# The London School of Economics and Political Science

Complexity methods for understanding global health governance, financing and delivery arrangements - from system-wide dynamics to neglected tropical disease control in Uganda

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## Abstract

This thesis aims to understand how methodological and conceptual approaches to complexity in quantitative analysis can improve evidence and decision-making, specifically for schistosomiasis control in Uganda and more broadly within global health. Engaging directly with the complexity through methodological choices provided new insights into policies and practices in global health. In Paper 1, I provided an overview of actors and power dynamics in global health, by describing the changing landscape of global health actors as it relates to relative shifts in power over time. This is accomplished by capturing the emergent, dynamic network structure of development aid for health in the period encompassing the 'MDG era', between 1990 and 2015. This paper was published in the Journal of Health Policy and Planning (https://doi.org/10.1093/heapol/czac025).

Paper 2 aimed to develop evidence for decision-making in response to the needs of policymakers and practitioners, with a focus on schistosomiasis transmission and control activities in Uganda. This was accomplished by (1) capturing the perspectives of national and sub-national decision-makers on schistosomiasis transmission using participatory modelling, and (2) using the participatory modelling outputs to inform mathematical model simulations in response to the evidence needs. The implementation of this approach challenged the balance of power between international and domestic actors in the development of evidence and decisions regarding the delivery of global health interventions. This paper was published in BMJ Global Health (http://dx.doi.org/10.1136/bmjgh-2021-007113).

Paper 3 used the outcomes of the participatory systems mapping workshops and individual-based simulations to guide the scope and content of economic evaluations of schistosomiasis interventions. The results indicated that the most cost-effective scenario is a system of implementation reliant on volunteers from within communities and donated drugs. As anticipated, when all else is held equal, including these costs result in lower cost-effectiveness ratios relative to other interventions. Further, the results bring into question the purpose of continuing interventions which are not predicted to achieve the desired targets within the 30-year time horizon. This paper highlighted potential opportunities for schistosomiasis intervention design and implementation which is more aligned with the aims of equitable, country-led sustainable development.

Paper 4 shifted the focus within the discussion of evidence for decision-making in global health to consider one particular type, peer-reviewed publications, which is most often considered as 'best practice' in evidence-based decision-making. A systematic review captured the network of authors who had published on MDA. These results constituted the sampling frame for a remote survey to elucidate perspectives on their roles in policy and practice related to MDA. The findings highlighted the ongoing structural disparities in research leadership and found broad concern about opportunities and about disconnects that limit engagement between researchers and decision-makers for use of primary research in policy and decision-making processes. Paper 4 was published in the Journal of Public Health Policy (https://doi.org/10.1057/s41271-021-00294-x).

Broadly speaking, the papers in this thesis have shown that while reductionist, linear perspectives may be part of the reason for the continuation of ineffectual policies and practices, the confluence of politics, power relations, and economies in the context of a complex system of actors and processes also plays a significant role with regards to policy and practice decision-making. This was observed in relation to schistosomiasis in Uganda and more broadly in global health at the system level. This thesis uses language and methods common in health sciences to communicate critiques in a way that can be engaged with by health policy-makers, practitioners, and many public health researchers. Finally, this thesis showed the possibilities for using network-based and computational models for understanding complexity within the global health 'system'.

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## 1 Introduction

While the gains in alleviating the burden of ill-health have been substantial, the targets laid out in the Millennium Development Goals 2000—2015 were not met and the Sustainable Development Goals 2016—2030 are not on track to be met within the specified timeframe. The lack of information and guidance for decision-makers in policy and practice has restrained their ability to utilize all available information about global health interventions and has often led to the indiscriminate implementation of interventions because it was shown to "work" at some time in some place. Coupled with a top-down approach to decision-making for policy and practice, this strategy has led, unsurprisingly, to disappointing results. Further, the dearth of information about these decision-making processes and the identification of evidentiary needs has led to an exacerbation of the research-practice gap which plagues the implementation sciences. The resultant ineffectual policies, inefficient distribution of resources, and continued implementation of inadequate or inappropriate interventions are cause for great concern as the pressure to achieve success grows.

One contributing factor underlying these issues is a reductionist or linear approach to analyses across global health. Much of the evidence base for decision-making in all aspects of global health is derived from studies which are not designed to engage with the complexity of the system. To address this gap, researchers who study global health have suggested the application of complex systems approaches, both theoretical frameworks and methodologies, to provide further insights into the global health system. For example, Hill (2011) argues for understanding global health governance as a complex adaptive system. The dynamic interactions and relationships between actors and processes are often interrogated through observational studies using qualitative methodologies. While these approaches do capture some of the complex aspects of the system, the methodologies used do not, and indeed are not intended to, systematically distil and quantify complexities. This is the gap that the papers in this thesis speak to. I focus on the dynamic, non-linear relationships between actors and processes across the governance, financial, and delivery arrangements which comprise the global health system and engage with the interplay between the development of evidence and its potential role to support policy and practice.

This introduction to the thesis proceeds as follows. I first provide a brief overview of my motivations behind this research in Section 1.1. Then the background and cross-cutting concepts specify the scope and boundaries of the papers through key definitions and terms in Section 1.2 and Section 1.3 This is followed by the relevant background regarding the contexts and cases in Section 1.4 and methodological choices in Section 1.5.

#### 1.1 My motivations

I wanted to take a moment to introduce myself at the beginning of this dissertation. The motivations underpinning the research presented in this thesis were initiated by my professional experiences as an epidemiologist and data analyst. The resultant thesis was shaped by the COVID-19 pandemic, which encompassed the second half of my PhD programme. I present here a brief overview of these experiences as they relate to my research to provide you with some perspective as to the personal drivers, topic choices, and methodological decisions presented in this thesis.

#### 1.1.1 Pathway to LSE

"Do the best you can until you know better. Then when you know better, do better." *Maya Angelou* 

Ultimately, I know that I was blessed being born into my life – I have had access to quality health care and education and the freedom to pursue happiness. This life is short and I am just trying to spend my time in the service of others who were not afforded the same opportunities. For a long time, I felt that the work I was doing as an epidemiologist and data analyst was a means to this end. The measurement and evaluation of health interventions was an exercise in holding people accountable for the sake of beneficiaries – determining whether people did what they said they were going to do with the limited resources available could (and did) affect large-scale change. The development and reporting of burden estimates, an exercise in counting and guesstimates, articulated the suffering of populations. While I do think there is some substance to these perspectives, as I write them, they sound so naïve and uninformed.

I left to pursue a PhD because things weren't adding up anymore. In my job at the time, I contributed to the writing of policies and guidance that did not reflect the information in the literature or data reported from the ground. I developed evidence to support large financial decisions guided by donor interest instead of recipient needs or realities. I facilitated expert advisory meetings where all of the relevant evidence for decision-making was convened, but where the actual decisions were made during the presentations in a small room off the plenary. From where I sit now, the deeply uncomfortable feelings of complicity which instigated my leave were also naïve and uninformed.

Before my PhD, the entirety of my post-secondary education included very minimal exposure to theories and concepts outside of the physical and medical sciences. I also held jobs while pursuing my university degrees, so was not afforded the privilege of time for contemplating extracurricular materials - I spent my little free time with classical literature. And, at least in the programmes I attended, materials which questioned the integrity of the objectivity of the content and processes we were learning were not represented on the syllabi. Once I realised that I was part of a larger system than I had initially perceived, one driven by competing aims and power dynamics, I decided to step back and find a space where I could continue to work in a way that is reflective of my original intentions. The thesis presented here is the result of a process of wrangling with how to best support those without access to the health care and services needed to achieve a state of well-being. Ultimately, in my own small way, I have tried to create room for people to speak for themselves, amplify these voices when I can, and articulate my perspectives on power and justice using the language and methods I know.

As I am someone who thrives in research in applied settings, early on in my PhD, at the encouragement of my advisor, Professor Tim Allen, I turned part of my proposal into a response to a grant call. This was funded and I took on the role of Lead Investigator of the Localised Evidence and Decision-making (LEAD) Project, hosted at LSE's Firoz Lalji Institute for Africa. I managed the project, both in terms of administrative and research activities. Multiple research assistants and fellows were hired on the project, with intended fieldwork in Uganda, Malawi, Kenya, and Tanzania through 2019 and 2020. The data collection and analyses in Paper 2 [Chapter 3] and Paper 3 [Chapter 4] are based on the original intent of the LEAD Project, while the research in Paper 4 [Chapter 5] is specific responses to the COVID-19 pandemic, as is discussed below.

#### 1.1.2 Impacts of Covid-19

Half of my PhD took place during the COVID-19 pandemic. All of this thesis was written during the global pandemic and the accompanying disruptions to society. For many like myself,

obtaining a PhD is not a likely path, but one that requires financial risk and personal sacrifice for the pursuit of something "more." For me, the pandemic exacerbated these burdens while also severing my ability to conduct my planned research. I have not interacted in person with colleagues, professors, or fellow PhD students for nearly two years. In the meantime, I lost the last two of my living grandparents and a beloved uncle, all of whom I had to mourn separated from my family on another continent, attending one funeral live-streamed on Facebook and another on Zoom (fortunately there was no live-streamed event for my grandfather as these turned out to be quite traumatic experiences.) My partner lost his job and our flat in London fell apart, with a flooded kitchen and a rat infestation, during the first lockdown. Due to my immigration status as an international student, I had to continue my PhD on a full-time basis or lose LSE's support for our UK visas and leave the country within 30 days. Of course, we could have gone back to the US, but had nowhere to live, no work, and, importantly, no access to health insurance. In addition, throughout 2020, President Trump was still in office and the COVID-19 situation in the US was very bleak. It is from this position that we moved to the rugged west Cornwall coast, where we could afford to ride out the pandemic until my PhD was completed and just take a pause to breathe in the sea air.

When the pandemic first began, grant funding for data collection related to my thesis project was largely earmarked for salaries for two UK-based graduate students and several research assistants in Kenya, Malawi, Tanzania, and Uganda. The cancellation of fieldwork meant that all of their expected incomes would be eliminated, while they also experienced the economic instability and uncertainties arising from country-specific, government-mandated COVID-19 mitigation efforts. This weighed heavily on me and therefore I devised to keep everyone employed, while remaining true to the original intent of the research funding, through the development of two smaller COVID-related projects. We were fortunate to receive the rapid approval for the reallocation of funding from the grant-making organisation and ethics approvals for these new research streams. The results of these projects included two peer-reviewed journal articles and a report for the Ugandan Ministry of Health<sup>1</sup>.

The restraints of the pandemic also pushed me to look inward as to what I contribute as an academic. Just as the first cases of SARS-CoV-2 emerged in Wuhan, I was completing an electronic survey of researchers, sampled from the results of a systematic literature search. While initially intended as a networking exercise to map researchers (and their contact details) working on a similar topic in my locations of interest, I became interested in further examining this one particular type of knowledge base on which academics are so focused. This survey turned into a bibliographic analysis of published peer-reviewed literature (published and included in this thesis as "Opportunities and disconnects in the use of primary research on schistosomiasis and soiltransmitted helminths for policy and practice: results from a survey of researchers") and instigated the idea to develop a "living" database of information from published articles. These pieces of work have inspired me to consider how I might proceed as an academic in the vein of becoming a conscientious contributor to the expanse of peer-reviewed literature. This work was not planned at the onset of my PhD, but a direct result of meditation in the state-ordered confinement of the UK's stay-at-home orders.

