels, engaged in perpetual negotiation with one another.

### **7.2.2 How are information artefacts mobilised in the digital mediation of healthcare meanings? How are they characterised?**

The analysis brought to light a wide range of informational artefacts, of many types, mobilised in the digital mediation of healthcare meanings. Empirical data on these artefacts was presented in Chapter 5, and further analysed in sections 6.1 and 6.3 of Chapter 6. Perhaps the most familiar of these to the outside observer were the information products created by each organisation, the leaflets, websites and databases by means of which healthcare meanings were circulated beyond the originating organisations to the patients and clinicians who were their users and target interlocutors. These information products were presented by informants as being mobilised in the service of communicative aims, as *proxy interlocutors*, carrying the intentions of the various human actors engaged in their creation and circulation. Reflecting the variety of expertise groups involved was the variety of intents that were ascribed to information products, from sophisticated, socially-informed intentions such as educating users, bridging the gap between clinical knowledge and patient experience, facilitating the clinical relationship, and helping patients to cope, to more mechanical models such as containing and delivering content. At the publisher, particularly, but also to some extent at the charity, information products were mobilised to disseminate, and update, scientific truths, in order to inform clinical practice and patients alike. Some informants spoke of the capacity of information products to interact with users, one of several concepts that demonstrated the belief of informants in the ability of information artefacts to enact real world change.

The creators and disseminators of information products certainly mobilised these artefacts in the service of communicative aims. In addition, the users of the products were also presented as mobilising these products to serve their own aims, actively seeking and

accessing information in contexts ranging from the leaflet in the patient's bedside table to digital code-based searching within electronic patient record (EPR) systems. Users of information products were not simply presented as recipients of a one-way flow of meanings directed at them, but as participating, if in a limited way, in a two-way dialogue, directing commentary and feedback towards the information providers, as well as supplying their own personal data in order to optimise search results and personalise products. Finally, users were presented as disengaging at times from the products, effectively demobilising them as artefacts and shutting down the flow of meanings.

Information products were not the only artefacts shown to be mobilised in the digital mediation of healthcare meanings. Systems and standards of various types were also mobilised. Publishing systems were designed and built by systems developers, selected by business managers and content workers, implemented by information technologists, and used by content workers and technical content developers. The publisher had recently implemented a content management system to manage the content destined for their websites and other publications, and informants from all groups spoke about their different activities and perspectives around the design, development, selection, implementation and use of that system, alongside the use of applications such as MS Word and MS Excel. Informants spoke of the broad intention to use the content management system and the encoding it supported to promote reuse of content in different contexts, including integrating with hospital systems. MS Word was used to take in the contributions of authors, while Excel was used to organise and record choices of research evidence to cite within publications. At the charity, the focus in the early interviews was on the redevelopment of its website as a distribution channel for its content and, in the later sessions, on the question of which content management system to select. The benefits of a content management system were still being actively debated and explored across different expertise groups at the charity, with conclusions not yet reached. What was clearer was the mobilisation of applications such as Word and InDesign by the charity to support the process of content creation, with authors and editors working in Word, graphic designers managing the change to InDesign in order to

perfect layout, and a combination of information technologists and graphic designers completing the final translation of content for publication on the website. This process of translating content across multiple formats was what the charity most hoped to simplify and streamline via their new, as yet unchosen, content management system, though the benefits were by no means uniformly recognised by all informants.

Systems informants connected with the publisher presented a final, more radical potential mobilisation of systems in content delivery. This was in the dynamic configuration of content according to interlocutor need. Informants also presented systems as actively self-mobilising to a degree, helping, sustaining, and improving care of patients, prompting user questions, recording user progress, and linking and directing users through information. Even in these situations, when the active mobilisation of the artefact was distant from the human actor with which it originated, these artefacts were considered in this study to be acting as proxy interlocutors, in the service of the communicative aim of a human actor, no matter how distant that actor might be from the point of mobilisation.

Standards of various types were shown to be widely mobilised to enable continuity as meanings were transferred across different contexts and to ensure that meanings had as broad a contextual applicability as possible. These standards included standard terminologies such as MeSH, actively used by information specialists to help locate relevant clinical research to inform products, and SNOMED coding, used, in contrast, somewhat unwillingly by editors. Even as they mobilised SNOMED, both editors and the technical content developer criticised its use as speculative, identifying that it served no immediate communicative purpose, having no real context of use as yet, though possibly facilitating future systems integration. Wider than the use of standard terminologies, standard formats such as HTML, PDF and XML were also mobilised by various actors in the chain to carry meanings safely through multiple technical environments to their interlocutors.

Information artefacts were certainly characterised as material, forming both raw material and finished product of the daily work of all of the informants in the study. The



characteristics of this materiality varied greatly across the different expertise groups and for this reason the materiality of media artefacts will be considered in more detail in the answer to the next question.

### **7.2.3 How do specialist expertise and digital artefacts work in combination to promote or hinder communicative transparency?**

The empirical data bearing on this question was considered in Chapter 6. The analysis showed that artefacts and expertise were described in the interview data as entering into complex relationships where they combined and interacted with interlocutors and with each other. A striking example of the interactions that took place between expertise and artefacts was found in the blended standards of practice and artefact that shaped the work of systematic review of clinical research evidence, upon which the products of the publisher were built. The standard artefacts and methodologies of systematic review were mobilised to clarify the truth claims of scientific research. The information products created by the publisher then sought to further interpret, contextualise, and disseminate this “truth,” in ways that could be mobilised to support the everyday work and lives of clinicians and patients, bridging the gap between clarity at the epidemiological level and the needs of individual cases. The combined expertises of information specialists, clinical authors, and clinical editors were mediated by the expertise of systems and technical content developers, and their work was achieved via the standard artefacts of the randomised control trial (RCT) and the systematic review (SR), appraised against criteria captured in the standardised Population, Intervention, Comparison, Outcome (PICO) framework. The mobilisation of this standard framework was intended to enable those without clinical expertise to assess the quality of clinical research.

Although many of the experts considered by this study relied on specialist applications and systems to help them complete their work, the relationship between expertise and such specialist systems was not always one of straightforward enablement. Informants in the study highlighted occasions when they had to use their expertise to remedy the glitches and breaks in meaning that could result from the use of content production applications such as InDesign and Word and, especially, when transferring content from

these production applications into web publication formats such as HTML. Graphic designers, production editors, and technical content developers all reported spending effort and applying expertise in fixing material errors in content, errors resulting from torque between content and the standard formats required by applications. Information specialists, too, spent effort and applied their expertise in correcting informational errors, in their case resulting from problems with the MeSH encoding of the research papers returned in the course of their literature surveillance. Both authors and editors were presented as struggling to align their communicative intentions with the formal restrictions of authoring systems. In particular, the systems-mediated, data-driven approach under consideration at the publisher for appraising research was identified as eliciting a different type of expertise from editors than the more interpretive, text-driven approaches they were accustomed to.

Systems-mediated production of content also introduced the possibility of automated changes to content and the prospect of clinical editors having to take responsibility for and validate systems-mediated changes without a full understanding of how such changes were made. Since there was a symmetrical lack of understanding of the motives and meaning of automated change by the technical developers who implemented it, the practice of automated change necessarily resulted in a shared ownership of meanings, mediated via systems in a *de facto* collaboration between artefact, editor, and developer. Another level of collaboration included the work of information technologists who implemented generic systems into particular contexts such as the publisher and charity which were the focus of this study. This work of implementation depended on marrying a technical understanding of systems with sensitivity to the meanings circulating within them and yet it was work that emerged from the analysis in this study as simultaneously inaccessible to those with content expertise and uninteresting to those with systems development expertise. Delegated with relief by both sides to those with specialist implementation expertise, this was another example of expertise and artefact interoperating to form new configurations for the shaping of meaning with resulting ambiguity around the assignment of communicative intent. Systems design and

development, too, emerged in the study as work of interpretation, as systems developers described the way in which they worked from user requirements to design and build systems. Developers introduced a further subtle challenge to transparency as they questioned the truth validity of their clients' requirements, embedding their own decisions into systems which were then presented to their users for acceptance testing as fully functional artefacts. Such separation of decision-making along expertise lines could, I suggest, diminish the capacity for transparent collaboration in the creation of shared meanings.

The different expertise groups contributing to the study expressed markedly different perspectives on the communicative artefacts they shared. Systems workers, on the whole, were enthusiasts for systems-mediated explicitness and transparency, while content workers were more sceptical, questioning the value of complex technical solutions to "problems" of data integrity they could not themselves see. Systems informants expressed a tendency to hide complexity from users in a move that may have been intended as supportive but which, ultimately, hindered achievement of mutual understanding. Discussions on the encoding standard of XML, in particular, emphasised the relationship between artefacts and expertise. For those in systems roles, the use of the XML standard format enabled transparent encoding of meanings, but content workers, in contrast, found the technology and the systems built upon XML difficult to work with, resulting in a situation where clinical authors and editors needed specialist support from those with systems expertise to translate their communicative intentions into digital artefacts. In the contexts examined in this study, the mediation of XML was not limited to the material constraints it introduced, but also by the technical expertise it required in order to encode meanings. Even as those in content roles struggled to express their communicative intentions through this medium, those in systems roles mourned a perceived loss of purity and transparency in the standard format which they associated with XML's attainment of communicative mainstream use.

Both the communicative aims of information products and the material composition of the artefacts through which those aims were mediated were presented differently by the

different expertise groups in the study. Even when the same terminology was used, terms were often given different meanings by the various groups. The variety of terms and usages revealed different understandings of the relationship between artefacts and meaning with, for example, content informants favouring terms relating form to meaning and systems informants favouring terms relating form to process which demonstrated an aggregative, bottom-up approach to meaning. Concerns were voiced by informants about the gap in holistic understanding that arose from the separation between content expertise and systems expertise. Informants saw this gap as precluding a holistic understanding of interactions between the different forms of artefact and expertise mobilised in the digital sharing of healthcare meanings. The necessary collaborations that resulted between different expertise groups suggest that transparent communication between these groups can be confirmed as a key foundation in the transparent sharing of digitally mediated healthcare meanings.

#### **7.2.4 What factors exacerbate challenges to communicative transparency in the digital mediation of healthcare meanings, and what factors mitigate them?**

In Chapter 2, I defined communicative transparency in Habermasian terms as the meeting of the discourse validity claims of truth, truthfulness, and rightness, supporting an idealised goal of a balanced, growing, and consensual understanding of healthcare. In Chapter 2, section 2.6, I suggested that mediation might either challenge, or support, transparency in the sharing of healthcare meanings. If any of the layers of meaning introduced via mediating factors such as expertise and artefact failed to meet the validity claims of truth, truthfulness, and rightness, then the potential for communicative transparency would be challenged. Conversely, so long as mediating layers continued to meet these validity claims, then transparency would be supported. When mediating layers met the necessary validity claims, then discourse could be deepened by mediation, and the potential for communicative transparency was increased. Empirical data relevant to this was considered in Chapter 6. Here, I summarise the findings on the meeting, or failure to meet, of each of the validity claims of truth, truthfulness, and rightness in the context of digitally mediated healthcare meanings. I then summarise the findings on the

factors that appeared to exacerbate or mitigate challenges to transparency in the digital mediation of healthcare meanings.

#### *7.2.4.1 Truth*

Identifying and disseminating scientific, clinical, and experiential truth were identified as the *raison d'être* of both the publisher and the charity. At the publisher, the rigour of method in systematic review was shown to promote transparency by imposing principles of explicitness, by which the parameters of shared truth could be established. Information specialists worked to define parameters of truth and ensured that these were adhered to as far as possible as they identified and appraised research. In the next stage of content preparation, clinical editors removed explicitness and added interpretation to focus reader attention on aspects they felt to be of maximum relevance. Care was taken to preserve the “truths” identified by the research under analysis, but these were not always presented directly to readers so that, to some extent, the validity claim to truth was displaced by a claim to truthfulness, as the reader was expected to rely on the interpretative ability of the editors. At the charity, truth validity claims were established and safeguarded through authorial validation and the subsequent editorial preservation of accuracy. There was a timeliness factor to truth in both organisations, with a great deal of effort expended in updating content in line with advances in clinical research and practice. The “truth” that was identified, preserved, and circulated by these organisations was not static, but dynamically changing. In both organisations, healthcare truth claims were made, reshaped, or remade, by content actors without specific healthcare expertise who relied on formal systems and standards to support them to establish and preserve truth. The systems informants in the study did not display an understanding of the range of expertise employed by content actors in the establishing and preserving of truth, and their lack of familiarity with these expertises raised the possibility of systems that might not fully support either the truth validity claims as initially raised, or the subsequent interpretation or preservation of those truths by editors.