This is the COVID-related context of the thesis you are currently reading. While I have touched on some of the explicit results of a PhD research plan being derailed by a global pandemic, I should reiterate that the entirety of this thesis was written during the pandemic and was therefore wholly affected by this situation and the resultant physical and emotional stressors. I think it is important to memorialise my experience and put it right up front so the reader can better understand some of the methodological and other research decisions. If the past couple of years hadn't been so difficult in so many ways, I might be disappointed that the resultant piece of work from my PhD process turned out a bit more disjointed, and the underlying research may

<sup>&</sup>lt;sup>1</sup> See Fergus et al. (2021); Storer et al. (2022)

be a bit less interesting, than I had initially planned. But actually, as the work presented here shows, all processes, including PhDs, are the results of complex social, economic, biological, political systems and the interactions between these systems.

## 1.2 Research questions of the thesis

The overarching research question of this thesis is as follows:

How can methodological and conceptual approaches to complexity in quantitative analysis improve evidence and decision-making, specifically for schistosomiasis control in Uganda and more broadly within global health?

The sub-questions, addressed by each of the papers in this thesis, are as follows:

- 1. Using dynamic network analyses, how did the distribution of global health actors and the power dynamics evolve through the MDG-era?
- 2. How does linking participatory and computational modelling improve the quality of evidence with regard to schistosomiasis interventions in Uganda?
- 3. Drawing on the specifics of programmes in Uganda, how do the outputs of participatory and computational modelling impact the results of economic evaluations of mass drug administration for schistosomiasis?
- 4. Using network sampling and remote surveys, what do we learn from the perspectives of primary data gatherers and researchers working on mass drug administration in reference to their roles in policy and practice?

## 1.3 Background

Public health, population health, international health, global health: these terms have been used interchangeably by individuals engaging in activities related to the health and well-being of populations. For the purposes of this thesis, narrow and specific definitions of what constitutes global health and its components were utilized to bound the research. More specifically, the scope of this thesis is defined by a specific set of conditions and constructs where governance, financial, and delivery decisions regarding the implementation of health interventions are not derived from the localities where they are taking place. The ideas in this thesis emerged from the frontiers of literature on evidence for decision-making and methods of knowledge synthesis, as a way to interrogate the shortcomings in achieving certain population health targets and engage with the complex nature of the global health system. This section defines the key concepts and terms of global health and its interventions, actors, and evidence-based decision-making to provide a backdrop and orientation for the thesis.

## 1.3.1 Defining "global health"

Global health is itself a contested term, in that some reasonably argue that there is little fundamentally different between its previous iterations of colonial health or international health<sup>2</sup>. While I agree on a conceptual level with these arguments, and especially regarding issues of autonomy, equity, and justice, this research requires a description of the global health system to provide a framework to engage with, which includes defined components to be disassembled and examined.

<sup>&</sup>lt;sup>2</sup> See for examples, Fried et al. (2010); Peters (2017)

Soon after the ratification of the MDGs by the United Nations (UN) member states in the year 2000, a push to meet the health-related challenges began, including from actors outside of the established international system. Over the past 17 years, the system has undergone a transition, from one of bilateral and multilateral institutional arrangements between nation-states to a varied landscape where private firms, philanthropies, and civil and non-governmental organizations have joined the "traditional" actors and exert substantial power and influence (Szlezák et al., 2010). The research presented here is structured within the definition of global health developed by (Hoffman et al., 2015) as a system of "transnational actors that have a primary intent to improve health and the [bilateral, multilateral, and] polylateral arrangements for governance, finance and delivery within which these actors operate<sup>3,4</sup>." The focus on *transnational* actors certainly implies a top-down approach to the governance, financial, and delivery decisions in the system. A manifestation of this rests in the Millenium Development Goals (MDGs) and the subsequent Sustainable Development Goals (SDGs)<sup>5</sup> and the call for "global action" on issues related to broad concepts of health and development. Paper 1 [Chapter 2] in this thesis describes one aspect of how the global health system has changed with the MDG-era. Next, I describe the primary output of the system, as approached by the papers in this thesis: global health interventions.

#### 1.3.2 Global health interventions

The emphasis of the MDGs and SDGs on specific disease problems encouraged the biomedical, disease-specific approach to tackling ill-health, despite the social-economic-political basis for their persistence<sup>6,7</sup>. Most global health interventions function as vertical programs, "directed, supervised, and executed, either wholly or to a great extent, by a specialized service using dedicated health workers" (Mills, 1983) to tackle a single health problem. These interventions are diametrically opposed to an integrated, or horizontal, approach where "disease control activities are functionally merged or tightly coordinated with multifunctional health care delivery" (Unger et al., 2003) and include "a variety of managerial or operational changes to health systems to bring together inputs, delivery, management and organization" (Dudley & Garner, 2011).

Vertical interventions are set up to deliver biomedical or technical solutions in the form of curative or preventative services. Some common examples include childhood vaccine campaigns and the distribution campaigns to deliver insecticide-treated nets for malaria. Another example, relevant to this thesis, is mass drug administration (MDA) of deworming tablets, used as a case in the context of schistosomiasis in Papers 2, 3, and 4 [Chapters 3, 4, and 5]. These interventions were devised outside of the recipient localities and are often implemented without the genuine input from local social structures and intended beneficiaries (Packard, 2016). It is in reference to this concept that the term "local" is used throughout this thesis. I use "local" to refer to context-specific units of analysis or interest, which may be defined as concrete or

<sup>&</sup>lt;sup>3</sup> This definition was chosen because it integrates and builds on the three prominent works defining "global health" from Frenk & Moon (2013); Hoffman et al. (2012); Szlezák et al. (2010).

<sup>&</sup>lt;sup>4</sup> The addition of "bilateral" and "multilateral" reflect my interpretation of *polylateral arrangements*, wherein it is the "third dimension" of diplomacy alongside bilateral and multilateral interactions (Wiseman, 2004). With this definition, *global health* can be explicitly differentiated from the previously *international health* by inclusion of polylateral relationships, referring to arrangements between at least one state and one non-state entity or between at least two non-state individuals or organizations (Wiseman, 2010).

<sup>&</sup>lt;sup>5</sup> Officially called "Transforming our world: the 2030 Agenda for Sustainable Development" (United Nations, 2016).

<sup>&</sup>lt;sup>6</sup> See Sustainable Development Goal 3.3: "By 2030, end the epidemics of AIDS, tuberculosis, malaria and neglected tropical diseases and combat hepatitis, water-borne diseases and other communicable diseases" (United Nations, 2016).

<sup>&</sup>lt;sup>7</sup> While widely accepted conceptually (see e.g Farmer (2004); WHO (2017)), policy and practice often do not address the upstream determinants of ill-health.

abstract categories with similar characteristics known or hypothesized to have significant explicit or implicit impacts on the question under discussion. Building on this, the term "local" is often used in contrast to "global" and refers to an administrative unit which is often assumed to include enough variation to have a significant effect on the implementation aspects of a health intervention or an outcome of interest. While this was the initial perspective taken by the research project (Localised Evidence and Decision-making – LEAD) from which Papers 2, 3, and 4 [Chapters 3, 4, and 5] emerged, the idea of "local" evolved to take on a more nuanced and context-specific meaning as the research progressed. That is, while the term "local" refers to "district-level", "community-level", and "researcher-level" at different times throughout this thesis, it is not defined as any or all of these in an absolute sense.

This system where interventions are largely developed outside of the areas of implementation threatens the domestic ownership of health problems and solutions, as health issues are prioritised through policy and implementation processes largely decided by "global" actors (Brugha, 2008; Gill & Benatar, 2016). There has been substantial research on the benefits and disadvantages of vertical and horizontal approaches to delivering health services and an increased call for funding the horizontal, integrated interventions<sup>8</sup>. However, the vast majority of resources in global health are directed to the top-down, disease-specific, vertical global health interventions (IHME, 2016b). While most of these strategies have indeed led to decreases in the burdens of diseases, the results are not evenly distributed, as substantial as projected, nor sustainable in a healthy way for the long-term. In addition, the unintended consequences of vertical interventions, such as the additional workload burdens on overstretched health workers (WHO/PEPFAR, 2009), have had negative impacts on already weak health systems.

#### 1.3.3 Global health actors

The definition of global health discussed above includes "transnational actors" participating in the global health system's governance, financial, and delivery arrangements to produce global health interventions. A systematic review and mapping exercise identified 203 global health actors, comprised of global and civil society organizations and non-governmental organizations (NGOs), professional associations, public-private partnerships, national governments, UN system and intergovernmental entities, private industry, academic institutions, philanthropic organizations, and multilateral development banks (Hoffman et al., 2015). A survey of global health experts identified the eighteen most important actors in terms of the primary arrangements in the global health system: leadership, stewardship, ensuring the provision of global public goods, managing externalities, and direct country assistance (Hoffman et al., 2015) (see Table 1-1). While the list of actors in Table 1-1 is not complete and based on expert opinion from 2015, the perceived power of global health actors is clearly centred on those based in the United States and Switzerland.

As discussed previously, the composition of actors in the global health system has undergone a profound evolution since the turn of the 21<sup>st</sup> century. Between 1998 and 2000, there were ten significant private actors or private-public partnerships involved in global health and by the mid-2000s, there were more than 100 (McGoey, 2015). While for most of its existence, global (or international) health was guided by the normative and formal functions of international and bilateral relationships, the contribution of greater resources to health-related programming gave private actors an increasingly important role in the system. Total funding for global health interventions has increased from approximately USD 7 billion in 1990 to over USD 36 billion in 2015, with an increase in proportionate contributions by corporations and private foundations from 8% in 1990 to an annual average of 22% since the year 2000<sup>9</sup>. While this

<sup>&</sup>lt;sup>8</sup> See Mills (1983) Msuya (2005), Atun et al. (2008) for reviews of the debates.

<sup>&</sup>lt;sup>9</sup> Calculated using data from IHME (2016a).

increase in financial resources is welcome, there are concerns regarding transparency and accountability to the recipient organizations, intended beneficiaries, and the entire system of providing assistance<sup>10</sup>. Despite the altruistic rhetoric, private philanthropies and corporations are only obliged to their executive boards, not to populations of people, national governments, or international organizations, and are able to prioritize, withdraw or withhold support at any time<sup>11</sup>. The apolitical narrative around the provision of assistance for health in developing countries has made the involvement and intentions of private entities difficult to challenge when their activities are presented as altruistic ventures. Examining the structures and implications of these new actors in global health is an emerging field of research to which this project contributes. In particular, Paper 1 [Chapter 2] develops a typology of global health actors which encompasses both the traditional and "new" actors and provides a comprehensive set of categories to be used as the basis for further analyses.

Name of actor	Acronym	Headquarters location
World Health Organization	WHO	Switzerland
Bill and Melinda Gates Foundation	BMGF	United States
The Global Fund to Fight AIDS, Tuberculosis and Malaria	GFATM	Switzerland
Médecins Sans Frontières	MSF	Switzerland
UN Children's Fund	UNICEF	United States
World Bank	WB	United States
Centers for Disease Control and Prevention	CDC	United States
Unitaid		Switzerland
National Institutes of Health	NIH	United States
Roll Back Malaria Partnership	RBM	Switzerland
Save the Children International		United Kingdom
US Agency for International Development	USAID	United States
Stop TB Partnership		Switzerland
UN Population Fund	UNFP	Switzerland
Food and Agricultural Organization of the UN	FAO	Italy
Partnership for Maternal, Newborn and Child Health		Switzerland
Program for Appropriate Technology in Health	PATH	United States
UN Development Programme	UNDP	United States

Table 1-1 Top 18 most important global health actors, ranked by a survey of global health experts, and location of headquarters

Note: Adapted from Hoffman et al. (2015)

#### 1.3.4 Evidence-based decision-making in global health

The governance, financial, and delivery arrangements which ultimately produce global health interventions depend on decisions made by global health actors. The belief is that best practice is to ensure decisions are "evidence-based" with policy and practice decisions focused on "what works." While many sectors saw the institutionalization of evidence-based policy and practice in the late 1990s<sup>12</sup>, evidence-based decision-making in population and now global health dates back to the mid-19<sup>th</sup> century (Sackett et al., 1996), with its origin in the movement for evidence-based medicine<sup>13</sup>. The preference for "systematic and methodologically rigorous clinical research, emphasizing the use of science and de-emphasizing the use of intuition, unsystematic clinical experience, patient and professional values, and patho-psychologic rationale" (Dobrow et al., 2004) in evidence-based medicine has led to intense debates over the years. Many argue that the interpretations of evidence and the development of evidence-based treatments and protocols

<sup>&</sup>lt;sup>10</sup> For example, the largest private contributor, the Bill and Melinda Gates Foundation, scored at 46% on the 2016 Aid Transparency Index (see http://ati.publishwhatyoufund.org/).