#### *7.2.4.2 Truthfulness*

Informants placed a high value on matching truth with truthfulness, with content informants at the publisher articulating one of their core aims as minimising personal or political bias in the reporting of clinical research findings. Data-driven approaches to reporting clinical research placed a high value on validity claims based on evidential *truth*, while more interpretative, text-driven approaches relied more on claims to *truthfulness*, since underlying data was not made explicit to reinforce truth claims.

Claims to truthfulness, which are by definition tightly bound up with the intent of interlocutors, are difficult to establish when the identity of interlocutors is unclear. Both organisations made use of clinical and patient validation by named experts, alongside the reputation of their own organisations as “institutional interlocutors”, to establish truthfulness, but in spite of this the study brought to light several examples of obscured interlocutor identity, and, therefore, of obscured interlocutor intent with resulting problems for truthfulness claims. Sometimes, this arose from arguably benevolent intentions such as the presentation of generic content for user configuration to cultivate an impression of personalisation. Here, the pursuit of relevance, which could also be drawn as the validity claim of “rightness”, put the validity claim of truthfulness at risk. Linked to this strategic presentation of content, but with a less obviously benevolent motivation, was the drive to reuse or recontextualise content in order to reduce the material effort in the creation of mediated content. Perhaps the biggest impact on truthfulness claims made visible in my analysis was the introduction of economic goals into the definition of product content and configuration. This impact on truthfulness had the potential to be amplified further if the proponents of cost-effective methods of content working were to have a model of context which did not match the model held by either their collaborators or their co-interlocutors.

#### *7.2.4.3 Rightness*

In the digital healthcare contexts examined in this study, the validity claim of rightness was often established in terms of the applicability of content to its context of use. Presentations of healthcare which were appropriate for clinicians, for example, might not

always be helpful for patients due to their differing contexts of expertise. In contexts of such complexity, encompassing wide variations in expertise across all interlocutors, compounded by material variations imposed by technical environments, rightness could be a tricky claim to establish. Within the editorial process, as well as being arbiters of domain knowledge to fulfil the validity claim of truth, authors and editors acted as proxies for clinicians as users, endeavouring by this means to meet the contextual requirements of users and so to fulfil the validity claim of rightness. At times there was a marked difference between the perception of rightness at this social level and rightness at a systems level. In particular, some of those in systems roles, failing to acknowledge editorial and authorial insight into the context of use of their content, sought, instead, to ensure applicability of content to context by enabling the receiving interlocutors, particularly doctors, to configure their own information. Like all validity claims, the validity claim of rightness can only be met when it is accepted by all participating interlocutors; therefore, to fulfil this criterion for transparency, there needs to be a high degree of consistency across interlocutor views of the communicative context.

#### *7.2.4.4 Factors exacerbating challenges to transparency*

Communicative transparency is an idealised aim and real-world achievement of it is beset with challenges. Challenges to transparency were seen to be exacerbated in a number of ways in the digital mediation of healthcare meanings. Some of these were associated with the materiality of digital media and, in particular, with the intractability of standardised formats and their inability to mould intuitively to the intent of their users. Often, rather than materiality *per se*, exacerbations arose from a lack of a shared understanding of aspects of materiality between those with different expertises who collaborated to create digital healthcare information artefacts. Specifically, the study showed the lack of a common understanding of digital materiality between holders of systems expertise, and holders of content expertise. There was also the implication, from holders of both systems and content expertise, that some truths were so subtle and complex as to evade digital encoding altogether – that there were meanings that simply could not be expressed in this digital medium.

Further exacerbations arose, as might be expected, from the distance between interlocutors common to all forms of mediated communication. The separation between users and creators of digitally mediated healthcare information is perhaps particularly notable due to the great number and variety of interlocutors involved in the creation of artefacts. In the organisations in this study, authorship was attributed to the clinical experts whose specialist expertise influenced and shaped the nature of the content, and, perhaps, also to the organisations themselves. But the range and contributions of the non-clinical interlocutors whose various expertises also influenced and shaped the nature of the content were not fully visible to users, exacerbating challenges to transparency. Creators of digital healthcare content were described as working in the absence of clear contexts of use in attempts to create content for future contexts, such as electronic patient record systems, that did not yet exist. Users of digital healthcare content were described as configuring their own content access in ways not visible to its originators and working via “black box” systems that obscured the communicative connection between creators and users of meaning.

More challenges to transparency arose when originating interlocutors had openly conflicting communicative aims. These situations were rare, but a notable example emerged in the drive towards creating decontextualised content that would support reuse in the interests of economic efficiency. Enthusiastically adopted by systems developers and business managers, this approach was at odds with the meaning- and interlocutor-centric visions of many of the study’s informants, who struggled to make sense of systems devised to support the economically-driven aim of context-independence. More common than openly conflicting aims were challenges arising from a lack of mutual insight between originating interlocutors. Study informants from all expertise groups appeared hampered in collaboration by their lack of insight into the perspectives of other roles. Examples were found in the lack of recognition on the part of systems informants of the nuanced understanding of context held by content workers, and, in parallel, the lack of recognition on the part of content informants of the importance of such recognition for effective collaboration. Challenges to truth validity claims made by other



expertise groups were common, for example when developers expressed scepticism about the requirements expressed by content workers, or when content informants expressed scepticism about the efficiency claims made by systems workers.

Perhaps the most fundamental risk to transparency identified in this study was the lack of a mutual validity framework between holders of the collaborating expertises contributing to the creation and dissemination of healthcare information artefacts. This was manifested in differences in models of communicative intent, in models of interlocutors, and in models of information artefacts, as discussed in sections 6.2 and 6.4 of Chapter 6. In summary, those in systems and content roles, in particular, were shown to have differences in their understanding of the nature of the communicative action enacted in the digitally mediated sharing of healthcare meanings.

In this study, I have presented the view that personally held models of communication shape the actions of interlocutors in the sharing of meanings. Where these models are oriented to support different validity claims, the divergence between them can raise challenges to transparency. There were indications that such challenges were exacerbated, firstly, by a lack of mutual insight into the concerns of collaborating expertise groups, secondly, by functional separation if this was combined with working in isolation, and thirdly, by the concealment of complexity between co-interlocutors. It appears that isolated specialist working can diminish interlocutor awareness of the richly layered expertise involved in the digital mediation of healthcare meanings and, in so doing, reduce the capacity for meaningful, discursive collaboration, placing undue pressure on intermediary roles such as that of the information technologist.

#### *7.2.4.5 Factors mitigating challenges to transparency*

The study identified a number of mitigating factors working against the inevitable challenges to promote transparency. One of these was the constant checking and validation that took place at both organisations as content accumulated meanings on its journey through the mediating factors of expertises and systems. This checking promoted the meeting of validity claims, most obviously claims to truth but equally claims to

truthfulness and rightness. The strong models of context of use which were held by content informants seemed to lessen contextual barriers to transparency, promoting the success of validity claims to rightness, in particular. Both systems and content informants spoke of choosing informational formats to support transparency, for example, by adding text to data presentations to socialise them, adding rightness to the truth of data.

Just as isolation in working practices was described in relation to lack of understanding between expertise groups, so discursive contact between expertise groups was seen to promote mutual understanding and foster common purpose. Content and systems roles were described as working together, in situations which, though they might not have been comfortable for participants, opened up collaborative space for new shared framings of communicative aims. Although the limitations of the data within this study meant that this process was empirically observable only in the early stages of such collaborations, it is likely that harmony in models of discourse in the form of alignment between rightness at a systems level and rightness at a social level could promote the success of validity claims to rightness. Likewise, it might be expected that clarity around the identity and roles of interlocutors might promote the meeting of validity claims to truthfulness.

In the digital mediation of healthcare meanings, I have argued that systems and artefacts are used as proxies, carrying the communicative intent of their creators. The three-way mutual understanding between systems workers, content workers, and the target healthcare interlocutors of clinicians and patients, plays a central part in the shaping of these proxies. The transparent, discursive building of understanding between collaborating expertises appears to be crucial in achieving a transparent healthcare discourse.

### **7.3 Strengths and weaknesses of the study and methodology**

The ideas that led to this study emerged from two sets of observations I made in real-life. The first observation was of the intersection between the vastly different perspectives held by editorial and systems contributors in the digitisation of publishing activity that I observed as an editor and producer of digital information products. The second

observation was of the intersection between editorial and clinical perspectives in the creation of healthcare information that I encountered when, as a consumer healthcare editor working for the first time with clinicians, I came face-to-face with the collision between clinical knowledge and lived experience.

The first observation led me to theoretical explorations of digitisation (e.g. Laurel 1991; Mitchell 1994; Landow 1997, Bolter and Grusin 2000), and eventually to write a Masters dissertation on the digitisation of poetry. The second led me to explore the complexities of medical communication (e.g. Gwyn, 2002; Seale, 2002) and eventually to enrol at the London School of Economics and Political Science to embark on this research, where I began to ponder what might happen if all three of these perspectives – content, systems, and healthcare – convened to engage at once with the clinical/experiential collision compounded by the content/systems divide.

As I began to explore the meetings between the different perspectives of healthcare, content, and systems, I was fascinated and daunted by what seemed the sheer impossibility of communicating meaningfully across such disciplinary gulfs. My early reading and inspiration focused on descriptive empirical studies in a Foucauldian tradition (e.g. Knorr Cetina, 1999; Mol, 2002) whose empirical tracings of scientific work emphasised subjective difference and questioned even the possibility of a unified rational science in the face of such cultural and individual divergence. In the early stages of my preparation, I expected to reach similar conclusions in this study as I questioned the possibility of a rational digitally-mediated healthcare discourse.

As I progressed through my fieldwork using my findings from each interview to inform the guide for the next, I found my expectations changing. Of course, the interviews revealed many instances of confusion, of complexity, and of failed or distorted communication. But over and over again, despite the challenges and the problems, I observed informant interlocutors in all groups picking themselves up from disappointment, seeking the reasons for failure, and reworking their ideas to find other routes to communicate. The will to successfully communicate seemed stronger than all of

the many challenges I had so painstakingly identified and to account for this continuing belief in the potential for success even when its reality seemed so distant I sought a new framing for the analysis of my data, which I found in Habermas's idealised notion of a universal pragmatics and which led me eventually to the theoretical and conceptual framework outlined in Chapter 2.

My own professional involvement in digital healthcare publishing influenced more than my choice of subject matter. To an extent, all researchers act as interlocutors in the discourse they record and analyse, but in the case of this research, my professional status as a fellow producer of digital information beyond my status as a researcher brought practical benefits. Participants at the charity, the publisher, and the system vendor were familiar with the products that I worked on, lending a certain "insider" (Kanuha, 2001; Hammersley and Atkinson, 2007 pp. 86-89) credibility to my investigations, encouraging the decision to grant me access to informants. For the system vendor, I represented both a potential client and, more generally, provided an insight into the preoccupations of publishers as users of systems, whereas for the charity and publisher, I was a "fellow traveller", and one with whom they were immediately keen to share observations and experiences. From the outset, the interviews were informal, and, I hope, exploratory, for all participants. Beyond the interviews that I recorded and analysed, I took part in many more informal conversations, which went unrecorded, where I freely shared not only my own experiences, but my contacts, methods, and even on one occasion, content transformation scripts that I had written. I saw these minor practical contributions as a way of paying back the informants for the generous donation of their time and insight into the research.

Practical questions of access to informants aside, it was important to maintain reflexive awareness of the way my personal involvement in the subject matter of the interviews shaped the emerging research evidence (Hammersley and Atkinson, 2007; Finlay 2002). I was keen to avoid leading the interviewees towards those themes that I myself, as a practitioner, might have expected to find, and so elicited concepts from participants using open questions (see section 3.3.2, Chapter 3 for details). I then cross-fertilized subsequent

interviews with these concepts. Rather than create an *a priori* theoretically driven coding schema, and risk introducing undue personal or theoretical bias, my initial coding of the data was limited to *entities*; real-world phenomena as presented by the interlocutors (see section 3.4.2, Chapter 3). To ensure that my identification of key themes was empirically driven by the contributions of informants rather than by my own prejudices, I identified these themes based on frequency counts of references to entities within the data, and embarked on thematic interpretation only once a body of data had accumulated around the theory-light entity codes.

I am reasonably confident that the access which my insider status granted me to informants, and the ease with which I was able to establish rapport with those informants, outweighed the risk of bias that my status within the digital publishing community conferred. I was, and remain, a ‘native’ in the digital publishing community, and position this research as the work of an active, reflexive researcher.

In contrast to more descriptive methods I had previously studied, the benchmark notion of the validity claims of truth, truthfulness, and rightness, developed from Habermas and introduced in section 2.1 of Chapter 2, provided a normative framework for the assessment of transparency in communication, enabling me to draw conclusions within the discourse frame without seeking outcome measures external to the field of communication. Unavoidably, the tight focus on validity claims as a means for establishing social transparency meant that other factors relating to the digital mediation of healthcare meanings could not be fully examined, including more complex personal motivations for action. While I had initially expected the empirical work to focus on seemingly unresolvable issues such as the gulf between the subjective experience of illness and the population level analysis favoured by evidence based medicine, in practice, informants were either silent on these knotty issues or focused on practical resolution. I do not doubt that a different style of interviewing might have coaxed more problematic, less discursively rational contributions from informants, but for the contributions which informants made to my fieldwork, contributions that managed to be

simultaneously optimistic, committed, at times bemused, and sometimes wry, the Habermasian framing seemed to be fully appropriate.

In this study, I attempt to theorise mediated communication in a way that is consistent with Habermas's normative framework, but is informed by a sensitivity to the detail of personal lived experience which is such a feature of descriptive critical studies, mixing the precision of formal pragmatics with critical observation to treat digitally mediated healthcare information as a single complex discourse. The adoption of the framework of universal pragmatics put a very precise examination of meaning at the centre of the analysis, and appropriately so, since the study is concerned with identifying possible factors leading to miscommunication that might hinder the attainment of mutual understanding.

The pragmatics-based conceptual framework set out in section 2.8 of Chapter 2 was able to account only tangentially for extra-communicative factors and only where these could be clearly seen to have a bearing on the raising and resolution of validity claims. So, for example, the framework identified the possible implications of economic goals to challenge transparency in mediated communication, but was not able to accommodate a detailed exposition of the nature, provenance, and wider implications of such economic goals. In this way, the framework enabled markers to be placed identifying such issues, but was then silent on how those extra-communicative factors played out more broadly. Although a study focusing mainly on the social impact of the drive to reduce the material weight of the digital artefact might need to seek alternative analytical frameworks to fully explore the many social and economic drivers towards efficiency in healthcare, for the purposes of this study, it was sufficient to note that these factors seemed to be present and that they had potential to systematically distort mediated communication.

The framework also raised, but could not wholly resolve, questions around the distribution of power in digitally mediated healthcare discourse. Analysis of the flow of discourse, and particularly of impediments to this flow, suggested, following Bohman (2000), that novel asymmetries in power were at play in the digitally mediated healthcare

discourse, and that these were different from the asymmetries in power identified (by, e.g. Parsons 1951, Mishler 1984, Scambler and Britten 2001, Gwyn 2002) in the communicative baseline of the classic face-to-face healthcare encounter. But while Habermas's communicative action framework, subsequently developed by Bohman, provided a means to identify distorted communication and associated it with barriers to emancipation, it provides no lens through which to view the impacts of such power asymmetries in the broader world beyond the discursive frame.

The study was able to demonstrate the potential for disruption of the healthcare power balance, with clinicians potentially disempowered by systems that enforced their reliance on a technical interpretation of their messages, but again, while highlighting the implications for communicative transparency, the study remained silent on the broader implications of clinical disempowerment in the wider healthcare context. Similarly, while the study acknowledged the institutional contexts within which interlocutors were set, an analysis of the structure of these institutions and the implications of these structures for healthcare was beyond the scope of my conceptual framework. Finally, questions were raised around digital literacies, opening the door for a broader discussion of social exclusion which, beyond the potential for discursive exclusion, could not be fully addressed within this study.

Empirically, the most obvious omission from the study was the voice of the target interlocutors; the clinicians and patients who made up the users of the digital healthcare information products created by the study informants. These target interlocutors were represented in the study only as described in the accounts of the study informants. Despite their apparent empirical marginalisation, patients and clinicians remain key to the analysis, providing the communicative baseline for the study. Both patients and clinicians were indirectly represented in the enactment of meaning, providing a context of use for the information products, and in some instances, through those clinicians who also held an author role generating text and other meaningful input into the information products. It might seem a weakness of the research design, then, that these interlocutors, so central to the exchange of healthcare meanings, were not asked to participate in the interviews.

They were certainly present in the minds of their various interlocutors, and it is only this second hand, filtered perception which is examined in this study.

Their exclusion was partly due to the practicalities of fieldwork, and the need to limit the amount of data to a manageable quantity while adequately covering different types of content and systems expertise. Thus, their exclusion was a necessary limitation for practical reasons. But in addition to this practical consideration, I was keen that the spotlight of this study would shine on those participants in healthcare discourse that are so habitually marginalised as to become invisible; the content and systems workers who inhabit a world removed from the traditional healthcare settings of clinic and hospital, and who must negotiate, shape and exchange healthcare meanings without the benefit of formal clinical education or experience. Giving space to patients and clinicians as contributing interlocutors, while bringing alive the clinical context surrounding healthcare information products, might have carried a high risk of re-marginalising the same contributing interlocutors I hoped to centralise. Care is taken throughout my analysis not to draw inferences about the perspectives of patients and clinicians in this study.

I acknowledge, nevertheless, that there would be much to learn from a study that brought target interlocutors into the frame as informants and not just as abstractions in the minds of their interlocutors. Likewise, and for similar reasons, the voices of authors were silent as informants. Of all the collaborating interlocutors, authors might be expected to be closest to the communicative baseline of the face-to-face healthcare encounter, and so a future direct examination of their perspective, not least on their fellow interlocutors, would doubtless be richly illuminating.

The methodology employed, with interview guides progressively shaped by preceding interviews, amplified the focus on key concepts, ensuring that these were thoroughly examined by a range of informants, but perhaps also narrowed the focus and removed what might have been equally interesting avenues for exploration. In particular, one early surprise was the lack of explicit consideration in the interview data of disease entities. I



had expected sickness, and the ways in which it was conceptualised and encoded by informants, to become a key theme in the research, but once the first interviews had passed by with little discussion of sickness or disease, the focus of the study had moved elsewhere, and it would have been artificial, and run counter to the sampling methodology, to reinstate disease entities as a theme.

#### **7.4 Contribution and suggestions for further work**

This study has examined the digitally mediated discourse of healthcare, focusing particularly on the contribution of often-neglected interlocutors such as editors, researchers, and technical developers. While the primary interlocutors in healthcare discourse are clinicians and their patients, this study has extended the boundaries of what is considered healthcare discourse, to encompass the contributing interlocutors of content workers, such as authors, editors, and others, and systems workers, such as systems developers and information technologists. I have argued that all of these interlocutors contribute to and shape the central healthcare discourse, and further, that movement towards the goal of transparency in the primary healthcare discourse depends on transparency throughout the discourse. I argue that challenges to transparency which arise amongst the contributing interlocutors play out theoretically as challenges to transparency between the primary interlocutors of clinicians and patients, though these primary interlocutors did not contribute empirically as informants, providing instead an idealised communicative baseline against which mediating factors were measured

The study contributes to the theoretical understanding of mediated discourse, by adopting the context-transcendent validity claims of truth, truthfulness and rightness set out in Habermas's universal pragmatics. These validity claims are used as the basis of an analytical framework for identifying challenges to communicative transparency which arise in mediated communication. This study examined the digital mediation of healthcare, but similar empirical frameworks could be constructed to identify challenges to transparency in any mediated discourse, particularly those where specialist expertise and technical artefacts make up the mediating factors. The first step in applying this

approach to other mediated discourses would be to identify the communicative baseline, or the primary interlocutors, before seeking the wider boundaries of the discourse and identifying the contributing interlocutors. The validity claims raised by all participating interlocutors could then be considered in an holistic examination of the mediated discourse with the presumption that unmet validity claims from any of the interlocutors, contributing or primary, would raise challenges to communicative transparency and therefore the risk of systemic distortion of communication.

A particular contribution of this approach to the theorisation of mediated communication is the support for a wide frame of theoretical discursive analysis, enabling the accommodation of both primary and contributing interlocutors in an holistic theoretical view of mediation. I argue that this holistic view of discourse is maintained even when the empirical informants, as in the example of this study, are drawn from only one of the customary media fields of production or consumption. The treatment of information artefacts as *proxy interlocutors*, in particular, enables the accommodation of technically mediated communication within a discourse framing, without the morally problematic need to ascribe communicative agency to non-human actors. Information artefacts acting as proxy interlocutors may, indeed, make an active contribution to the sharing of meaning, but it is, I suggest, on behalf of the human actors whose communicative intent they enact. Acting as proxy interlocutors, information artefacts such as systems can be said to increase the transparency of mediated communication, layering meaning into each piece of information that passes through them. So long as validity claims can be raised and met in each of these locutionary acts, including, crucially, the claim for truthfulness, which necessitates a clear relationship between the artefact and the human interlocutor on whose behalf it acts, then information artefacts, acting as proxy interlocutors, can deepen the discourse and extend communicative transparency.

Of course, such a framework is equally applicable, if not more so, to studies that examine the contexts of both production and consumption. The context transcendence of validity claims makes this framework highly applicable across a range of communicative

contexts, whatever the particular mediating factors that might challenge transparent communication.

The insights generated by the study on the collaborative discursive resolution of novel informational concepts such as those raised by the implementation of new systems are of course of interest to the study of other instances of cross-disciplinary mediation and in particular to the study of the digitisation of content and of communications. More broadly, these insights are applicable to studies of innovation, in particular where innovation crosses disciplinary boundaries and there is a need to accommodate different kinds of potentially conflicting standards. Finally, if perhaps most obviously, the study contributes a new framing for work in healthcare communication, bringing new interlocutors into view and broadening the definition of the healthcare encounter. This opens the door to a fruitful examination of the interactions between clinical, patient, and other kinds of mediating interlocutors which would bring value in a range of healthcare studies.

## **7.5 Conclusion**

In this study, I have analysed a digitally mediated healthcare discourse that contains more active interlocutors than might have been imagined. I have suggested that, in seeking to increase communicative transparency around the sharing of healthcare information, it is important to consider the mediating interlocutors of systems and content workers as actively participating interlocutors and, moreover, to ensure that their actions in mediating the healthcare discourse are in themselves transparent. I suggest that communicative transparency emerges from shared frames of reference, from shared understanding of context, and from shared models of interlocutors and of communication. The empirical research in the study highlighted examples of collaborating interlocutors discursively raising and meeting validity claims, strengthening and deepening the discourse, and moving towards increased transparency. Conversely, the study also raised examples of conflicting validity frameworks existing without resolution and considered

how such conflicts might prepare the ground for communicative disconnects and obscurity in the digital mediation of healthcare meanings.

I began this research by questioning whether it was possible for digital mediation to increase the transparency of healthcare communication, with transparency understood to mean the shared mutual understanding defined by Habermas as the goal of communicative action. I conclude that it is indeed possible, providing that all participating interlocutors, including holders of mediating systems and content roles, as well holders of clinical and patient roles, participate openly in the healthcare discourse, raising and meeting validity claims to truth, truthfulness, and rightness. It is when these validity claims fail to be met, by some, any, or all of these participating interlocutors, that challenges to transparency are introduced. In framing the research theoretically, I also asked what particular challenges to communicative transparency arose from the digital mediation of healthcare meanings. I found that the challenges were rarely to validity claims to truth, falling more frequently under the category of truthfulness, particularly when interlocutor identity was obscured, and, most frequently, to rightness, challenged by shifting contexts, and, most notably, when collaborating interlocutors did not share the same validity framework. When seeking to improve the transparency of digitally mediated health information, therefore, I suggest that the goal should not simply be clear and unambiguous mediated statements – “truths” – but an explicit understanding of the communicative principles applied by key interlocutors and the information artefacts that serve as their proxies.