<sup>&</sup>lt;sup>11</sup> This concept has been discussed at length in the works of e.g. Bruen & Brugha (2014); Brugha (2008); Falkner (2011); Gill & Benatar (2016).

<sup>&</sup>lt;sup>12</sup> For example, the UK's government reforms after 1997 with the "commitment to policy-making based on hard evidence and, as in education, or NHS reforms, or fighting crime, we must always be looking at the outcomes of policies" (then-Prime Minister Tony Blair, as quoted in Davies (2012).)

<sup>&</sup>lt;sup>13</sup> See Head (2010); Oliver, Innvar, et al. (2014); Orton et al. (2011); Shelton (2014) for the history of evidence-based medicine and public health.

restrict physicians and the physician-patient relationship (Claridge & Fabian, 2005; Mykhalovskiy & Weir, 2004). By the mid-20<sup>st</sup> century, the demands placed on clinicians to follow strict evidence-based health guidelines inpatient treatment led to the argument that politicians and other policy-makers should likewise create evidence-based health policies for population-based practitioners to follow (Oliver, Innvar, et al., 2014; Peckham, 2012). This diffusion of evidence-based medicine to non-clinical policy settings brought the same conceptual and philosophical debates about the values associated with evidence interpretation and application, but with the additional political dimension by nature of its focus on populations and social processes instead of individual patients (Peckham, 2012).

#### 1.4 Cross-cutting concepts

Building on the definitions discussed in the previous section, next I describe the cross-cutting concepts from which the papers in this thesis emerged. Beginning with the disease problems health interventions are intended to address, the discourse surrounding states of ill-health have increasingly come to include complex biological, social, economic and political processes and systems<sup>14</sup>. While the theoretical discourse of single determinant has been displaced by that of multiplicity in cause, risk, and manifestation of disease, the older, linear models of cause and effect remain the dominant discourse in policy and practice<sup>15</sup>. Using this as a point of departure, this section reviews the literature on complex interventions to illustrate the challenges in understanding their progress and effectiveness. I then turn to a discussion of evidence-based policy and practice to understand how some aspects of decision-making and evidence utilization may restrict the ability to adequately and appropriately respond to the complex nature of global health problems.

#### 1.4.1 Examining complex interventions

Despite the remarkable progress, there are substantial challenges facing continued reduction in disease burden for populations across the world. As exemplified by the failure to achieve the Millennium Development Goals for health<sup>16</sup>, some argue that it is the piecemeal, compartmentalized promotion and implementation of global health policies and interventions that have catalysed the disappointing and unexpected results (Diez Roux, 2011; Homer & Hirsch, 2006; Sterman, 2006). In particular, it is contended that "conventional forms of problem framing, action planning, and evaluation often exclude or ignore those features of dynamic complexity that make public health challenges so formidable and public health responses so innovative" (Leischow & Milstein, 2006). This "conventional" approach is referring to the dominant reductionist model which has persisted in science and diffused across epistemological boundaries since the 17<sup>th</sup>-century works of Descartes (Best et al., 2003)<sup>17</sup>. In health sciences and evaluation, reductionism might be called the "classic" perspective, credited with precipitating various linear approaches to theories of change as well as the fixation on individual components (Adam & de Savigny, 2012). As humans continue to benefit enormously from classic approaches to hypothesis generation and testing in pharmaceutical trials, surgical procedures, etc., decision-makers focused on non-clinical settings require alternative, even complementary,

<sup>&</sup>lt;sup>14</sup> Refer to footnote 6.

<sup>&</sup>lt;sup>15</sup> The theoretical displacement is discussed in the works of Anderson et al. (2013); Craig et al. (2008); Plsek & Greenhalgh (2001).

<sup>&</sup>lt;sup>16</sup> See Galatsidas & Sheehy (2017) for details.

<sup>&</sup>lt;sup>17</sup> Reductionism relies on the core assumption that "phenomena are best understood by breaking them into parts and then studying the parts in terms of cause and effect" (Best et al., 2003).

approaches because while the "scientific method requires the ability to conduct controlled experiments, discriminate among rival hypotheses, and replicate results... Medical interventions and health policies are embedded in intricate networks of physical, biological, ecological, technical, economic, social, political, and other relationships" (Sterman, 2006). While acknowledging the necessity of the reductionist perspective in some contexts, it is the holistic approach to understanding the complexity of population-based global health interventions with which this thesis engages. Papers 2 and 3 [Papers 3 and 4], in particular, address this on a methodological level by using individual-based modelling approaches to accommodate these concepts.

Theoretical and applied research have systematically identified and categorized the sources of complexity in multilevel population-based interventions which are not captured by utilizing the reductionist perspective<sup>18</sup>. To begin with, the synergistic and antagonistic interactions between intervention components contribute to the unexpected effects outside of controlled environments (Adam & de Savigny, 2012; Lewin et al., 2017). For example, some mass deworming campaigns have several distinct, yet complementary services, such as Water, Sanitation, and Hygiene (WASH) or nutrition activities (Nikolay et al., 2015), which are linked together and will influence each other to produce a summative effect of the whole intervention which may be greater or less than that of the individual parts. Other sources of complexity include the adaptability and flexibility of the intervention in local contexts, where the implementation is not standardized, but takes on "different forms in different contexts, while [ideally] still conforming to specific, theory-driven processes" (Hawe et al., 2004). From another angle, the adaptivity of the local context itself and the evolution of various systems involved with an intervention, including the behaviours of the implementers and intended beneficiaries, contribute to dynamic longitudinal processes inherent in complex population-based interventions (Galea et al., 2010; Petticrew, 2015). These features configure nonlinear relationships, especially feedback loops and phase transitions (Galea et al., 2010; Petticrew et al., 2013), and are dependent on the classic ecologic models of transmission dynamics for infectious diseases<sup>19</sup>. Additional sources of complexity include differential moderating effects at individual and various cluster (e.g. population) levels, including those related to context (Hawe et al., 2004; Craig et al., 2008; Mills et al., 2008). It is important to remember that these features describing complex interventions are not divorced from classic reductionism, but rather a progression in perspective and approach (already dominant in the physical sciences) whereby theories of complex systems are built from intimate and specialized understandings of the parts.

Research that "produces generalizable knowledge about effective [intervention] delivery... and a better understanding of the 'determinants of performance,' i.e., the factors that lead to successful delivery of health interventions in a way that maximizes health outcomes" (Kruk et al., 2016) has been cited as the most urgent health priority facing global health. It is therefore vital that the features of complexity discussed above are incorporated into the planning, implementation, and evaluation of global health interventions. Given the availability of data and the technological and methodological advances, we are now in a position to synthesize this information in a way that is beneficial to global health policy-makers and practitioners. However, in order to present knowledge in a meaningful and impactful way, we must understand the ways in which policy and practice decisions are made and how knowledge is utilized in these processes. From a practical standpoint, Papers 2 and 3 [Chapter 3 and 4] propose that simply asking individuals the content and format of evidence needed for their decision-making processes presents an opportunity to address some of these deficiencies.

<sup>&</sup>lt;sup>18</sup> See Craig et al. (2008); Petticrew et al. (2013) for theoretical reviews on complexity in population health and Jones et al. (2006); Kaplan et al. (2002); Tengs et al. (2005) for a few examples of complexity identification in practice from diabetes, small pox, nicotine addiction, respectively.

<sup>&</sup>lt;sup>19</sup> See Earn et al. (2000) for a discussion of models of transmission dynamics, as they are referred to in this context, and Feng et al. (2002) for a specific example in the case of schistosomiasis.

#### 1.4.2 Evidence and decision-making for global health policy and practice

All of the papers in this thesis begin from the complexity perspective regarding the financing, governance and delivery of global health interventions, as described above. It is therefore imperative that we find ways to accommodate these complexities and uncertainties to maximise intervention efficacy and effectiveness. It is considered best practice to base policy and practice decisions on evidence, and then to evaluate their progress and feed this information back into the system (Davies, 2012). This is not only true in global health but has become an important feature of decision-making processes across fields and sectors. The papers in this thesis consider evidence and decision-making from the perspectives of health workers and policy-makers (Papers 2 and 3 [Chapters 3 and 4]), as well as the researchers involved in developing a specific type of evidence (Paper 4 [Chapter 5].) This section describes evidence-based policy and practice in global health, beginning with its theoretical underpinnings and followed by a discussion of its components, namely evidence and evidence utilization for decision-making.

Since the early 1970s, practitioners and academics have been concerned with the ways in which evidence could be incorporated into health policy and practice, creating a distinct field of interdisciplinary research on evidence-based policy and practice (Oliver, Lorenc, et al., 2014). The theoretical and empirical work can essentially be categorized into three groups (Innvaer et al., 2002; Oliver, Lorenc, et al., 2014): those focused on applied methods of "bridging the gap" between research and policy (e.g. Caplan (1979)), those focused on the models of research uptake by decision-makers (e.g. Weiss (1979)), and the more contemporary focus on knowledge translation or brokerage (e.g. Sabba (2007)). While different in their focus, there are several common threads and assumptions held within the field that have recently been challenged. Most work has employed the theory of two "camps," wherein the primary barrier to research utilization was identified as the cultural and institutional differences between researchers and decision-makers, also referred to as the "barriers and facilitators" approach (Oliver, Lorenc, et al., 2014). Over the past decade, some have disputed this simplistic notion of decision-making for health policy and practice by using case studies to demonstrate how epistemological, disciplinary and political boundaries can traverse professional differences (Jung & Nutley, 2008; Smith & Joyce, 2012). Theoretical approaches to policy-making as a contested arena of negotiation have also been introduced as another counter to the "two-camp" theory<sup>20</sup>, although have not been widely integrated due to a perceived lack of practical application (Lomas & Brown, 2009).

As a result of the dominant theoretical approach, the majority of research within the field was designed to increase evidence uptake, where "evidence" was referring almost exclusively to peer-reviewed research conducted by university-based academics and "uptake" assumed that the best decisions are made based on this type of work (Oliver, Lorenc, et al., 2014). This misses some key features of decision-making in policy and practice, where local data and practice guidelines have been shown to be the most utilized and valued pieces of information and academic research was considered lacking in relevance (Oliver & de Vocht, 2017). While the research on evidence-based decision-making in health policy and practice is nearly fifty years old, recent literature suggests that the field is on the cusp of a paradigm shift. It seems likely from the discourse coming from the new, prominent global health actors discussed earlier that interest and demand for theoretical and empirical work on evidence-based policy and practice will increase in the near term.

While a narrow notion of evidence is often deployed in research on evidence-based policy and planning, there exists a substantial literature on the nature of evidence and our

<sup>&</sup>lt;sup>20</sup> For example, see Sabatier & Weible (2014) on policy process "stages" and B. D. Jones & Baumgartner (2012) on theories of punctuated equilibrium and government information processing.

perceptions of evidence more broadly. In this literature, evidence is considered the "body of facts or information indicating whether a belief or proposition is true or valid" (Benmarhnia et al., 2017). Dobrow et al. (2004) have suggested that the notions of what constitutes evidence can be discussed as two basic orientations: the philosophical-normative and the practicaloperational. The notion of an objective reality and the ability for evidence to provide justification based in "truth" forms the basis of the philosophical-normative orientation toward evidence (Greenhalgh, 2014). This approach has been the one most often prioritized in the process of developing evidence-based policy and practice. Evidence is viewed as a sum of its structural components, such as validity and reliability, features which are "independent of its content or substance" (Schum, 1994). The focus is on the pursuit of the ideal evidence to justify a specific policy or recommendation and is thought of as unrelated to the context in which this pursuit has arisen. The scientific method and hypothesis-testing through experimentation beget the philosophical-normative orientation. In contrast, the practical-operational orientation suggests that "what constitutes evidence [is] context-based ... and evidence is defined less by its quality, and more by its relevance, applicability or generalizability to a specific context" (Dobrow 2004). The timing and context of policy development determine how evidence is defined as well as the prioritization of certain pieces or bodies of evidence (Hyder et al., 2011). Importantly, there is no veridical justification sought for decisions because evidence is "characterized by its emergent and provisional nature, being inevitably incomplete and inconclusive" (Dobrow 2004). Bringing these perspectives into this research project allows us to introduce insights from other disciplines into the work on decision-making in global health.

Given the complex nature of global health interventions, several bodies of evidence are needed to support the multi-layered theories of change. The philosophical-normative orientation positions randomized control trials (RCTs) atop the hierarchy of evidence for the strong fidelity to internal validity. The policy development body in global health, the World Health Organization (WHO), preferences meta-analyses of RCTs to inform the development of intervention guidelines (WHO, 2014). This type of context-deficient, hierarchical perspective restricts decision-makers. For example, a meta-analysis of the efficacy of current drugs for soiltransmitted helminth infections found differential cure rates across parasite types (Keiser & Utzinger, 2008). While this type of evidence is important and relevant because it informs the dosage recommendations for specific anthelminthic drugs, average treatment effects would be inappropriate for answering most other questions related to deworming interventions because they do not necessarily provide evidence of causation in complex systems, especially where substantial heterogeneity exists. Despite this, "[they] are seen as accurate, objective and largely independent of 'expert' knowledge that is often regarded as manipulable, politically biased, or otherwise suspect... [analysis and interpretation] is supposed to require no prior knowledge, whether suspect or not, which is seen as a great advantage" (Deaton & Cartwright, 2016). This can lead to the situation where "a local success is supplanted by the notion that unless it used the controls, randomization [, and achieved statistical validity]... it is of minimal usefulness" (Adams, 2013). From the practical-operational orientation, the most important evidence would inform on why a particular outcome school-based deworming was observed, not simply whether "it worked." This evidence might take the form of non-randomized, non-experimental studies to describe the context and provide information on the mechanisms activated by the intervention. Unfortunately, this type of evidence is often perceived as low-quality and is not frequently included in evidence synthesis or made available to decision-makers in a meaningful way.

Policy-makers and practitioners refer to the individuals engaged in the governance, financial, and delivery processes in global health. Decisions regarding these processes are nearly universally conducted under the credo of evidence-based decision-making. It has been demonstrated that identical evidence utilized by different decision-makers yields different outcomes, thus it cannot only be the nature of the evidence by which policy and practice decisions are made (Graham & Zelikow, 1999). Different outcomes arise from the intersection of evidence with the internal and external contexts of the decision-making processes (Dobrow 2004). Examining the utilization of evidence as a concept builds from the work on research utilization and knowledge transfer. and is based on the linear three-stage process model of decision-making first proposed by Rich (1997). The identification, interpretation, and application of evidence processes intersect with the goals and values of the decision-makers, organizational needs and preferences, knowledge and skill of the practitioners, and resource constraints to result in decisions about policy and practice (Gibbs, 2003; Littell, 2013; Sutcliffe & Court, 2005). As Head (2010) points out, "[decisions] in the real world are not deduced from empirical-analytical modes, but from politics and practical judgement." While these are important concepts, they adhere to the simplified theory of "two camps" discussed in a later section.

An important aspect of evidence utilization emerges from social research on power dynamics in the context of the perpetuation of policies and practices that have been shown ineffective at achieving the stated goals. Given the backgrounds of some involved in decisionmaking processes, physicians and epidemiologists, for instance, it can be difficult to reconcile the rhetoric and actions with the information available about an intervention's effectiveness. This was exemplified by Parker & Allen (2014) in relation to MDA interventions for deworming, who noted that "[just] as economic and political forces shape the way in which policy is formulated, so they also shape responses to data suggesting that the uptake of drugs falls short of the requisite levels to control [Neglected Tropical Diseases]. These responses take multiple forms, but collectively reveal an endeavour to set aside discomforting information[,] control the terms of the debate and marginalize critics." It has been suggested that this 'unknowing' can be instrumentalized, or more specifically "the multifaceted ways that ignorance can be harnessed as a resource, enabling knowledge to be deflected, obscured, concealed or magnified in a way that increases the scope of what remains unintelligible" (McGoey, 2012)<sup>21</sup>. These dynamics and processes are aided by the apolitical narrative surrounding global health interventions discussed previously, and fueled, in part, by the self-interest of global health actors<sup>22</sup>.

Next, I discuss the research frontiers regarding the needs of decision-makers who recommend and implement evidence-based policies and practices in reference to global health interventions. Much of the literature on this topic emerges from work on impact evaluations, which makes sense because this is a space where the work of researchers, policy-makers, and practitioners meet. Impact evaluations are "part of a broader agenda of evidence-based policy-making...[in which they] assess the changes in the well-being of individuals that can be attributed to a particular project, program, or policy" (World Bank et al., 2016). One view is that the evaluations provide accountability by determining whether projects, programs, and policies have achieved their desired outcomes, and at the global level, are central to building a knowledge base, or body of evidence, about a particular intervention (World Bank et al., 2016). The discussion on complex interventions (Section 3.1) is central to that of impact evaluations and the evidence needs of decision-makers in global health because it emphasizes the complexity of factors and processes that should be accounted for in any assessment of outcomes and impact.

In the context of finite resources, the allocation of these resources and the competition for funding can become urgent and contentious (Leviton, 2017). Practitioners of intervention

<sup>&</sup>lt;sup>21</sup> This is supported by Geissler (2013) who suggests that "'Unknowing' can be a significant dimension of scientific medical research: Those involved in advancing important scientific knowledge know certain aspects of the reality they work on and in and yet do not know, do not want to know, should not know, or actively unknow them by way of oversight, ignorance, discursive conventions, and alternative terminology."

<sup>&</sup>lt;sup>22</sup> These topics have been studied at length over the past two decades, by e.g. Easterly (2007), and in a broader context of foreign aid in general by, e.g. Collier (2008) and Sen (2001), and even by Jeffery Sachs, albeit through a different lens, who recently remarked that the "moral justification of aid, as powerful and adequate as it is, is matched by an equally important case of self-interest" (Sachs, 2017).

delivery need to understand how interventions would work in their own setting, policy-makers need to understand under which circumstances an intervention will maximize the benefit for the health of a population, and practitioners of finance arrangements need to understand elements of both with the additional caveat of maximizing an organization's resource output (Leviton, 2017). These needs can be formulated as three distinct causal questions about an intervention (Cartwright, 2011): does it work somewhere, does it work more generally (i.e. play a "wide enough" causal role), and will it work "here"? The first question is essentially about an intervention's efficacy. At present, the most accepted method to determine efficacy is through experimental study designs utilizing randomized control trials (RCTs). While, as discussed earlier, there are hypothesis-testing questions that are elucidated by RCTs or the synthesis of RCT results, for many global health interventions, RCTs are unethical or inappropriate in terms of time and resources. For example, the efficacy of MDA for deworming should be monitored for at least five years, given that this is the lower-bound estimate for transmission interruption to occur under ideal implementation conditions (Montresor et al., 2015)<sup>23</sup>.

Beyond the question of efficacy, policy-makers and practitioners need to consider the potential of interventions where variations in populations, setting, and treatments have not been studied directly (Cook et al., 2001). While sometimes referred to as external validity, this thesis takes the perspective that external validity is a relatively immature concept and that the term implies a binary state that is "often unhelpful [and] directs us toward simple extrapolation" (Deaton & Cartwright, 2016). This thesis develops on this perspective and suggests that the extension of results beyond the evaluation of a single study is dependent upon the question being asked of it. For example, Burchett et al. (2013) described the focus of implementation practitioners on "whether research conducted in one setting is applicable (i.e. implementable) and transferable (i.e. as effective)" in their own settings. In the same vein, Leviton (2017) described the needs of policy-makers as "uncertainty reduction" when risking "scarce public health resources." In other words, these are not decisions made in a vacuum of RCT results. Further, this perspective "frees external validity from some restrictions of inductive logic because it involves assessing the likelihood of effectiveness using a range of information, not just accumulation of definitive tests in a limited number of instances" (Leviton, 2017). Thus, we must ascertain how to best collect, analyse, and present evidence (or *knowledge*) that is fit for purpose when used by practitioners and policy-makers.

#### 1.5 Contexts and cases of this thesis

As described at the beginning of this introductory section, this thesis examines the interplay between the development of evidence for policy and practice with the dynamic relationships of actors and decision-making processes. Paper 1 [Chapter 2] is set at the macro-level of the global health system to examine the landscape of actors and to set the stage for the subsequent papers in this thesis. Thus the context for this paper at the system level considers global health as defined in Section 1.2.1 of this introduction. Papers 2, 3, and 4 [Chapters 3, 4, 5] are set within the context of neglected tropical diseases, with Papers 2 and 3 [Chapters 3 and 4] engaging specifically with schistosomiasis control measures in Uganda and Paper 4 [Chapter 5] engaging with the researchers who produce evidence underpinning a global health response to these diseases. Since these papers were published in relevant public health or medical journals, these audiences were assumed to possess some of this topical knowledge. Therefore, the remainder of this section provides some background beyond that which is included in the individual papers to better position the readers of this thesis.

<sup>&</sup>lt;sup>23</sup> In fact, most MDA RCTs do not last longer than 18 months and many last less than one year (Clarke et al., 2017), and it is therefore unsurprising that transmission interruption is not reported.

Neglected tropical diseases (NTDs) have been designated as a target for "global action" in the Sustainable Development Goals (Engels, 2016; United Nations, 2016). NTDs are a group of twenty conditions<sup>24</sup> that are prevalent in tropical climates and disproportionately impact impoverished communities (WHO, 2022). It is estimated that most of the world's population experiencing extreme poverty (living on less than \$1.90 per day) are living with at least one NTD infection (Molyneux et al., 2021). As such, NTD is not a medical or biological classification but rather a term which has its origins in the late 1970s, used to describe a network of laboratories supported by the Rockefeller Foundation. Scientists in this network applied molecular biology and immunology knowledge and methods to the study of the diseases of the poor, or the 'great neglected diseases (GND) of mankind' (Keating, 2014; Molyneux et al., 2021). In more recent times, the neglect of these conditions has more often been attributed to policy makers and donor organisations (Molyneux et al., 2005) than the research scientists. Yet to this day, the impacts of these diseases remain widespread and devastating. It is estimated that together the NTDs contribute 1% of the total disease burden experienced globally, or approximately 19 million disability-adjusted life years<sup>25</sup> (WHO, 2020b).