## **Endnote**

Five years have passed since I completed the fieldwork which informed this study. As I complete this conclusion, in the autumn of 2013, the Content Management System (CMS) over which the publisher, the systems developers, and their implementation consultants expended so much thought and energy is no longer on the market. It has been subsumed into the product offerings of the parent company which acquired its creators part way through my fieldwork. The company for which the implementation consultants I

interviewed worked is no longer in business. The publisher, once again, is in the midst of implementing a brand new system to manage research information within its clinical and patient products.

The digital mediation of healthcare moves on. The authors of a recent editorial in the BMJ apply the by now familiar logic of digital automation to the systematic review, citing the emergence of new digital artefacts and new types of expertise, and raising the optimistic prospect that “updating might one day become almost effortless, immediate, and universal” (Tsafnat et al. 2013: 139). It might indeed; provided, I would argue, that validity claims of truth, truthfulness and rightness can be raised, and resolved, by *all* interlocutors in this healthcare discourse, regardless of their disciplinary orientation, and the nature of their locutionary contribution.

## Appendix A: List of informants

<b>Name<sup>25</sup></b>	<b>Role</b>	<b>Organisation</b>
Ben	Business development director	Supplier to publisher
Carl	Implementation consultant	Supplier to publisher
Chris	Implementation consultant	Supplier to publisher
Curt	CEO	Supplier to publisher
David	Developer	Publisher
Dee	Developer	Supplier to publisher
Elle	Clinical editor	Publisher
Emma	Clinical editor	Publisher
Eric	Education and publications manager	Charity
Eve	Educational consultant	Charity
Gerry	Graphic designer	Charity
Gill	Graphic designer	Charity
Ian	Information technologist	Charity
Isaac	Information technologist	Charity
Ivan	Information technologist	Publisher
Louis	Medical librarian / information specialist	Publisher
Pat	Production editor	Charity
Penny	Production editor	Charity
Theo	Technical director	Supplier to publisher

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<sup>25</sup> The names used in this study have been allocated alphabetically, based on the role of the informants, to preserve anonymity.

## Appendix B: Case Summaries

These summaries provide an experiential framework as a counterpoint to the conceptual framework which shapes the study. This appendix provides a link between the context of digitally mediated healthcare meanings, as experienced by those who create those meanings, and the theoretically-driven exploration of the mediated discourse in Chapters 4, 5, and 6 of the thesis. The summaries cover four rounds of interviewing, two each for the charity and the publisher, and this appendix is accordingly structured into four sub-sections.

### Charity interviews, round 1: June - November 2006

I carried out my first interview for this research in the summer of 2006, with the education and publications manager from the charity. This interview took place over the telephone.

#### Charity interview 1: Education and publications manager ("Eric")

*"With proposals for digital products, you can't always tell what you'd end up with"*

Eric was responsible for the education and publications output of the charity. He headed a small in-house team of editors, who worked closely with designers and IT staff to create and manage both print and digital publications.

Eric spoke about the goals of his organisation in the area of digital publishing, and described the range and volume of print and electronic publications the charity produced at that time. Print publications included booklets and leaflets for patients and reports for medical professionals, and were all made available in digital formats on the organisation's own website. Further output formats were CD- or DVD-ROM, and audio CDs. Eric described recent improvements the organisation had made to the accessibility and manageability of their website.

In addition to creating the materials, his department was responsible for awarding and

administering grants to producers wishing to create educational materials for both patients and health professionals. He voiced concerns about the complexity, expense and unpredictable outcomes of these grant-funded digital projects, and sent me a copy of the guidelines the organisation had produced to minimise the associated risks.

He told me about his investigations into using digital development agencies in future. His team had recently commissioned a report on digital strategies of similar charities, which he sent to me after the call. He talked about an enthusiasm from the organisation to pursue digital publishing opportunities, coupled with an uncertainty on the best direction to take. He also touched on the technical infrastructure and applications currently in place to support digital publishing, and the budgets involved, both in terms of funding and expenditure.

Following this first conversation, Eric agreed that I could travel to the organisation's offices in the north of England to meet more of the education and publications team face-to-face and interview them about their daily work. I made the trip in the late autumn, and was able to spend a whole day with various members of the team, interviewing some individually, and others in pairs. Working from interview guides that I had prepared based on information I had gathered in the first interview with Eric, I invited all participants to talk about their organisation, the disease which was its focus, their own daily work within that organisation, the colleagues and tools they encountered in the course of that work, and about the audience for that work.

#### **Charity interview 2: Graphic Designers ("Gerry" and "Gill")**

*"We think on our feet, we have to do a lot more than just design"*

*"You try to inform people, don't you"*

Gerry and Gill formed the in-house graphic design team of the charity. Their work was fast-paced, intricate, and highly technically-mediated, and touched all print and online publications produced internally by the organisation. This wasn't limited to the educational materials



managed by Eric's team, but also included marketing and corporate materials. Both enthusiastic users of Apple computers, they talked at length about the technologies and applications they used, what they liked and didn't like about them, and about their professional backgrounds in advertising agencies. They also shared their understanding of the disease which was the focus of the organisation, including its effects on the patients who suffer from it, some of whom they came into contact with in the course of their work.

The bulk of the conversation focused on the detailed steps of the workflows they followed each day as they took text from the editors and worked it into final publications, delivering either to digital platforms created and maintained by the IT team, or to external printers. In the course of this discussion, they raised their particular challenges; from high-level issues such as capturing audience attention, to the mundane detail of working through technical glitches, and also talked about their hopes and expectations for the future direction of their work.

### **Charity interview 3: Production editor ("Pat")**

*"...the need for absolute accuracy, and being very very precise in definitions, and the explanations that you give to people..."*

Working alongside another production editor<sup>26</sup>, Pat was involved in commissioning, generating, and finalising text to go into the printed and online publications created by the charity. She described the process of generating the text for the leaflets and booklets she edited, and talked about the people she worked alongside. Her position in the workflow was between the medical editors, authors, and lay reviewers on one side, and the graphic designers on the other, becoming involved again as a quality control step between the graphic designers and printers. She also described the role the production editors played in the updating of content following publication.

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<sup>26</sup> The second production editor, "Penny", took part in the subsequent workshop, which is summarised later in this appendix.

The translation of complex medical terminology into plain English was an important focus for Pat. She related her work at the charity to her past work in legal publishing, and described the numerous databases and other forms of specialist referential information she used in the course of her work. She also spoke about the impact of the disease covered in the publications on those who suffer from it. When talking about future developments in electronic publishing, Pat voiced concerns about complexity and expense, and highlighted the desire to be well informed of the implications of particular technologies before proceeding.

The longest of the day's sessions was an in-depth and wide-ranging discussion with Eric and an educational consultant, Eve. For this session, I had added to the interview guide specific questions stemming from the digital strategy report which Eric had sent to me after our first phone call.

**Charity interview 4: Education and publications manager ("Eric") and educational consultant ("Eve")**

*"Technology's not the important thing... the important thing here is about making patients cope better with their chronic illness."*

Eve was an external consultant, with an academic background in pedagogy, and her focus was on educating patients. She spoke in detail about the relationship between clinical knowledge and the patient experience, and the role of the information produced by the organisation both within and alongside that relationship. Both she and Eric voiced concerns about the complexity and expense of digital products, and discussed their approaches to mitigating the associated risks.

Eve spoke about the range of disciplines involved in creating digital content. Both participants talked about the specific situation of patients with the disease covered by their charity, and the way the characteristics of the disease influenced the types of digital information most likely to be of use to patients.

Eve also raised the idea of mobilising a wider external community of expertise to advise the charity on potential future digital development. While expressing concerns about the charity's low level of digital expertise and low numbers of staff, both Eric and Eve spoke about the high quality of the print materials the charity created and disseminated and the charity's familiarity with print distribution. Eric spoke in detail about some of the digital projects the charity was involved in, such as the move to a new web platform. Both participants talked about specific digital content projects that the charity had funded in the past, and about the decision to stop funding digital content projects pending the development of formalised evaluation methods. Both participants also compared their position in terms of digital strategy with that of other medical charities.

Following the long session with Eric and Eve, I carried out a final wrap up interview with Eric, in which he further explored some of the issues around the move to digital publishing which were facing the organisation.

#### **Charity interview 5: Education and publications manager ("Eric")**

*"Everything has to be right, really, to make it really top quality"*

Eric talked about the charity's dependence on clinical experts, who gave their time for free to author and edit publications. He considered various methods of producing publications using internal or external resource, and some of the concerns raised by each approach, from maintaining the right range and level of skill in a small in-house team to finding trustworthy external suppliers. Eric also considered the benefits and the challenges of introducing more interactivity into digital information products, and the potential difference between an interesting information product and a useful one.

## **Publisher interviews, round 1: February - June 2007**

In early 2007 I recruited the publisher to the study via one of their suppliers, a systems development company based in the Netherlands which had created the content management system used by publisher. My contact in the systems development company introduced me to an information technologist from the publisher, and he in turn introduced me to colleagues in the content teams. Again, through my contact in the systems development company, I was introduced to a third company, a firm of implementation consultants who had worked with the system developers to configure and roll out the content management system for the publishing company to use. The patterning of institutional actors in this group of interviews was therefore complex from the outset, but convening participants from this range of institutional settings allowed me to explore perspectives which would have been hidden had I chosen to limit participants to employees of the publisher.

My data gathering for this group of cases began with a face-to-face meeting with an information technologist from the publishing company, in their London offices.

### **Publisher interview 1: Information technologist ("Ivan")**

*"we have to manage our content in such a way that it can be served via any delivery channel to any user at any point they need it"*

*"That's what makes it exciting"*

Ivan worked in a managerial role in the technology department at the publisher, focusing on strategic systems development, serving as a bridge between the needs of the business and the solutions developed by the technology team. His background was in commercial IT.

Ivan spoke about the vision and mission of his organisation as a whole, and the importance of quality and trustworthiness. He described, and via his laptop, demonstrated, the close relationship between the clinician-focused content produced by the organisation and the

patient-focused content derived from it, mentioning the importance of translating clinical language for lay audiences and also relating the work to trends in healthcare such as shared decision making. He talked about the needs of clinical and lay users in relation to the information products his organisation produced, about international market distribution, and about commercial relationships with clients, as well as talking me through usage statistics for the organisation's websites. He touched upon the relationship of evidence-based content to expert opinion, and the contrast between purely commercial organisations he had worked for in the past, and the more influence-driven goals of the publisher. In this context, he talked about building relationships with other healthcare institutions. He also spoke of the need for flexible system-based delivery to support access to content, and of the positioning of the outputs of his organisation alongside other relevant specialist outputs such as primary research literature.

Ivan listed the different professional disciplines he worked alongside, starting from business and marketing staff, and progressing through product development onto project implementation, including editorial, operational, technical, design, and sales. He concluded the interview by describing his vision and enthusiasm for flexible, customised publishing based on system-managed content components.

In the same week of my first interview with Ivan, I met the implementation consultants, who were working on rolling out the new content management system (CMS) for the publisher. This session was part interview, using the same guide I used for other participants, and part corporate presentation, as the consultants introduced me to the work and focus of their company. The company was based in the Netherlands, but the interview took place in London.

#### **Technology suppliers interview 1: Implementation Consultants ("Carl" and "Chris")**

*"one of the things we do is making knowledge explicit"*

Carl and Chris worked for an IT consultancy company with almost 400 employees. The

company focus was on supporting client companies with knowledge-intensive processes; clients were mostly based in the Netherlands but with a small number based in other northern European countries. Carl described past implementations with clients such as telecom companies and government offices, where his organisation had analysed knowledge flows around the client companies and mapped them to technical infrastructure. Carl and Chris then spoke about the developing discipline of knowledge management, particularly in relation to the medical information they had worked with in the medical publishing company. They talked about the methods they employed to group content to serve the needs of different user perspectives, to facilitate the separation of editorial concerns from business concerns, and also covered technical solutions they had developed to support intelligent search. Chris spoke of the need to allow for human intervention in information processing to support those cases which could not be easily automated. He related this approach to the application of standardised nomenclatures to medical content.

Chris described the CMS implementation project with the medical publisher and its similarity to a project with another publisher with similar requirements. He talked about the challenge of moving to models of content generation which were separated from the eventual publication context, and about potential future developments with the medical publisher. Carl talked in general about the business justification for companies interested in starting up knowledge management projects. Finally, Carl identified trust as a core concept to be addressed by knowledge management applications.

The following week I travelled to the Netherlands, to the offices of the company that had developed the CMS which had recently been implemented by the medical publishing company. There, I had arranged to interview members of the senior management and development teams, starting with the business development director who, like the implementation consultants I had spoken to the previous week, had prepared a corporate presentation on the company. I wrapped my questions from the interview guide around his presentation.

## Technology suppliers interview 2: Business Development Director ("Ben")

*" the more complex it is, the better fit for our technology"*

Qualified with a master's degree in business economics, Ben had worked as a programmer and technical project manager before moving into sales. He had set up and sold his own company, before joining this current company in order to lead its repositioning away from being technically-driven towards being business-driven. He recalled that when he joined, the main product of the company, an XML<sup>27</sup> database, was sold to smaller organisations, and was treated almost as a technical toy. Once a business layer was wrapped around the core database then the company became more financially successful.

Ben talked about the process of XML becoming mainstream, evidenced by the interest of big technology players in incorporating XML-driven solutions into their product offerings. Then he introduced his company's client portfolio, which was weighted towards the aerospace industry, and described his company's entry into that specialist market, driven by its adherence to data standards. Standardisation was important to the company, partly as a key to moving into specialist areas where the company had little domain expertise, but also as a process to which key members of the team were actively committed, serving on standards committees of various types. Ben expressed the company's commitment to open rather than proprietary standards, driven by customer preference. He described the way the CMS product had emerged from work to support the creation of technical manuals in multiple languages, and was now being sold into other environments, such as publishers. He described the process of working with aerospace companies to define requirements, then building these developments into the generic product lines.

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<sup>27</sup> XML – eXtensible Markup Language, a standard coding language suited to data exchange between applications, and particularly suited to encoding semi-structured, discursive texts

### **Technology suppliers interview 3: CEO ("Curt")**

*" we started to do early implementations, and basically explore the technology, and we simply liked it "*

Curt was one of the original founders of the small research company that had grown into the current commercial organisation. He talked about the early days of the research company, working with an educational publisher on single-source publishing in the 1990s. The founders of the company were attracted by the challenge of the structured document environment offered by the then emerging technology of XML. Curt contrasted relational data models with the hierarchical model proposed by XML, and praised the practical flexibility and speed afforded by XML. He spoke about the company's strategy of maximising compliance with open standards, which he put partly down to a personal dislike of the limitations imposed by vendor lock-in, and partly as a strategy to focus on product development rather than implementation consultancy. He also described the experience of sitting on standards committees, spoke about the centrality of standards within the aerospace industry, and talked about the customisation of the generic CMS product for vertical markets such as aerospace, publishing, e-learning or the oil industry, and the domain experts the company was hiring from these industries.

Curt spoke about the challenges of conceptualising, and particularly of authoring, componentised content, as supported by the company's CMS product, describing the authoring process as being more like mathematics than writing. He identified, too, challenges for the users of the authored content, who might be presented with the same content multiple times in different contexts, without realising it. He skated over questions of ownership and accountability stemming from such obscure authorship, suggesting that the question of what variations could be served to users was more interesting than who owned or was responsible for the content.



#### **Technology suppliers interview 4: Technical Director ("Theo")**

*" we listen, and we hear open standards, so we practise open standards "*

Theo was a co-founder of the original research company, along with Curt, and he described how the original team had developed the company's core XML database product in response to a specific information management problem. He linked the success of the company to the mainstream acceptance of XML, citing the commitment of the company to open standards, and placing this in the context of a market-driven shift to open standards by all technology providers, including those whose early success had been built on proprietary formats. He contrasted the freedom of early days of XML development with the later more standardised approach. Alongside the growing familiarity of customers with XML technology, Theo described the challenges of shifting from traditional authoring models to an information management approach, where he identified issues around componentisation and reuseability. He suggested that content creation processes would change and new disciplines such as information management would gain prominence, to formally consider structure and context alongside content.

Theo described the way in which his company developed and sold systems in both market-specific and generic versions, and how these related to one another. He stressed the importance of maintaining a robust generic core to the systems and minimising customisation, so that the company could focus on developing that core system rather than consulting on implementation, and contrasted that with the approach of competitors. He felt that the differentiation between his company and its competitors lay not in the technology they provided, but the way in which they worked with customers to ensure best practice was encapsulated into the core product.

Theo ended by recounting a personal anecdote about the medical publishing company that were now his clients; he recalled that his father, as a medical student in a developing country, had benefited from free access to the publisher's information, and that memory drove him to want to serve the publisher well, so that they could continue to serve the world.

### **Technology suppliers interview 5: Developer ("Dee")**

*"you have the most freedom when less is there"*

Dee had been a member of the development team for 6 years, and had been attracted to the company because of its use of XML and commitment to open standards. She spoke of her enthusiasm for elegance and simplicity in technical solutions, and her preference for hands-on development rather than other activities such as consulting or standards-setting. She talked about her current day to day work, which consisted of improving the CMS in response to customer feedback, in contrast to her previous work, which focused on developing the foundations of the system in response to customer requirements.

Dee talked about the importance of clarity and simplicity in code, which she felt was appreciated by customers. She felt the company had benefited from having customers who were well-informed technically and knew what they needed the system to do. She described some of her particular frustrations with aspects of the XML standard that were not consistent, which caused problems for developers. She talked about various developer communities she had joined, where such technical issues could be shared and resolved with other developers from different companies.

Over the following weeks, I visited the offices of the medical publisher several times, to meet and interview members of the content teams involved in creating information products. These were highly specialist roles, focusing on medical content.

### **Publisher interview 2: Medical librarian / Information specialist ("Louis")**

*"our requirements are slightly different from other people's"*

A qualified librarian, whose past employers included a medical school library and the National Institute of Clinical Excellence, Louis worked in the information specialist team at the publisher, searching for and appraising clinical research literature to inform the products

created by his department, and to service contracts with external clients. He contrasted the innovation and dynamism of his current work with the library-based work he did in his early career. He talked about the personal importance for him of working for a company which was highly regarded, and where helping people was more important than making money, although he also spoke about the company's current commercial drive to replace recently lost supply contracts and expand the product range. He compared the work of his current to the systematic reviewing of clinical trials carried out by the Cochrane Collaboration<sup>28</sup>, describing the methodological rigour they shared, in contrast to the less thorough approach adopted by other more commercial organisations.

Louis talked me through the process of creating evidence based content. He described the collaborative process of scoping topics, in which he championed methodological rigour and clarity, working with expert clinical authors and the internal editorial team to resolve different views on what evidence should be included or excluded in a review. He talked about the deadline-driven nature of the work and the complex scheduling that was required, and about the need to quickly familiarise himself with unfamiliar medical topics and terminology, and to skim read abstracts in order to appraise a study on its methodology, regardless of its content.

Louis talked about the specialist databases he used to source abstracts in relation to his allocated topics, and the processes of searching and filtration he applied to those database in order to surface relevant papers for appraisal. He referred to the hierarchy between systematic reviews and randomised control trials, and how these study types were used as filters when sifting search results, and also spoke about the controlled vocabularies which were used to index papers by topic within the databases. He produced some examples of search strategies he had created and talked me through what they meant and how he had gone about putting together the complex strings of search terms and operators, and described how he would adapt the search strategy to run on different databases.

Louis identified the high volume of published research as a key challenge, and described his efforts to focus his search strategies to ensure they returned a manageable number of

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<sup>28</sup> The Cochrane Collaboration is an international not-for-profit association of researchers who systematically review clinical research evidence in order to inform evidence-based practice

abstracts to appraise. He described the appraisal of most abstracts as straightforward, with perhaps 10% requiring a higher level of interpretation due to the complexity of the topic, or to lack of clarity in the abstract. He described the systems used by the team to support abstract appraisal and talked about the new CMS which was just about to be introduced to his team. Finally, Louis talked about the work his team did to support patient-oriented products, which was broader and less systematic than the work on the clinician-facing systematic review product.

My first interview with a clinical editor was cut short when my informant was called to a meeting, so the information below was gathered in the course of two interviews, with a 3-month gap between them.

**Publisher interview 3: Clinical editor ("Elle")**

*" I would like to build on my medical background and do something that is relevant for today's world "*

Elle had a medical degree, but had never practised medicine, having gone straight into publishing work following medical school. She had a further degree in medical informatics and in her current job worked on product development and special projects. She described how clinical editors worked with information specialists and expert authors to create content for clinical products, and contrasted that with the broader approach taken for the patient-focused content, which used freelance medical writers to translate and then augment the clinical content.

Elle spoke about her informatics degree, and what she had brought from it into her current role, including an understanding of terminologies and classification systems. She observed that the problems of implementing standardised terminologies, such as inconsistent coverage, or multiple ways of coding the same condition, had not been covered in her degree. She suggested this was because at that point they had not yet become apparent. She felt that practising clinicians would consider coding against standardised terminologies to

be an administrative practice, and would not need to know the complexities of how the coding systems worked, whereas for a publishing organisation using the codes to map to clinical systems, it was more important to understand the mechanics of how the codes worked.

Elle also identified the clinical pathway, a standardised patient journey for a particular condition, as an important concept she had taken away from her informatics training and built on in her work at the publisher, when she had worked on a pilot project to provide evidential support for an electronic stroke pathway. The third concept from her informatics training that she had built on in her work was the decision support system. Again, she had worked on a pilot for this sort of system, identifying relevant clinical questions to support decision making.

Elle spoke about the mechanics of data exchange involved in creating evidence reviews in the team, and her hopes for how the new CMS would link review content with the underpinning references to provide a database for future reuse. She felt the information management involved in this could be a challenge for editors without an informatics background.

#### **Publisher interview 4: Clinical Editor ("Elle")**

*"There are sort of blurry edges "*

Elle talked me through the process of creating content, starting with topic selection, possibly driven by customer demand, or suggestions from authors or website users. She touched on the limitations of using a highly structured approach, and then explained the highly interactive, conversational approach of questions going back and forth between information specialists, editors, and authors. She commented that the information specialists liked to make everything explicit, to avoid problems in search and appraisal, but that this explicitness would be removed again by the editors before publication, as it might not be compatible with the subtlety required when making decisions on clinical relevance. She discussed the problem of small scale studies when it was hard to be certain about the significance of the

results, and the importance of clearly conveying such uncertainty.

Elle highlighted the problem of mismatch between questions that were important for clinicians, and questions that had been answered in research studies, and the resulting tension this created for the creators of the reviews. She described the process by which the editors submit interventions they have classified as unknown effectiveness to the national health technology assessment agency as suggestions for further research.

Elle contrasted clinical editorial work with the work of a practising clinician, with the editor focused on providing the explicit information needed by the clinician to support decisions on the treatment of individual patients. She suggested that in clinical practice, decision making was not as evidence-based as the editors might like. Working at the publisher had sharpened her understanding of both the potential and the limitations of evidence-based medicine. She had developed a critical appreciation of the importance of methodological rigour, which was essential to ensure that the inclusion or exclusion of evidence was not influenced by the preferences of individual authors. She talked about the hierarchy of evidence, and the issue of evidence gaps, which occur when no high quality evidence can be found on a particular topic. She felt that the distinctions between the levels of evidence was not clear to many practising clinicians, and described editorial approaches to clarifying evidence quality.

### **Publisher interviews, round 3: February - March 2008**

Eight months passed before I returned to the publisher to complete my final interviews, starting once again with Ivan, who told me about the changes that had happened since my last visit.