At present, seven of these NTDs have been designated by the WHO to be controlled or eliminated through the mass administration of pharmaceuticals, without individual diagnostic testing, to individuals living in areas of high risk or prevalence (WHO/NTD, 2017). This intervention is called mass drug administration (MDA), or preventative chemotherapy, and is considered a "global health intervention" because it was largely devised and often implemented by entities not originating in endemic areas. In addition, MDA is primarily governed (at the macro level) and funded through multilateral arrangements between global-level actors. Schistosomiasis is among the most prevalent of NTDs and is targeted for control using the drug praziquantel, with a prioritization of targeted MDA in schools (WHO/NTD, 2017). Schistosomiasis in Uganda, and the interplay of this "global health intervention" with locallyderived solutions for its control and elimination, is the focus of Paper 2 and Paper 3 [Chapter 3 and Chapter 4]. MDA for multiple NTDs is the focus of Paper 4 [Chapter 5] and is also discussed in brief in Paper 2 and Paper 3 [Chapter 3 and Chapter 4]. The remainder of this section proceeds as follows. First, I present background details about schistosomiasis and mass drug administration. I then present pertinent context related to the history and socioeconomic context of Uganda, including details regarding its health system and health policy structure. I then briefly describe the history and context of schistosomiasis control in Uganda, including the roles of global health actors in the funding, implementation and evaluation of control initiatives.

#### 1.5.1 Schistosomiasis

Schistosomiasis is the focus of Paper 2 and Paper 3 [Chapter 3 and Chapter 4]. It is a disease caused by parasitic worms in both acute and chronic manifestations. Haematuria, the bloody urine associated with *Schistosoma haematobium* infection, has been described in humans since ancient times. In fact, haematuria was thought to indicate a special relationship with the god Zeth (Ziskind, 2009). *S. haematobium* eggs were discovered in two Egyptian mummies dating from 1250 BC to 1000 BC (Ruffer, 1910). There is also evidence of circulating schistosome antigen present in mummies (Deelder et al., 1990; Miller et al., 1992). While this provides

<sup>&</sup>lt;sup>24</sup> This diverse set of conditions includes: Buruli ulcer, Chagas disease, dengue and chikungunya, dracunculiasis (Guinea-worm disease), echinococcosis, foodborne trematodiases, human African trypanosomiasis (sleeping sickness), leishmaniasis, leprosy (Hansen's disease), lymphatic filariasis, mycetoma, chromoblastomycosis and other deep mycoses, onchocerciasis (river blindness), rabies, scabies and other ectoparasitoses, schistosomiasis, soil-transmitted helminthiases, snakebite envenoming, taeniasis/cysticercosis, trachoma, and yaws and other endemic treponematoses (WHO, 2022).

<sup>&</sup>lt;sup>25</sup> Disability adjusted life year (DALY) = The sum of years of potential life lost due to premature mortality and the years of productive life lost due to disability (WHO, 2017a)

evidence of the presence of schistosomiasis for thousands of years, its recognition as a disease problem in the earliest medical literature is less clear, as the interpretation of written accounts of the disease in the medical papyri and hieroglyphs of that era remain contested (Cox, 2002). The first definitive account of schistosomiasis in the modern era is considered by some to be that of an epidemic amongst Napoleon Bonaparte's army in Egypt in 1798 in which "a most stubborn haematuria manifested itself amongst the soldiers of the French army... continual and very abundant sweats diminished quantity of urine...becoming thick and bloody" (Cox, 2002). The relationship between *S. haematobium* worms and the disease was described by Theodore Bilharz and Wilhelm Griesinger in 1851-1852 in Cairo. Later on, in 1915 Robert Leiper described the complete life cycle and established *S. mansoni* was a separate species. During this same time period, *S. japonicum* was described in horses, cattle, and humans by Japanese physicians (Cox, 2002).

In terms of transmission, people are infected when *Schistosoma* parasites penetrate the skin during contact with infested waters (Figure 1-1); this can frequently occur where routine social, economic, and hygiene activities are based around fresh water sources. These are very time- and place-specific considerations that are difficult to generalise and respond to with large-scale, rigid global health interventions designed through vertical implementation strategies. For example, Figure 1-1 was co-created with researchers and practitioners in an area of northern Uganda for use with adult male fisherfolk and ultimately drawn by a Ugandan artist who spent time in the area observing the health officers and community members in their daily activities<sup>26</sup>. The figure depicts the daily activities of the target population which contribute to the cycle of transmission, being conducted by individuals along a shoreline explicitly drawn to resemble the place- and time-specific communities where this tool would be employed. Most depictions of the *Schistosoma* life cycle are not placed within the contexts of human activities or the natural habitats, which makes them less effective for public health education and behaviour change efforts.

However, while useful for the purposes it was intended, there are important missing dimensions of schistosomiasis transmission in Figure 1-1. For example, environmentally drawn water transported to other locations for hygiene activities or the roles of preschool-aged children and livestock are recognised as key contributors to the continuation of community transmission (Standley et al., 2012; Stothard et al., 2011; Stothard, Campbell, et al., 2017). In particular, potential untreated reservoirs limit the effectiveness of MDA activities in sustained decreases in schistosomiasis prevalence levels, these include inputs from zoonotic sources, very young children, adolescents, and adults, including pregnant women (Lo et al., 2022; WHO, 2022).

<sup>&</sup>lt;sup>26</sup> For more information on the process, see (WHO, 2017a) (accessed 3 June 2022)

29/12/2021 Eigure 1-1Schistosoma life cycle



-life-cycle.ipg (1415×10

Note: This figure was developed by the Visual Arts - Localised Evidence and Decision-making (LEAD) Project, https://www.astatesconsediguesconsediguesconsediguesconsediguesconsediguesconsediguesconsediguesconsediguesconsediguesconsediguesconsed 29 December 2021)

The main forms of schistosomiasis are urogenital and intestinal, caused by five *Schistosoma* species. The papers in this thesis primarily engage with schistosomiasis caused by *S. haematobium* (associated with urogenital manifestations) and *S. mansoni* (associated with intestinal manifestations), which are the main causes of the disease in Africa. The symptoms of schistosomiasis are the results of reactions to the eggs, which are laid in our blood vessels after the worm matures in the human body. Symptoms include abdominal pain, diarrhoea, bloody stool and urine, and enlargement of the spleen or liver. Anaemia is especially prevalent in children with schistosomiasis and causes considerable morbidity and other related impacts. The populations most impacted by the burden of schistosomiasis are those living in rural locations in Asia and Africa, where it is estimated that 90% of the burden lies<sup>27</sup>.

#### 1.5.2 Mass drug administration

Mass drug administration as a global health intervention is the focus of one paper in this thesis, Paper 4 [Chapter 5], and also included in Paper 2 [Chapter 3] and Paper 3 [Chapter 4] in the context of schistosomiasis control measures. This section details the nature by which mass drug administration is considered representative of "global health interventions" as described previously in Section 1.2.2.

Mass drug administration (MDA) for select NTDs represents a high-priority, evidencebased global health intervention directed by networks of global actors engaged in the governance, financial, and delivery arrangements to facilitate its continued implementation. The first NTD control programme defined by these global-level, polylateral arrangements was

<sup>&</sup>lt;sup>27</sup> <u>https://www.who.int/news-room/fact-sheets/detail/schistosomiasis</u> (accessed 29 December 2021)

onchocerciasis by the creation of the World Bank's first health initiative in 1974, the Onchocerciasis Control Program (OCP) (World Bank, 2014). After a decade of vector control initiatives, a paradigm shift for the OCP occurred and laid the groundwork for what would come to define NTD control for subsequent decades. The multinational pharmaceutical company Merck & Co committed to donating as much of the onchocerciasis drug, ivermectin, as needed for as long as it takes to reach elimination (Molyneux, 1995; Molyneux et al., 2021). This model of free or subsidised NTD drugs from pharmaceutical companies, delivered by NGOs and governments health systems through MDA programmes, which are in turn governed by global or regional bodies, was adapted to the contexts of lymphatic filariasis, trachoma, soil-transmitted helminths, and schistosomiasis in the 1990s and early 2000s (Webster et al., 2014; World Bank, 2014).

Prior to this contemporary form of polylateral global arrangements for MDA, interventions aimed at the mass treatment of helminthiasis had been implemented across the world for at least a century (Ettling, 1981). It is often cited that the first mass anthelminthic treatment campaigns were implemented by the Rockefeller Foundation's Sanitation Commissions in the early 1900s to eliminate hookworm from the poverty-stricken populations of the southern United States (Anderson 2002 mimicry, Ferrel 1914). Intestinal worms were called "the germ of laziness" infecting the poor populations and described as the upstream cause of their poverty - even though poor nutrition and living conditions were far greater adversaries of a productive life (Kunitz, 1988). As with today's MDA strategies, the target populations for these campaigns were geographically varied, often focused on key groups, such as factory workers or school children. In contrast, however, all individuals were confirmed with infections prior to treatment (Ettling, 1981). Despite substantial financial investment over a decade, the intervention did not eliminate hookworm but was responsible for a substantial number of deaths attributable to the ingestion of the toxic drug used against hookworm at the time (Humphreys, 2009). The US-based programme was disbanded, but the Rockefeller Foundation's efforts against hookworm were continued through similar programmes across the Caribbean, South America, and Asia (Brown, 1976; Kavadi, 2016). Thus from the early 20th century, there was a precedent for non-governmental organisations and private entities to engage with the governance, financial, and delivery arrangements to control and eliminate helminth infections.

The concept of using MDA, that is, mass treatment without individual diagnosis, for widespread helminthiasis burden reduction emerged following the development of new drugs, advances in ecological theories of transmission, and implementation successes seen across Asia (Crompton, 2000; Molyneux et al., 2021; Webster et al., 2014). The international governing body on health policy, the World Health Assembly (WHA), explicitly linked schistosomiasis and soil-transmitted helminth control when Resolution WHA 54.19 was adopted in 2001 (WHO, 2001). The resolution called for the establishment of control programmes in countries endemic for schistosomiasis and soil-transmitted helminths and focused on targeted MDA to school-age children. In addition to the health benefits, burden reduction through MDA was presented as the most cost-effective 'magic bullet' to ''rescue the bottom billion (Hotez et al., 2009),'' sentiments which echoed the earlier policy links between helminthiasis and lack of economic productivity. Donors, policy-makers, and practitioners began to pursue MDA for these diseases with enthusiasm, turning the global effort into the ''largest public health program ever attempted'' (Bundy et al., 2017; ONE, 2009).

Following the public prioritisation of schistosomiasis and soil-transmitted helminths by the WHA, the Schistosomiasis Control Initiative (SCI) was founded by Professor Alan Fenwick OBE at Imperial College with support from the Bill and Melinda Gates Foundation, in what were amongst their first large-scale investments in global health interventions (Fenwick et al., 2009, 2021). SCI began managing the governance, financial, and delivery arrangements of MDA for schistosomiasis, as well as integrated MDA with soil-transmitted helminths, across several countries in Africa (Fenwick et al., 2021; Molyneux et al., 2021). These efforts were bolstered by the donations of deworming tablets by Johnson & Johnson, GlaxoSmithKline, and MerckKGaA (Molyneux et al., 2021). Thus the coalition of stakeholders in MDA programmes for schistosomiasis has diversified since the early 2000s, most substantially by the involvement of the private sector and MDA-focused civil society organisations, mirroring the rapid proliferation of specialist NGOs seen across the global health landscape. As described, MDA can be seen as developed and driven by actors outside of the areas of disease prevalence and programme implementation. Paper 2 [Chapter 3] in this thesis provides insights as to the degree to which MDA may be considered a priority intervention when the perspectives of public health practitioners in Uganda are explicitly included in the modelling of intervention effectiveness.