#### **Publisher interview 5: Information Technologist ("Ivan")**

*" the sum of the whole is greater than the sum of the parts "*

Ivan spoke positively about the company restructure that had happened in recent months, and about the commercial diversification that had taken place, with new contracts being set up with a wider range of clients and major investment in new product lines. He spoke about the way in which the CMS, newly implemented on my first visit, was now being used by more departments and product teams, and imagined a cross-product user journey drawing on content from multiple divisions, facilitated by the single underpinning technology of the CMS. He talked about the CMS-driven mechanism to deliver content to one of the new external client websites.

Ivan described past problems with technical development, which he ascribed to a lack of strategic input from the technology team. He expressed hope that this problem would be resolved now that the technology team was growing in influence and recognised as providers of important strategic guidance as well as implementation services. He outlined again the principle of storing single source data and reusing it for different purposes, rather than capturing and storing the same data many times. He highlighted another, newer, guiding principle of monetising the content of the organisation, which development he related to his earlier view, that influence was the main focus, and commercial success less so, by citing commercial success as a driver for increased influence. He also described a shift towards group-wide rather than divisional thinking in terms of maximising revenue.

Ivan described the structure of his new team, made up of data and systems analysts whose remit was to monitor the range of systems running across the company and ensure they were meeting strategic business requirements, with the aim of adopting more strategically-driven systems into the team as they were specified. He described the tension between the desire to

streamline technology solutions and the desire to diversify and grow product offerings via innovation and acquisitions, and talked about methods of discovering market needs in order to drive strategic development. He expressed concern that his organisation focused too much on content at the expense of embedded system solutions, but finished on a positive note, identifying change as what had made his 20 year career in publishing exciting.

Two weeks later I returned to the publisher's offices for the last time to complete my last two interviews with the team, one with a developer who worked on the CMS and one with a clinical editor who had also been closely involved with the CMS implementation.

#### **Publisher interview 6: Developer ("David")**

*" we have quite alive products"*

A Java developer with a background in working on large websites, David had been attracted to the role in the publisher's development team 4 or 5 years previously because of its central London location. A member of the implementation team for the CMS, he now led a team of 3 developers responsible for its further development and maintenance. He listed 7 product lines which were migrating or had already migrated into the CMS, and described his close relationships with those divisions that he had worked closely alongside prior to the recent restructure. He described the company's strategic ambition to have a single content bucket from which the various products were derived, and the unusually high level of customisation the implementation team had done to support that aim. Looking back, he suggested the approach had been over-engineered and would have been better handled incrementally. As a consequence he voiced an intention to keep current and future product migrations simpler.

He talked about the different teams he worked with in order to drive implementations, and mentioned his wish that developers be involved up front in the specification of implementation solutions. He described one commercial deal where a contract had been signed committing the team to deliver against an aggressive deadline, and spoke about the design of a loosely-structured, discursive delivery format to suit the particular needs of that customer, in contrast



to the highly structured formats used internally to support complex clinical content. He described the iterative process of designing structured XML schemas based on existing content that had been created without formal rules in a proprietary system, and then migrated through subsequent systems, and then spoke about the problem of recreating the old structure from the remodelled content in order to continue to supply clients who were not willing to migrate their own systems to the new schema.

David explained the challenges of working with academic, non-technical editors who could not understand the restrictions imposed by the structure of XML, and the difficulty of agreeing development priorities with such a diverse team. His solutions included nominating a single point of contact with the business, and using the company's past experience of an unsuccessful CMS implementation to win editors over to the new CMS.

David had also developed a tool for coding content with standard clinical terminologies, which he described as interesting but academic, with no business requirement behind it. He described the current technical environment for this tool, which was separate to the CMS, and considered how it would be best to operationalise it if the business need arose. He finished by describing how early business enthusiasm for breaking content into small components for reuse had waned when it had become clear how context-dependent many of those smaller content components were in practice.

#### **Publisher interview 7: Clinical editor ("Emma")**

*"detail orientation is not always accompanied with a great deal of flair, and expertise, and willingness to be brave"*

Although a clinical editor, Emma had a background as a medical librarian, having moved into the editorial team from her prior role in the information specialist team. She identified this shift as unusual, with only one other non-clinician having made a similar shift into a clinical editorial team, and linked the opportunity to the early stage of product development at which

both these shifts had been made.

Emma headed up the clinical editor team on the clinical systematic review product, and held the role of joint deputy editor on the product. She had worked closely with developers from the technology department on the implementation of the CMS. She talked about the project to code content against clinical terminologies, and felt that though the coding had been implemented to deliver against a customer requirement, in practice it was not useful and not used. She put this down to the complexity of the particular terminology chosen and inconsistencies within it, which she ascribed to the genesis of the terminology within the medical insurance industry.

Emma described the company's search for tools to adequately manage its evidence data, to improve the efficiency in the appraisal process. She described the text-heavy analysis of benefits and harms which was currently produced, and talked about ways of summarising this in a way that was both easier for readers to grasp and quicker to produce, and described the search to find a specialist company to support the extraction, graphical representation and publication of this specialist data. She also highlighted the restructure which had taken the technology team out of the publishing department as having led to greater formality in the relationship between the editors and developers, describing the strong social ties that had built up between these teams while they were part of the same department.

Emma finished by discussing the expense of creating the systematic review product as it currently stood, and the consequent needs to find reuse opportunities and to streamline the process. She considered the different ways in which the product might be created if it were to focus on data rather than text, and the different skillsets which might be needed, including stronger numerical skills to go along with the current clinical skillset.

At the end of March 2008, three weeks after my final visit to the publisher's offices, I made a second and final visit to the offices of the developers of the CMS, in the Netherlands. I interviewed the CEO, "Curt", together with the Business Development Director, "Ben". Even greater changes had happened in the year since my first visit, with the company having been purchased by a large company identified in the first round of

interviews as a competitor. With these changes in mind, I was a little surprised on arrival at the new, bigger offices to find the old company nameplate installed on the door, indicating that perhaps the changes had not proved as far-reaching as I had imagined.

**Technology suppliers interview 6: CEO ("Curt"); Business Development Director ("Ben")**

*"there are no secrets, everything should be done in a proper way "*

*"Millions of consumers, yeah. Yeah that's really fun"*

Curt began by describing the circumstances leading to the acquisition of his, which he and Ben agreed had been driven by the strength of their relationship, a shared vision, and competitive pricing. Curt was attracted by the opportunity to distribute his system worldwide, growing their customer base from around 100 to 20,000 in one leap, but also pointed out that his company still acted as an autonomous unit, as an XML solution centre within the parent US-based company, which had over 30,000 employees.

Ben and Curt described the phone calls and face to face interactions they were having with their new parent company as they worked towards integration. Curt had made 20 visits to the US over the previous year. Curt felt that although the new company had brought more formality to product specifications, the ways of working within his group had been preserved. He had recently added a development team based in China, so that his day was shaped by early morning communication with China via email, and late evening communication with the US via phone. Curt had visited the Chinese office but was yet to meet his new development team face to face. Challenges in communication meant that discrete pieces of work that could be worked on in isolation were sent out to China; Curt felt it would be impossible to truly co-develop with the China-based team.

Bigger changes had happened in sales, with Ben's role adapting into providing support to large sales teams rather than closing deals himself. Curt joked about the stepped up security arrangements, with security passes and ID cards for all staff, and controlled access to the server rooms. Both Ben and Curt were relieved to now be insulated from the whims of venture capitalists, by virtue of being a subsidiary of a parent company.

Curt spoke enthusiastically about new products that the team was developing, focusing on content delivery rather than content management. He spoke of the high level of trust the parent company had invested in the team in allowing them to lead on the technical development. Curt and Ben then both spoke about the sales strategies employed by the new parent company, with heavy discounting in the expectation of upsell opportunities. They both felt that they had managed to maintain their previous informal relationships with their existing customers, but recognised that things might be different following future expansion. They described the formality of the internal processes in the new parent company, and the complexity of the tax implications. Looking to the future, Curt identified information management rather than content management as an avenue he was keen to explore, incorporating semantic technology into his systems.

Curt talked about the centrality of open standards to the concept of information management, and the difference between the purist approach followed by the company he had founded, and the more pragmatic approach followed by the new parent company, whose shift to open standards was prompted by commercial strategy. He put forward the view that the currently understood definition of a document was changing, to become something more granular, and described how the technology he worked on would help manage structured fragments of information without breaking up the documents containing it. This was what he considered to be the vision he shared with the new parent company. He talked about the need to add semantic information to make this information-centric approach work, and the challenge of managing documents in many formats in a meaningful way.

### **Charity interviews, round 2: June - October 2008**

Almost two years after my first visit to the charity's offices, I contacted Eric again, in the summer of 2008. A lot had changed in the charity as a whole, and in the education and publications department in particular. Our conversation took place by phone.

**Charity interview 6: Education and publications manager ("Eric")**

*" It was just an eye opener really, to see people struggling with the site "*

Eric told me about the redevelopment of the charity's website that had just been completed. He spoke about the focus group testing of the site that he and others from the team had been involved in. He also told me about some restructuring that the organisation had been through since my visit, which had resulted in some changes in priorities. He talked about some of the different roles and people who were now involved with the work of his team. Finally, Eric touched on the content management needs of the charity and the challenge of bringing together print and web workflows.

At the end of our call, Eric agreed that I could come back to the charity's offices to talk to the team again. This time, rather than interview people individually, he planned to hold a workshop-style discussion with multiple participants, so that I could record the interactions between different participants as they worked their way through various real-life concerns. I travelled back to the charity's offices in the north of England in the autumn of 2008. With five participants, often talking over each other, the resulting recording took some disentangling, but gave me a richer insight into the dynamics of the team than I could have obtained in individual interviews.

**Charity interview 7: Themed workshop discussion, including Education and publications manager ("Eric") ; Graphic designer ("Gill"); Production editors ("Pat" and "Penny"); Information Technologist ("Ian")**

*"The web content is going to be quite different, more layered and sexy and interesting and vibrant and colourful and attractive (laughter)." (Production editor)*

*"Ideally this should all be transparent from you guys. We'll figure out a way for you just to write your content in and hit a button, basically, and the computer should do the rest."*

(Information technologist)

Eric opened the workshop by highlighting the issue of how to optimise workflows so that print and web content could be created simultaneously. Penny joked good-humouredly about the ambitions of the team for the digital content, which Eric then addressed more seriously. Pat brought up the user focus group sessions she had attended, and the weaknesses these had highlighted in the web materials, and then she and Penny explained the detail of the process involved in the revision of existing content. When they reached the technical translation between print and web forms of content, and the problems that arose as a result of that process, Gill, the graphic designer, was called to join the workshop to fill in the detail.

I had not met Ian, the information technologist, on my previous visit. He was a recent recruit to the organisation, coming from a background in educational IT support in a school. As the discussion around technical issues developed between the production editors and the graphic designer, he began to suggest practical solutions and approaches.

Eric moved the conversation on to cover the question of which CMS to choose, in particular the pros and cons of open source as opposed to proprietary systems. Ian confidently expressed a preference for the flexibility of open source systems, which he contrasted with the constraints imposed by proprietary systems. The production editors then joined in the developing conversation as everyone expressed concerns about the dangers of moving forward with sub-optimal technology systems or partners.

Eric then spoke about the requirements the charity might have of a CMS. Ian and Eric considered the potential scale of the task of migrating existing content into a CMS, and how this might be achieved. The production editors discussed with Ian and Eric the pros and cons of migrating the data using in house resources. Neither the production editors nor Eric relished the prospect of spending internal resource on this task.

As the discussion went on, Penny and Eric voiced their wish to see the markup code behind the text that they were working on, something that their current system did not allow. The conversation developed to discuss the challenges of working with content stored in chunks to facilitate reuse rather than as whole documents or booklets. Ian advocated this approach, while Penny questioned its usefulness for the charity. Ian, Eric and Penny worked through the implications in detail.