In terms of global-level policy, in the more than twenty years following the 2001 WHA Resolution, there have been three technical manuals and two roadmaps toward elimination (Lo et al., 2022). The London Declaration on Neglected Tropical Diseases in 2012 was a seminal event, where a global agreement to donate the drugs for MDA, including for schistosomiasis, was reached between private, civil society organisations, and public sector entities (Uniting to Combat NTDs, 2012). Most recently, the 2022 WHO guidelines for schistosomiasis were published<sup>28</sup>. These guidelines acknowledged many of the previous criticisms, most importantly those related to the treatment inequities for preschool-aged children. While the guidelines created the space for addressing these issues through stating directives and recommendations, the document did not necessarily provide substantive or specific pathways to alleviate many of the concerns.

Despite all of these efforts, the success of achieving widespread reductions in schistosomiasis burden and the success of MDA programmes as a whole to date are contested. Success is determined by its definition and differing conclusions have been reached even when the same evidence is considered. As a starting point, there is consensus that the deworming medication for schistosomiasis, praziquantel, is relatively safe and effective when used in accordance with its guidelines (WHO, 2022). The potential for treatment success is considered relatively high at the individual level. When the mode of treatment delivery and population prevalence are considered, empirical evidence from countries where schistosomiasis elimination occurred have included multi-faceted, multi-sectoral efforts - results not achieved through MDA alone (Bergquist et al., 2017; Rollinson et al., 2013; Tanaka & Tsuji, 1997). In addition, metaanalyses have shown that MDA campaigns targeting schistosomiasis are largely ineffective at improving child health outcomes (Taylor-Robinson & Garner, 2017; Welch et al., 2017). These results are supported by modelling studies that have shown the current recommendations for MDA implementation are not predicted to achieve the WHO targets of morbidity control or elimination as a public health problem within the specified timelines (Li et al., 2019; Toor et al., 2018).

Cost-effectiveness analyses have long been at the forefront of evidence supporting the implementation of MDA. In the early 2000s, it was argued that the delivery of donated deworming tablets through "aggressive regional vertical interventions" and managed by public-private partnerships could eliminate disease burden and lift populations out of poverty – all without the costs of long-term diagnostic capacity or engagement with the wider health sectors that were associated with HIV, TB, and malaria control (Allen & Parker, 2011a; Molyneux et al., 2005). Integrating NTDs through MDA was considered to be a "pro-poor" policy linked with both improving human rights and increasing economic activity (Hotez et al., 2006). These perspectives were bolstered by cost-effectiveness and long-term productivity analyses from a series of high-profile studies in Kenya, which indicated that significant gains have been achieved amongst individuals who attended schools where MDA had been implemented<sup>29</sup>. However, some have contested the data collection, analysis, and interpretations of these studies. A re-

<sup>&</sup>lt;sup>28</sup> See Lo et al. (2022); WHO (2022)

<sup>&</sup>lt;sup>29</sup> See for examples Baird et al. (2016); Kremer & Miguel (2007); Miguel & Kremer (2004)

analysis of the data from a group of epidemiologists ignited a contentious debate which came to be known as the "Worm Wars."<sup>30</sup> As with evidence use for determining success of public health programmes generally, ultimately, the interpretation of the evidence is up to the users' aims and objectives. The crux of cost-effectiveness for MDA for any of the NTDs lies in its use of "volunteers", usually assumed to be community health workers or teachers, for intervention implementation and donated ("free") tablets. Paper 3 [Chapter 4] in this thesis engages with these aspects of 'cost-effectiveness' in the context of MDA for schistosomiasis in Uganda. This paper provides an analytical critique of the standard components that have historically been used to measure cost-effectiveness for schistosomiasis interventions in Uganda and more generally.

#### 1.5.3 The Ugandan context

Schistosomiasis in Uganda is the focus of two papers in this thesis, Paper 2 and Paper 3 [Chapter 3 and Chapter 4]. This section provides an overview of the Ugandan context, including its relevant history, socioeconomic and demographic situations, and health system and health policy structure. It ends with an overview of schistosomiasis control in Uganda. While the context of Uganda is important, it is also necessary to acknowledge the country-specific facets of schistosomiasis control and elimination activities are outcomes of the dynamics and interests of the global actors and contexts related to MDA described above. This thesis engages with this global, non-country-specific, space in the other two papers of the thesis, Paper 1 and Paper 4 [Chapter 2 and Chapter 5].

Much of Uganda's recent history was shaped by its water bodies. While geographically considered a landlocked country in East Africa, Uganda shares at least one major water resource with its border-contiguous neighbours, Kenya, South Sudan, the Democratic Republic of the Congo, Rwanda, and Tanzania. These water bodies constitute Uganda's designation as a country in the African Great Lakes Region and lie almost entirely within the Nile river basin. The largest of these are Lake Victoria in the south and Lake Albert in the northwest of the country. The Protectorate of Uganda was initially formed when the United Kingdom combined territories to further its commercial interests in protecting water trade routes in the late 19th century. Since Uganda's independence from the United Kingdom in 1962, the country has experienced several phases of social, political and economic strife and growth. In recent years, the World Bank has classified Uganda as a low- and middle-income country and a heavily indebted poor country (World Bank, 2022). While fish is its fourth-largest export, the local relationships with water include all aspects of the social, economic, and individual- and community-level health facets of personal life (UNECE, 2022). Thus, given its transmission cycle discussed above, the prevalence and transmission of schistosomiasis, as well as its control and elimination, are components of the larger complex system of geography, politics, and history of Uganda.

Along these lines, another aspect of contextual consideration for schistosomiasis and its control in Uganda is the country's health system and health policy structures. Health services in Uganda are provided through the private and public sectors. The private sector consists of non-profit organisations, mainly based within religious NGOs, for-profit providers, and traditional or complementary medicine practitioners (Baine & Kasangaki, 2014, p. 201; Musoke et al., 2020). The public sector is organized as a hierarchical structure from health centres to general hospitals at the district level then up to a network of regional- and national-level referral hospitals (Ministry of Health, 2013). Governance of the public health sector is primarily centred on district-level administration and service delivery. Uganda's adoption of the District Health System structure was formed largely through devolution in the late 1990s (WHO, 1987). This structural strategy, which places decision-making at the district level, was endorsed at the WHO's "Health for All" conference in 1987 as a way to achieve more equitable health care access by

<sup>&</sup>lt;sup>30</sup> See Belluz (2015); Evans (2015) for anthologies of the discourse through various mediums.

localised, adaptive approaches to intervention and service delivery (Henriksson et al., 2017). In a similar vein, Uganda adopted the Community Health Worker programme in 2001, which was a formalised system of village health teams (VHTs), comprised of volunteers with a basic training in relevant health issues mandated with implementing community-based interventions, including some MDA implementation (Musoke et al., 2020).

In the public health sector, the responsibilities for schistosomiasis control and elimination activities are situated under the Vector Control Division (VCD) within the Ministry of Health, which operates along the same hierarchical lines as described above. The VCD was established in the early 1920s. Initially focused on urban malaria transmission, where nonimmune colonial officers and labourers were most often located, the success of early initiatives resulted in a roll-out of coverage across the protectorate and an expansion of the VCD mandate to include additional infectious diseases, including human trypanosomiasis, onchocerciasis, and schistosomiasis (Dunne et al., 2006; Uganda Vector Control Division, 2015). The VCD fell into near-collapse during military rule in the 1970s and was not rehabilitated again until the early 1990s, with the aid of a loan from the African Development Bank (Dunne et al., 2006; Kolaczinski et al., 2007). The VCD began working in bilateral partnerships and engaging with non-governmental entities to build capacity in implementation research, including relationships of particular importance with regard to schistosomiasis, such as with the Kenyan Ministry of Health, the Kenyan Medical Research Institute (KEMRI), and the Danish Bilharziasis Laboratory (Dunne et al., 2006). The first iteration of what is now the VCD's National Bilharziasis and Worm Control Programme (NBCP) was established in the mid-1990s. With the assistance of their partners, mapping exercises confirmed that schistosomiasis was still a problem in areas where it was previously described during the protectorate era (Kabatereine, Tukahebwa, et al., 2006).

In 2003, Uganda became the first African implementation partner of the Bill and Melinda Gates Foundation-backed SCI (Dunne et al., 2006), the organisation founded by Professor Fenwick discussed in Section 1.4.2 above. As with the VCD, the programme of annual MDA to select districts and sub-districts was managed at the central level with implementation decisions at the district level (Kolaczinski et al., 2007). SCI supported the NBCP with school-based MDA, delivered by teachers, and community-based MDA, delivered by community drug distributors (CDDs) (Kabatereine, Fleming, et al., 2006). This partnership also spurred regular data collection with annual surveys and other activities to monitor and evaluate progress (Fleming et al., 2009; Kabatereine et al., 2007; Stothard, Kabatereine, et al., 2017). The programme was initially hailed as a success by many as initial decreases in prevalence rates were reported (Kabatereine et al., 2007), and SCI and the Bill and Melinda Gates Foundation continued to expand their MDA implementation efforts while fostering a network of partnerships with endemic countries and NGOs.

Many communities in Uganda were accustomed to mass disease control initiatives, as mass treatment campaigns had been previously implemented, including those targeting trypanosomiasis in the 1980s and widespread child immunization campaigns (Parker & Allen, 2011). As the annual campaigns went on, critiques arose regarding the overall effectiveness of MDA. There were indications that the decreases in prevalence waning, in some cases due to inadequate treatment frequency, non-adherence of the target populations, and the lack of treatment for preschool age children (Stothard et al., 2011). Others had begun to raise ethics concerns, especially around treating children without parental consent (Allen & Parker, 2011b). There were reports of community members objecting to MDA participation for themselves and the school children in areas of implementation in Uganda and elsewhere (Hastings, 2016; Muhumuza et al., 2015; Parker et al., 2008). Over half of Uganda's population is estimated to be at risk of schistosomiasis, as it continues to be ubiquitous among rural lakeshore communities in Uganda (ESPEN, 2021; Loewenberg, 2014) - this is after more than two decades of MDA implementation. This thesis engages with the process of evidence development which support the design and implementation of control programmes to shift the dynamics in ways which improve where, when, and how interventions are delivered.

#### 1.5.4 Summary of the contexts and cases

To present different scales of context, the papers engage with multiple facets of the global health system, specifically with the macro-level actor landscape (Paper 1 [Chapter 2]), the country- and disease-specific practitioner perspective (Paper 2 and Paper 3 [Chapter 3 and Chapter 4]), and at the global health intervention level (Paper 4 [Chapter 5]). In addition, the cases used for each of these scales of context represent different aspects of the financial, governance, and delivery arrangements which comprise the global health system. In Paper 1 [Chapter 2], transactions of development assistance financing for health are used as the case for the macro-level landscape. In Paper 2 and Paper 3 [Chapter 3 and Chapter 4], practitioners and policy-makers involved with schistosomiasis control and elimination activities in Uganda represent the country- and disease-specific practitioner perspective. In Paper 4 [Chapter 5], primary researchers of mass drug administration form the unit of analysis for the global health intervention perspective.