## **Appendix C: Coding schema**

Full thematic coding schema for the nodes of “functional role” and “healthcare”, with frequency counts for each term

### **1. Functional roles**

#### **1.1. Information professionals**

##### **1.1.1. Content roles**

- 1.1.1.1. Clinical editor (68)
- 1.1.1.2. Information specialist (56)
- 1.1.1.3. Graphic designer (52)
- 1.1.1.4. Author (51)
- 1.1.1.5. Production editor (41)
- 1.1.1.6. Educational consultant (11)
- 1.1.1.7. Researcher (8)
- 1.1.1.8. Medical informaticist (7)
- 1.1.1.9. Patient editor (7)
- 1.1.1.10. Peer reviewer (3)
- 1.1.1.11. Clinical coder (2)
- 1.1.1.12. Scientific editor (2)
- 1.1.1.13. Information manager (2)
- 1.1.1.14. Electronic media specialist (1)
- 1.1.1.15. Subject matter expert (1)

##### **1.1.2. Systems roles**

- 1.1.2.1. Information technologist (77)
  - 1.1.2.1.1. Systems implementation consultant (3)
  - 1.1.2.1.2. Database architect (2)
- 1.1.2.2. Developer (70)
- 1.1.2.3. Standards developer (2)

### **1.1.3. Business roles**

- 1.1.3.1. Business manager (12)
- 1.1.3.2. Sales director (11)
- 1.1.3.3. Publishing manager (9)
- 1.1.3.4. Marketing professional (5)
- 1.1.3.5. Salesperson (5)
- 1.1.3.6. Business analyst (3)
- 1.1.3.7. Account handler (2)
- 1.1.3.8. Project manager (2)
- 1.1.3.9. Customer support staff (1)
- 1.1.3.10. Sales engineer (1)

### **1.2. Health professionals**

- 1.2.1. Clinician (43)
- 1.2.2. Allied health professional (8)
- 1.2.3. Nurse (7)
- 1.2.4. Medical student (2)
- 1.2.5. Pharmacologist (1)

### **1.3. Lay roles**

- 1.3.1. Patient (38)
- 1.3.2. The public (21)
- 1.3.3. Website user (11)
- 1.3.4. Customer (5)
- 1.3.5. Reader (4)
- 1.3.6. Carer (3)

## **2. Healthcare**

### **2.1. Intervention (27)**

- 2.1.1. Drug (24)
- 2.1.2. Operation (7)



- 2.1.3. Test (4)
- 2.1.4. Cure (3)
- 2.1.5. Placebo (2)
- 2.1.6. Palliative care (1)

**2.2. Condition (conditions are listed in alphabetical order, without frequency counts<sup>29</sup>)**

- 2.2.1. Alcohol abuse
- 2.2.2. Anxiety
- 2.2.3. Arthritis
- 2.2.4. Autism
- 2.2.5. Cancer
- 2.2.6. Chronic disease
- 2.2.7. Constipation
- 2.2.8. Diabetes
- 2.2.9. Eye problems
- 2.2.10. Febrile seizures
- 2.2.11. Heart disease
- 2.2.12. HIV
- 2.2.13. Hypertension
- 2.2.14. Injury
- 2.2.15. Obesity
- 2.2.16. Stroke

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<sup>29</sup> Frequency counts are omitted for conditions to preserve the anonymity of the participating organisations, one of which focused on a particular condition, which scored disproportionately highly.

## Appendix D: Data analysis 1

The screenshot shown here is from the data analysis stage of the research. In this example the data had been first coded by subject role in NVivo according to the schema in Appendix C. The coded data was exported to Excel for further analysis. Left to right, the image shows the subject role; the informant ID (name); the informant role; the informant category; and the informant organisation. These columns were used to filter and sort the data. The coded interview data appears in the wide central column. The columns to the right hold categorisations of themes observed within this quote. In this example, the data is demonstrating themes in the categories of “inexpert” and “becoming expert”. The themes have been further categorised by the addition of keywords such as “informational”, “literacy”, and “healthcare”.

	A	B	C	D	E	F	I	J	K	L
	Subject role	Informant ID	Informant role	Informant category	Informant organisation	Quote	info		Expertise	
1										
2									Expert	Inexpert
										Becoming expert
74	patient	Ivan	Information technologist	Systems	publisher	clarity is that the patient understands what has been said to them, and there are statistics which say somewhere along the lines that if you go for a GP consultation you'll remember about 10% of what was actually said to you. And so the issue is how can you use information to improve the level of retention and level of understanding such that actually you'll remember 80% of what was shared with you. And again information prescription is all about that. It's I'll explain it you, I'll summarise it again and then I'll give you the information so you can read it in your own leisure time	yes		inexpert (informational)	personal medical information
79	patient	Elle	Clinical editor	Content	publisher	They have much more around diagnosis, of the treatments, treatment rationale, they also have a section where they list the questions that patients could ask their doctor when they attend a consultation. So it is much wider in a way, and really tailored to the language and the interest of the patients.	yes		inexpert (informational, communication, literacy)	becoming expert (informational)
86	patient	Eric	Education and publications manager	Business	charity	it might get, it might give information to people who have trouble getting it from the booklets, or who don't, I don't know, who either don't feel able to get it from the booklet because they don't (43:47 inaudible), Eve mentioned they've got a low reading ability, say, or they don't speak English, well, perhaps it wouldn't happen so much, but somebody who struggles with written text, say. Or people that, I don't know, just prefer watching television, which probably includes quite a lot of people, would rather watch it as a television program	yes		inexpert (informational, literacy)	becoming expert (healthcare)
	patient	Eve	Educational consultant	Content	charity	it should be for hard to reach people, people with poor literacy skills. There should be a focus on not only providing information but striving to educate, which brings about greater understanding.	yes		inexpert (informational, literacy)	becoming expert (healthcare)

## Appendix E: Data analysis 2

The screenshot shown here is from the data analysis part of the research. Here, frequency counts are being used to identify patterns and structure initial reporting. The numbers here are showing differences between the types of systems expertise identified by different types of informants.

	A	B	C	D	E
1	Expertise	Total	content	systems	business
2	technical content development	17	5	11	1
3	tool selection	13	1	5	7
4	systems development	7		6	1
5	systems design	4		4	
6	systems integration	2		2	
7	managing technical infrastructure	2		1	1
8	adapting systems	2		2	
9	standards development	1		1	
10	supporting implementation	1		1	
11					
12	analysis	15		13	2
13	process design	8	7	1	
14	problem solving	8	1	7	
15	interpreting requirements	6	1	4	1
16	knowledge representation	4		4	
17	communication	3	2	1	
18	knowledge of technical limitations	2		2	

## REFERENCES

- Ashenden, Samantha, and Owen, David (eds.) (1999) *Foucault Contra Habermas*  
London: Sage
- Austin, JL (1962) *How to do things with words* Oxford: Oxford University Press
- Blair, J Anthony and Johnson, Ralph H (1987) "Argumentation as Dialectical"  
*Argumentation* 1: 41
- Black AD, Car J, Pagliari C, Anandan C, Cresswell K, et al. (2011) "The Impact of eHealth on the Quality and Safety of Health Care: A Systematic Overview" *PLoS Med* 8(1): e1000387. doi:10.1371/journal.pmed.1000387
- Bluhm R (2005) "From hierarchy to network: A richer view of evidence for evidence-based medicine" *Perspectives in Biology and Medicine* 48(4): 535
- Bohman, James (2000) "'When Water Chokes': Ideology, Communication, and Practical Rationality" *Constellations* 7: 382
- Boivin, Antoine; Légaré, France; Lehoux, Pascale (2008) "Decision technologies as normative instruments: Exposing the values within" *Patient Education and Counseling* 73: 426
- Bolter, Jay David and Grusin, Richard (2000) *Remediation: Understanding New Media*  
Cambridge, MA: MIT Press
- Bowker, Geoffrey C and Star, Susan Leigh (1999) *Sorting Things Out: Classification and its consequences* Cambridge, MA: MIT Press
- Brown, Gillian and Yule, George (1983) *Discourse Analysis* Cambridge: Cambridge University Press

Charles, Cathy; Gafni, Amiram and Whelan, Tim (1997) "Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango)" *Social Science & Medicine* Vol. 44: 681

Cooke, Maeve (1994) *Language and Reason: A Study of Habermas's Pragmatics* Cambridge, MA: MIT Press

Cooke, Maeve (2001) "Meaning and Truth in Habermas's Pragmatics" *European Journal of Philosophy* 9: 1

Cooren, François and Matte, Frédéric (2010) "For a constitutive pragmatics: Obama, Médecins Sans Frontières and the measuring stick" *Pragmatics and Society* 1(1): 9

Cooren, François (2012) "Communication Theory at the Center: Ventriloquism and the Communicative Constitution of Reality" *Journal of Communication* 62: 1

Crossley, Nick (2004) "On systematically distorted communication: Bourdieu and the socio-analysis of publics" *The Sociological Review* 52: 88

Cummings, Louise (2005) *Pragmatics: A Multidisciplinary Perspective* Edinburgh: Edinburgh University Press

Deacon, David (2003) "Holism, communion and conversion: integrating media consumption and production research" *Media, Culture & Society* Vol. 25: 209

Dy, Sydney M., and Purnell, Tanjala S (2012) "Key concepts relevant to quality of complex and shared decision-making in health care: A literature review", *Social Science & Medicine*, Vol. 74: 582

Edwards, AG; Russell, IT; Stott, NC (1998) "Signal versus noise in the evidence base for medicine: an alternative to hierarchies of evidence?" *Family Practice*, 15 (4): 319

Fairclough, Norman (1995) *Media Discourse* London: Edward Arnold

Flick, Uwe (2002) *An Introduction to Qualitative Research* London: Sage

Floridi, Luciano (2002) "On the intrinsic value of information objects and the infosphere" *Ethics and Information Technology* 4: 287

Floridi, Luciano (2008) "Information Ethics, its Nature and Scope" In van den Hoven, Jeroen and Weckert, John (eds) *Information Technology and Moral Philosophy* Cambridge: Cambridge University Press

Foucault, Michel (1970) *The Order of Things* London: Tavistock

Foucault, Michel (1972) *The Archaeology of Knowledge*, trans. A.M. Sheridan Smith. London: Tavistock

Foucault, Michel (1973) *The Birth of the Clinic* London: Tavistock

Fox, Susannah (2011) *Health Topics*. Pew Internet & American Life Project, February 1, 2011, <http://www.pewinternet.org/Reports/2011/HealthTopics.aspx>, accessed on November 19, 2013

Gabe, Jonathan; Bury, Michael; Elston, Mary (2004) *Key Concepts in Medical Sociology*. SAGE Publications Ltd. Retrieved 17 August 2013, from <<http://www.myilibrary.com?ID=37049>>

Galle, Per (2002) "Philosophy of design: an editorial introduction" *Design Studies* 23: 211

Garnham, Nicholas (2000) *Emancipation, the media and modernity : arguments about the media and social theory* Oxford: Oxford University Press

Graham, W.S. (1979) "What is the language using us for?" In Graham, W.S. *Collected Poems* London: Faber & Faber

Greenhalgh, Trisha; Robb, Nadia; Scambler, Graham (2006) "Communicative and strategic action in interpreted consultations in primary health care: A Habermasian perspective" *Social Science & Medicine* 63:5 1170-1187

- Greenhalgh, Trisha (2010) "Getting your bearings: what is this paper about?" in *How to Read a Paper: The Basics of Evidence Based Medicine* London: BMJ Books
- Greenhalgh, Trisha and Swinglehurst, Deborah (2011) "Studying technology use as social practice: the untapped potential of ethnography" *BMC Medicine* 9:45
- Grice, H Paul (1989) *Studies in the Way of Words* Cambridge, Mass: Harvard University Press
- Guest, Greg; MacQueen, Kathleen M; Namey, Emily E (2012) *Applied Thematic Analysis* Thousand Oaks: Sage
- Guyatt GH, Oxman AD, Vist GE, Kunz R, Falck-Ytter Y, Alonso-Coello P, et al.(2008) "GRADE: an emerging consensus on rating quality of evidence and strength of recommendations" *BMJ*. 336(7650):924
- Gwyn, Richard (2002) *Communicating Health and Illness* London: Sage
- Habermas, Jürgen (1982) "A Reply to My Critics," in *Habermas: Critical Debates*, ed. Thompson and Held, Macmillan
- Habermas, Jürgen (1984) *The Theory of Communicative Action, Vol 1: Reason and the Rationalization of Society* Cambridge: Polity Press
- Habermas, Jürgen (1999) *On the Pragmatics of Communication* Cambridge: Polity Press
- Habermas, Jürgen (2006) "Political Communication in Media Society: Does Democracy Still Enjoy an Epistemic Dimension? The Impact of Normative Theory on Empirical Research" *Communication Theory* 16: 411-426
- Hammersley, M, and Atkinson, P (2007) *Ethnography: Principles in Practice* New York: Routledge

- Hawkins, Richard (1996) "Standards for Communication Technologies: Negotiating Institutional Biases in Network Design". In Mansell and Silverstone (eds.) *Communication By Design: The Politics of Information and Communication Technologies*. Oxford: Oxford University Press
- Haynes, R. B. (2006) "Of studies, syntheses, synopses, summaries, and systems: the "5S" evolution of information services for evidence-based health care decisions" *ACP Journal Club*, 145(3)
- Hofmann, Bjørn (2010) "The concept of disease – vague, complex, or just indefinable?" *Medicine, Healthcare and Philosophy* 13: 3
- Hongladarom, Soraj (2004) "Making Information Transparent as a Means to Close the Global Digital Divide" *Minds and Machines* 14: 85-99
- Houkes, Wybo and Vermaas, Pieter E (2002) "Design and use as plans: an action-theoretical account" *Design Studies* 23: 303
- Howick, Jeremy; Glasziou, Paul; Aronson, Jeffrey K (2009) "The evolution of evidence hierarchies: what can Bradford Hill's 'guidelines for causation' contribute?" *Journal of the Royal Society of Medicine* 2009 May 1; 102(5): 186–194
- Howick, Jeremy; Chalmers, Iain; Glasziou, Paul; Greenhalgh, Trish; Heneghan, Carl; Liberati, Alessandro; Moschetti, Ivan; Phillips, Bob and Thornton, Hazel (2011) *The 2011 Oxford CEBM Evidence Levels of Evidence* (Introductory Document). Oxford Centre for Evidence-Based Medicine. <http://www.cebm.net/index.aspx?o=5653>
- Jones, Ian Rees (2001) "Health care decision making and the politics of health." In Scambler, Graham (ed.), *Habermas, critical theory and health* London: Routledge
- Kanuha, VK (2001) "Being" native versus "Going Native": conducting social work research as an Insider *Social Work* 45: 439-447
- Kleinman, Arthur (1988) *The Illness Narratives: Suffering, Healing, and the Human Condition* New York: Basic Books



- Kleinman, Arthur et al (1994) "Pain as Human Experience: An Introduction." In Delvecchio Good, Mary-Jo et al (eds) (1992) *Pain as Human Experience: An Anthropological Perspective*. Berkley: University of California Press
- Knaapen, Loes (2013) "Being 'evidence-based' in the absence of evidence: The management of non-evidence in guideline development". *Social Studies of Science* 43(5) 681-706
- Knorr Cetina, Karin (1999) *Epistemic Cultures: How the sciences make knowledge* Cambridge, Mass: Harvard University Press
- Kreps, Gary L. and Neuhauser, Linda (2010) "New directions in eHealth communication: Opportunities and challenges" *Patient Education and Counseling* 78 ( 3): 329
- Lacan, Jacques (1977) *Écrits: A Selection*. trans. by Sheridan, Alan. London: Tavistock Publications
- Lambert, Helen (2006) "Accounting for EBM: Notions of evidence in medicine". *Social Science & Medicine* 62(11): 2633
- Landow, George P (1997) *Hyptertext 2.0: The convergence of contemporary critical theory and technology*. Baltimore: Johns Hopkins University Press
- Latour, Bruno (1991) "Technology is society made durable" In J. Law (Ed.) *A sociology of monsters. Essays on power, technology and domination* London: Routledge
- Laurel, Brenda (1991) *Computers as Theatre* New York: Addison-Wesley Publishing
- Lehoux, Pascale; Denis, Jean-Louis; Tailliez, Stephanie, and Hivon, Myriam "Dissemination of Health Technology Assessments: Identifying the Visions Guiding an Evolving Policy Innovation in Canada" *Journal of Health Politics, Policy and Law* 30 (4)
- Lehoux, Pascale (2006) *The Problem of Health Technology* New York: Routledge
- Levinson, Stephen C. (1983) *Pragmatics* Cambridge: Cambridge University Press

- Litt, Eden (2012) "Knock, Knock. Who's There? The Imagined Audience" *Journal of Broadcasting & Electronic Media* Vol. 56, Iss. 3
- Luoto, Jill; Maglione, Margaret A.; Johnsen, Breanne; Chang, Christine; Higgs, Elizabeth S.; Perry, Tanja; and Shekelle, Paul G (2013) "A Comparison of Frameworks Evaluating Evidence for Global Health Interventions" *PLoS Medicine* 10(7): e1001469
- Malterud, Kirsti (2001) "The art and science of clinical knowledge: evidence beyond measures and numbers" *The Lancet* Vol. 358, Iss. 9279: 397-400
- Mansell, Robin (1996) "Communication by design?" In Mansell and Silverstone (eds.) *Communication By Design: The Politics of Information and Communication Technologies*. Oxford: Oxford University Press
- Mansell, Robin (1995) Standards, industrial policy and innovation. In Hawkins, R, Mansell, R and Skea, J (eds) *Standards, Innovation and Competitiveness* Aldershot: Edward Elgar
- Mansell, Robin (2004) "Political economy, power and new media" *New Media & Society* 6(1):96
- Mansell, Robin and Silverstone, Roger (1996) Introduction. In Mansell and Silverstone (eds.) *Communication By Design: The Politics of Information and Communication Technologies*. Oxford: Oxford University Press
- Massanari, A.L. (2010) "Designing for imaginary friends: Information architecture, personas and the politics of user-centered design" *New Media and Society* 12 (3)
- Mey, Jacob L (2001) *Pragmatics: An Introduction* (2nd edition) Oxford: Blackwell
- Mishler, Elliot (1984) *The Discourse of Medicine: Dialectics of Medical Interviews* Norwood, NJ: Ablex.
- Mitchell, William J (1994) *The Reconfigured Eye: Visual Truth in the Post-photographic Era* Cambridge, MA: MIT Press

- Mol, Annemarie (2002) *The body multiple: ontology in medical practice* Durham and London: Duke University Press
- Moreira, Tiago (2007) "Entangled evidence: knowledge making in systematic reviews in healthcare" *Sociology of Health & Illness* 29 (2): 180
- Negroponte, Nicholas (1995) *Being Digital* London: Hodder & Staughton
- Oudshoorn, Nelly (2008) "Physical and digital proximity: emerging ways of health care in face-to-face and telemonitoring of heart-failure patients" *Sociology of health & illness* 31 (3): 390
- Owen, David (1999) "Orientation and Enlightenment: An Essay on Critique and Genealogy" in Ashenden, Samantha, and Owen, David (eds.) *Foucault Contra Habermas* London: Sage
- Parsons, T. (1951) *The Social System* . London: Routledge and Kegan Paul
- Prior, Lindsay (2003) "Belief, knowledge and expertise: the emergence of the lay expert in medical sociology" *Sociology of health & illness* 25 (3): 41
- Reich, Adam (2012) "Disciplined doctors: The electronic medical record and physicians' changing relationship to medical knowledge" *Social Science & Medicine* 74: 1021
- Rienstra, Byron & Hook, Derek (2006) "Weakening Habermas: the Undoing of Communicative Rationality" *Politikon: South African Journal of Political Studies*, 33:3, 13-339
- Quintas, Paul (1996) "Software by design" In Mansell and Silverstone (eds.) *Communication By Design: The Politics of Information and Communication Technologies*. Oxford: Oxford University Press
- Reis, Shmuel; Visser, Adriaan; Frankel, Richard (2013) "Health information and communication technology in healthcare communication: The good, the bad, and the

transformative” *Patient Education and Counseling*, Available online 31 October 2013, ISSN 0738-3991, <http://dx.doi.org/10.1016/j.pec.2013.10.007>

Sackett, David L; Rosenberg, William MC; Gray, JA Muir; Haynes, Brian R; Richardson, W Scott (1996) “Evidence based medicine: what it is and what it isn't” *BMJ* 1996;312:71

Saussure, Ferdinand de (1959) *Course in General Linguistics*, trans. Baskin, Wade. New York: McGraw-Hill

Scambler, Graham, and Britten, Nicky (2001) “System, lifeworld and doctor-patient interaction: Issues of trust in a changing world.” In Scambler, Graham (ed.), *Habermas, critical theory and health* London: Routledge

Schiffrin, Deborah (1994) *Approaches to Discourse* Cambridge, Mass: Blackwell

Seale, Clive (2002) *Media and Health* London: Sage

Searle, John (1969) *Speech Acts: An Essay in the Philosophy of Language*. Cambridge: Cambridge University Press

Shannon, Claude and Weaver, Warren (1949) *The Mathematical Theory of Communication* Urbana: University of Illinois Press

Shah, Rajiv C and Kesan, Jay P (2009) “Recipes for cookies: how institutions shape communication technologies” *New Media & Society* 11:3 315-336

Silverstone, Roger and Hirsch, Eric (eds.) (1992) *Consuming Technologies: Media and information in domestic spaces*. London: Routledge

Silverstone, Roger and Haddon, Les (1996) “Design and the domestication of information and communication technologies: Technical change and everyday life”. In Mansell and Silverstone (eds.) *Communication By Design: The Politics of Information and Communication Technologies*. Oxford: Oxford University Press

- Silverstone, Roger and Mansell, Robin (1996) "The politics of information and communication technologies". In Mansell and Silverstone (eds.) *Communication By Design: The Politics of Information and Communication Technologies*. Oxford: Oxford University Press
- Sperber, Dan and Wilson, Deirdre (1995) *Relevance: communication and cognition* (2nd edition) Oxford: Blackwell
- Star, Susan Leigh and Ruhleder, Karen (1996) "Steps toward an ecology of Infrastructure: Design and Access for Large Information Spaces." *Information Systems Research* 7(1): 111-134
- Stehr, Nico and Grundmann, Reiner (2011) *Experts: The knowledge and power of expertise* Abingdon: Routledge
- Stroetmann, K. A., Jones, T., Dobrev, A., & Stroetmann, V. N. (2006). "eHealth is Worth it: The economic benefits of implemented eHealth solutions at ten European sites." *European Communities*.
- Thompson, John B (1995) *The Media and Modernity: A Social Theory of the Media* Cambridge: Polity Press
- Thorgaard, Keld and Jensen, Uffe Juul (2011) "Evidence and the end of medicine" *Medicine Healthcare and Philosophy* 14: 273
- Timmermans, Stefan and Berg, Marc (2003a) *The Gold Standard: The Challenge of Evidence-based Medicine and Standardization in Healthcare* Philadelphia: Temple University Press
- Timmermans, Stefan and Berg, Marc (2003b) "The practice of medical technology" *Sociology of Health & Illness* 25: 97
- Timmermans, Stefan and Angell, Alison (2012) "Evidence Based Medicine, Clinical Uncertainty, and Learning to Doctor" in Broom, A., and Adams, J. (eds.). *Evidence-*

*based Healthcare in Context: Critical Social Science Perspectives*. Farnham: Ashgate Publishing, Ltd.

Tsafnat G, Dunn A, Glasziou P, Coiera E. (2013) “The automation of systematic reviews.” *BMJ* 2013;346: 139

Vincent, C. and J. Camp (2004) “Looking to the Internet for Models of Governance” *Ethics and Information Technology* 6(3): 161

Walseth, Liv Tveit and Schei, Edvin (2011) “Effecting change through dialogue: Habermas’ theory of communicative action as a tool in medical lifestyle interventions” *Medicine, Healthcare and Philosophy* 14: 81

Wilmott, Steven (2011) “Evidence, ethics and inclusion: a broader base for NICE” *Medicine, Healthcare and Philosophy* 14: 111

Winner, Langdon (1999; orig. 1980) Do artifacts have politics? In Mackenzie, Donald and Wajcman, Judy (eds) *The Social Shaping of Technology* Maidenhead: Open University Press