In Papers 2 and 3 [Chapters 3 and 4], schistosomiasis in the context of Uganda is used as a case to examine the development and use of evidence for decision-making. Schistosomiasis was first reported in Uganda in 1902 (Emmanuel & Ekkehard, 2008), and its impacts on economic activities in the country have been well-documented (Turner et al., 2015). The impact and uptake of disease control efforts for schistosomiasis and other NTDs have long been linked with the political and social policies in place at a given time and place (Parker & Allen, 2011). Given these factors, Uganda represents an important context in which to examine the concepts developed in the two papers. While the results of these papers are Uganda-specific, the flexibility of methods and application of concepts can be transferred to other contexts. In addition, Uganda represents a particular type of actor in the global health system, which is not only the recipient of donor funding to finance aspects of its health system, but also the recipient of interventions and evidence to support implementation strategies in ways that do not facilitate sustainability or autonomous decision-making.

Since the time of the Rockefeller Foundation's Sanitation Commissions, helminth infections have been linked with poverty and unproductive economic outcomes. These "germs of laziness" were deemed the impediments to economic productivity, most often without acknowledging the significant influence of factors such as poor nutrition and unhygienic living conditions, which are also widely-used indicators related to development (Kunitz, 1988). This notion persists as NTD control is rhetorically and politically linked to poverty reduction. Many in the NTD community have promoted MDA as the cheapest, easiest solution to eliminate poverty<sup>31</sup>, keeping it on the agenda for policy-makers and practitioners in the global health system. The most recent versions of MDA for schistosomiasis have been supported by evidence around their cost effectiveness for over twenty years. Paper 3 [Chapter 4] examines the degree to which MDA can be considered cost effective, and how the low costs used as advocacy tools are maintained by the use of volunteers in the areas of implementation. The goals of elimination of as a public health problem and transmission interruption have not been realised during any of the target time periods and are not on track to be achieved by the end of the current time period in 2030 (WHO, 2020a). In addition to the cost-effectiveness studies, published primary research papers on MDA are often cited as the evidence base for guidance related to implementation decisions. Paper 4 [Chapter 5] examines the publication network of authors and their relationships with the financing, governance, and delivery arrangements related to MDA at the global and country levels.

<sup>&</sup>lt;sup>31</sup> For examples see Engels (2017); Mistry (2012); Reuters (2017); The Economist (2017)

#### 1.6 Methodological approaches

As a starting point, I view methods as tools which should be employed based on their suitability to answer the questions at hand. The ultimate choice of method is based on a number of other factors, including the purpose, intended audience or beneficiary, data availability, and financial resources. I think innovation and advances in computational power and availability of technologies are important to answering questions posed in the social sciences, but I do not think that these need to be employed in response to every research question. My research background primarily consists of quantitative work related to disease burden estimation and intervention effectiveness, from the monitoring of individual intervention implementation activities through the evaluation of large scale global-level initiatives. This is the particular space that I challenge through the papers of this thesis. While there are other fields, such as health policy and systems research, that use social science methods that are not reductionist or linear, these methods are often preferenced in the measurement and evaluation of health interventions. As discussed at the beginning of the introduction to this thesis, the expected gains in health improvements have not been realised, and the current global goals for health are not predicted to be achieved within the specified time frames. One reason for this is that while many acknowledge that complexity exists -- that the financial, governance, and delivery arrangements in global health are not simple, linear processes -- the analytical frameworks used in global health research rarely incorporate the concept in explicit and meaningful ways. The methodological approaches in this thesis emerged from this background and address the gaps in accommodating complexity into this specific type of research on the financial, governance, and delivery arrangements in global health.

Complexity in this context refers to the multi-level, dynamic, non-linear processes which underpin specific types of evidence and decision-making in global health. Strategies and methods to analyse complex systems have become increasingly accessible with the growing availability of computing power and technologies. The speed and capacity with which large amounts of data can be analysed and interpretated in coherent and meaningful ways has transformed transdisciplinary efforts to apply complex systems approaches to understanding physical, biological and social systems (Bar-Yam, 2018). Methodological approaches to dealing with complexity directly address the issues encountered by applying the linear, reductionist approaches to analysing the financial, governance, and delivery arrangements in global health, as described in Section 1.3.1. Broadly speaking, these methods allow for the observation of collective behaviours or patterns which emerge from the actions and relationships of smaller components in a system (Mitchell, 2006). To manage the multi-level, non-linear, dynamic processes, these are data and computationally intensive activities. However, as demonstrated in this thesis, the methods are flexible and widely applicable as data collection and analytical tools. The remainder of this section provides an overview of the complex systems approaches used in this thesis, network analysis and individual-based modelling, with more in-depth descriptions of their applications in each of the papers.

#### 1.6.1 Network analysis

The connectivity, accessibility or relatedness of components in a complex system can be described in terms of their network properties (Bar-Yam, 2018). In their most basic form, networks are defined by topographical information about nodes and their links to other nodes (Bar-Yam, 2016). Network analysis allows for specific characteristics of a given node and their relationships to be described and analysed in relation to the network as a whole by explicitly defining them as components of the same system. Research on social networks, i.e. how individuals are connected in various ways that result in patterns and collective system-level behaviours, has been an important component of the social sciences, particularly in

anthropology, sociology, and psychology, since the early 1930s (Lazer, 2011). While the mathematical study of networks grew out of graph theory in the late 19<sup>th</sup> century, the theoretical nature of the work was not readily applicable to 'real world' observations (Mitchell, 2006). The study of networks and their applications grew rapidly in the 1990s and early 2000s in two relatively distinct forms, both addressing different conceptual barriers to the more widespread use of network analytics: one as used by economists and political scientists and the other by physicists and others working in the physical sciences. More recently, the conceptual and analytical frameworks to examining networks from the perspectives of the social and physical sciences have begun to converge. This thesis exists in this convergent space, using innovative applications derived from aspects of both social networks and graph theory to provide insights to research questions related to financial, governance, and delivery arrangements in global health. In this context, network approaches are used as both data collection and analytical tools.

Paper 1 [Chapter 2] investigates the relationships and dynamics of actors that make up the global health landscape. In this analysis, actors are represented by nodes and the relationships between them are represented by links, or edges between the nodes. The metrics of this network analysis relate the relative positionality of an individual actor to others in a given network as well as that network's overall structure. The importance of analysing power in global health has been widely discussed, with such analyses most often conducted through observational methods (Sriram et al., 2018). While network approaches have been described as an appropriate methodology to examine aspects of power in global health due to their capacity to capture the relationships between individual units and emergent system-level phenomena, the application has been relatively uncommon. This is potentially due to the data intensive nature of the method (Sriram et al., 2018). Paper 1[Chapter 2] addresses this gap by empirically examining power derived from financial arrangements in global health, as observed through measures of network centrality to describe how connected (or 'important') individual nodes are.

Papers 2 and 3 [Chapters 3 and 4] both utilise network approaches for data collection and analysis related to the governance and delivery of global health interventions. In these analyses, participatory modelling was used to generate shared conceptual depictions of schistosomiasis transmission and control activities by individuals at different levels of the health system and epidemiological contexts in Uganda. Recent methodological iterations of participatory modelling were built on the prominent work on poverty reduction and development led by the World Bank and research, such as Robert Chamber's work on Participatory Rural Appraisal, through the late 20th century (Chambers, 2006). The research in this thesis uses an approach called Participatory Systems Mapping (PSM), a process of data collection which ends with a 'systems map', a diagram of explicitly defined causally-linked factors, which visually depicts a defined 'system' from the perspective of participating discussants (Barbrook-Johnson & Penn, 2021). Examples of similar outputs include causal loop diagrams and stock-and-flow diagrams. In this context, the nodes represent factors directly or indirectly related to schistosomiasis transmission and the edges or links represent the perceived causal relationships between the factors. Depending on the aims and context, computational modelling and simulations can be informed by 'real world' information vis-a-vis these systems maps, which can be integrated as "formalized and shared representations of reality" (Voinov et al., 2018). For the purposes of this thesis, the systems maps were aggregated using graph theory, the result of which then framed the content of subsequent computational simulations and explicitly informed model parameter specifications, as discussed in the following Section 1.5.2. This innovative analytical approach linked the traditionally more observational, participatory modelling with the computationally-intensive simulations to produce evidence to support schistosomiasis control activities.

Paper 4 [Chapter 5] also uses a network approach to data collection and analysis. A systematic literature search was used to define the network of authors who had published primary research on mass drug administration (MDA), the primary recommended intervention

for schistosomiasis and other NTDs. This network formed the basis of the sampling frame for a survey of researchers on their perceived roles and engagement with the financial, governance, and delivery arrangements in global health. Author characteristics, such as affiliation type, location, research field, and relative position in the author list, were extracted and used to disaggregate the survey responses. While often cited as important contributors to the evidence base for decision-making regarding the design of MDA policy and delivery, this network of researchers has not been previously studied using this combination of bibliographic analysis and survey.

### 1.6.2 Individual-based modelling

As discussed above, Papers 2 and 3 [Chapters 3 and 4] rely on the use of individual-based modelling simulations to observe the impact of interventions on schistosomiasis prevalence. Individual based modelling (also called agent-based modelling, ABM) is a computational modelling approach in which system level emergent phenomena (for example, disease prevalence) can be observed through explicit modelling of individual (agent) level behaviors and their interactions with each other and the environment. For the purposes of this thesis, this method was chosen because the simulations are scalable, adaptable across contexts, flexible in the types of information that can be included, and also accessible in the ways that results can be communicated. Ultimately, as described in earlier sections, this method aligns with the examination of complex interventions, in that it can accommodate the stochastic, non-linear, and dynamic interactions between humans and the environment, which are characteristic of infectious diseases and schistosomiasis in particular. This differs from other common statistical models which often assume independence of observations, one directional causality, and noninterference.

### 1.7 Organisation of the thesis

As discussed above, this thesis consists of four papers. In relation to the Research Questions posed in Section 1.2, Paper 1 [Chapter 2] addresses Research Question 1, Paper 2 [Chapter 3] addresses Research Question 2, Paper 3 [Chapter 4] addresses Research Question 3, and Paper 4 [Chapter 5] addresses Research Question 4.

The organisation is as follows:

- Paper 1 [Chapter 2] ("Power across the global health landscape: Analysis of the Development Assistance for Health Network 1990—2015") describes the changing landscape of global health actors as it relates to relative shifts in power over time.
- Paper 2 [Chapter 3] ("Shifting the Dynamics: implementation of locally-driven, mixedmethods modelling to inform schistosomiasis control and elimination activities") describes the implementation of a methodological approach to challenge the balance of power in the development of evidence and decisions regarding the delivery of global health interventions.
- Paper 3 [Chapter 4] ("Revisiting the plan to 'rescue the bottom billion': an assessment of the costs and effectiveness associated with schistosomiasis control activities") follows in this vein by presenting an alternative perspective to assess the costs and effectiveness of deworming campaigns for schistosomiasis in Uganda.
- Paper 4 [Chapter 5] ("Opportunities and disconnects in the use of primary research on schistosomiasis and soil-transmitted helminths for policy and practice: results from a

survey of researchers") shift the focus within our discussion of evidence for decisionmaking in global health to consider one particular type of information, peer-reviewed publications for one specific global health intervention, which is most often considered as 'best practice' in evidence-based decision-making.

In terms of dissemination of this work, three of the four papers have been published in peer-reviewed academic journals and the fourth is in the submission process. Paper 1 [Chapter 2] ("Power across the global health landscape: Analysis of the Development Assistance for Health Network 1990—2015") has been published in the Journal of Health Policy and Planning (https://doi.org/10.1093/heapol/czac025). Paper 2 [Chapter 3] ("Shifting the Dynamics: implementation of locally-driven, mixed-methods modelling to inform schistosomiasis control and elimination activities") has been published in BMJ Global Health (http://dx.doi.org/10.1136/bmjgh-2021-007113.) Paper 4 [Chapter 5] ("Opportunities and disconnects in the use of primary research on schistosomiasis and soil-transmitted helminths for policy and practice: results from a survey of researchers") was published in the Journal of Public Health Policy (https://doi.org/10.1057/s41271-021-00294-x.) Finally, parts of the background materials presented in this introduction were published in 'Chapter 20: New Directions and Challenges for Health and Development' in the edited textbook "Poverty and Development" (https://global.oup.com/academic/product/poverty-and-development-9780199563241?lang=en&cc=mt).

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# 2 Power across the global health landscape: Analysis of the Development Assistance for Health network 1990—2015 (Paper 1)

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# Abstract

Power distribution across the global health landscape has undergone a fundamental shift over the past three decades. What was once a system comprised largely of bilateral and multilateral institutional arrangements between nation-states evolved into a varied landscape where these traditional actors were joined by a vast assemblage of private firms, philanthropies, nongovernmental organizations, public-private partnerships. Financial resources are an explicit power source within global health which direct how, where, and to whom health interventions are delivered, which health issues are (de)prioritised, how and by whom evidence to support policies and interventions is developed, and how we account for progress. Financial resource allocations are not isolated decisions, but rather outputs of negotiation processes and dynamics between actors who derive power from a multiplicity of sources. The aims of this paper are to examine the changes in the global health actor landscape and the shifts in power using data on disbursements of development assistance for health (DAH). A typology of actors was developed from previous literature and refined through an empirical analysis of DAH. The emergent network structure of DAH flows between global health actors and positionality of actors within the network were analysed between 1990 and 2015. The results reflect the dramatic shift in the numbers of actors, relationships between actors, and funding dispersal over this time period. Through a combination of the massive influx of new funding sources and a decrease in public spending, the majority control of financial resources in the DAH network receded from public entities to a vast array of civil society organisations (CSOs) and public-private partnerships (PPPs). The most prominent of these were the Bill and Melinda Gates Foundation (BMGF) and the Global Fund for AIDS, TB, and Malaria (GFATM), which rose to the third and fourth most central positions within the DAH network by 2015.

#### 2.1 Introduction

The transformation from *international* to *global* health has been described as a fundamental, system-wide shift in priorities and function (Packard, 1997, 2016; Brown *et al.*, 2006; Birn, 2009). This shift was accompanied by a changing landscape of actors who govern, fund, and deliver interventions and influence policies designed to alleviate suffering from ill-health and improve the well-being of the world's population. While these are meaningful ends in and of themselves, they were also viewed as means to reaching broader aims in response to research that showed ill-health was suppressing poverty reduction and economic growth (Packard, 1997; Szlezák *et al.*, 2010).

Over the past thirty years, the system has gone from one of bilateral and multilateral institutional arrangements between nation-states to a variegated landscape where these traditional actors have been joined by a vast assemblage of private firms, philanthropies, non-governmental organizations, public-private partnerships and others to provide resources to roughly the same number of aid recipient countries. These non-traditional actors exert considerable influence on global health prioritisation and agenda-setting, which was derived, at least in part, from the massive influx of funding ushered in by the United Nations Millennium Development Goals (MDGs) (Szlezák *et al.*, 2010), or 'the lamentable return of the Big Push,' as described by Easterly (2007). When viewed as the ability to influence and control resources of all types, power as distributed across the global health landscape has undergone a fundamental shift over the past three decades.

Financial resources are certainly an important source of explicit power within global health, and perhaps the easiest to recognize (Shiffman, 2014; Hanefeld and Walt, 2015). To wit, the allocation of financial resources facilitates how and where and to whom health interventions are delivered, which health issues are (de)prioritised, how and by whom evidence to support policies and interventions is developed, and how progress is measured and reported. Financial resource allocations are not isolated decisions, but rather outputs of negotiation processes and dynamics between actors who derive power from a multiplicity of sources. It is not simply that those who have the most money then have the most power to influence these decisions, but rather the interaction between, and composition of, different sources of power which "actors use to influence the thinking and actions of others" within the global health system (Moon, 2019).

While acknowledging that funding allocations are an important, though not an isolated or absolute, source of power, the aims of this paper are to examine the changes in the global health actor landscape and the shifts in power using data on disbursements of development assistance for health (DAH). Using a typology of actors developed from previous literature and refined through an empirical analysis of DAH, the characteristics of the global health landscape are described over the twenty-five year period leading up to and encompassing the MDG era (years 1990 through 2015.) To examine aspects of power, the emergent network structure of DAH flows between global health actors and positionality of actors within the network were analysed over this same time period. To provide additional context to the empirical analysis, the following background sections describe what is meant by the global health landscape in the context of this study, concepts from previous works on power in global health, and the use of networks as analytical tools to examine power.

# 2.2 Background

# 2.2.1 Global health landscape

The definition of "global health" depends on the context and one's aims. It is a contested term - in the first instance for its lack of distinction from international health (Peters, 2017) or public health (Fried et al., 2010). While this study proceeded with a definition of global health for its quantifiable components, its results can be comprehended within competing definitions of the system under investigation. Hoffman and Cole (2018) built on the previous work of Szlezák et al. (2010), Hoffman et al. (2012), and Frenk and Moon (2013) to define global health as a system of "transnational actors that have a primary intent to improve health and the polylateral arrangements for governance, finance, and delivery within which these actors operate." The finance, governance, and delivery arrangements are the observable and measurable outcomes of individual and institutional decisions, power dynamics and relationships between actors, and interactions with other sectors, which ultimately impact the health of world's population through resource allocation, normative guidance, health service delivery, and other outputs. This paper engages the lens of DAH to observe the components of this system. While this definition does present a useful framework for examining the global health system components, as it is used for the purposes of this study, an important limitation is that it does not capture some important nuances about the system, such as the dynamic interactions between the finance, governance, and delivery arrangements.

Various typologies have been articulated to describe the disputed landscape of actors in global health. Those involved in global health governance (Frenk and Moon, 2013; Clinton and Sridhar, 2017) and financing (McCoy *et al.*, 2009; IHME, 2016) were defined and analysed through the early 2010s. Sub-sector-specific analyses have described the actor composition of those focused on various health areas, such as HIV/AIDs (Shiffman, 2008) and mental health (Iemmi, 2019). Datasets of categorised global health actors include that of Hoffman and Cole (2018), who mapped the network of actors built from a sample of those with an online presence, and the ongoing work tracking global health financing by the Institute of Health Metrics and Evaluation (IHME, see e.g. IHME, 2017.) While providing robust analyses and important insights, most studies using these data do not interrogate the dynamic nature of the landscape of global health actors over time.

# 2.2.2 Power in global health

Power asymmetries exist across all facets of society and directly impact health outcomes. The unequal distribution of power at the global level was reported as one of the main contributors to "the poor health of poor people, the social gradient in health within countries, and the substantial health inequities between countries" by the World Health Organization's (WHO) Commission of Social Determinants of Health (Marmot 2008). It is important then to understand how power is structured across the governance, financial, and delivery arrangements within the global health system itself. As elsewhere, asymmetries of power and influence in global health are not straightforward concepts derived solely from economic resources, but emerge from a myriad of sources (Shiffman, 2014). As described in previous work on these concepts (Hanefeld and Walt, 2015; Sriram *et al.*, 2018; Moon, 2019), typologies of power in global health can be observed through theoretical approaches developed in international relations (see for example, Barnett and Duvall, 2005) and sociology (from which the work of Pierre Bourdieu has been highlighted.) While certainly not the only applicable frameworks of power, these approaches introduce an accessible conceptual articulation and vocabulary to the discussion of global health.

As exemplified by Hanefeld and Walt (2015), Bourdieu's theory of capitals (see Bourdieu, 1977; Bourdieu, 1986) as a framework to analyse actor power in the global health context is particularly useful in explaining the shifts in power dynamics as the system evolved from colonial health to international health and through the phases of the current global health system. These shifts are caused by the dispersion of, and interactions between, the economic, cultural, social, and symbolic capitals. In their example, IHME and the WHO are reliant on the Bill and Melinda Gates Foundation (BMGF) for economic capital (i.e. funding). Direct financial support of these actors with technical expertise puts BMGF in a position to influence *cultural capital* (e.g. epistemic knowledge, recognized expertise) by deciding where to direct research funding — the outputs of which eventually become the evidence base (e.g. a database from IHME) for health policy and practice. Furthering this example, the dynamics of *social capital* (the links between networks of organizations and individuals) can be observed through the composition of WHO advisory boards and expert forums, where subject matter experts are convened alongside representatives from BMGF, the Global Fund for AIDS, TB, and Malaria (GFATM), the private sector, and other interested parties to influence and develop WHO-backed policies (Brugha, 2010; D'Souza and Parkhurst, 2018.) These forums have important implications for decision-making from the global down to the local or project levels. The WHO's status as the global authority on norms and standards allows it to set guidelines and directives related to all matters of health policy and practice (its symbolic capital), which are then taken up and disseminated by member states despite the organisation's lack of legal status. Importantly, the framework of capitals leads to a description of the system as a dynamic network of relationships and interactions between actors in global health, previously described by Shiffman (2015) as a field of power relations.

In reference to the need for additional scholarship on power in global health, including the role of the medical journals, the editor of The Lancet remarked that all sources of power and the decisions that arise from power dynamics "should all be a much greater subject of scrutiny" (Horton, 2014). A recent survey of research on power in health policy and systems research concluded that there exists a need for greater methodological and theoretical diversification to engage with the topic (Sriram *et al.*, 2018). With some notable exceptions, such as (Moon, 2019), most available research uses one health area or country location as a case study, which makes it difficult to assess the global health system as a whole or assert that results are indicative of system-wide patterns (Sriram *et al.*, 2018).

#### 2.2.3 Networks as analytical tools of power

While the control of financial resources may be the most easily recognisable form of power (Shiffman, 2014, 2015; Hanefeld and Walt, 2015), its quantification is more complex. Financial power cannot be captured by only observing the financial relationships between two actors, but needs to incorporate how these actors and their relationships fit into the structural properties of the system at large (Menashy and Shields, 2017). Investigating these types of relationships and dynamics has been previously accomplished with network analysis. With the intent of applying mathematical graph theory, network analyses are conducted on relational data in matrix form (see for example Chiesi, 2015.) Actors are represented by nodes and the relationships between them are represented by edges. The metrics of network analysis relate the relative positionality of an individual actor to others in a given network as well as that network's overall structure. Of particular interest related to concepts of power are the measures of centrality, which describe how connected (or 'important') individual nodes are. Centrality measures have been used to describe power and explain different social phenomenon in networks in a variety of contexts across fields of research (see for examples Cook *et al.*, 1983; Padgett and Ansell, 1993.)

Network analyses have been suggested as an appropriate methodology to examine power in the contexts of global health (Sriram *et al.*, 2018), but not yet frequently applied. This may be due, at least in part, to constraints in data availability, as network analyses are particularly data

intensive. Where it has been previously applied in health and development, research has demonstrated the utility of network analyses to examine power dynamics and relationships. In one study, the distribution of power amongst Taiwanese participants in health policy reform was examined by (Wang, 2013), and provided important insights as to the positionality of various actors and their abilities to influence or manipulate a specific policy process. In another case, Menashy and Shields (2017) analysed the network structure of global partnerships focused on education in international development and found that bilateral donors, CSOs, and multilateral organisations were the most highly connected (or central), giving them the ability to shape the flow of information and ideas across the network, which in turn influenced education policies and practice. In the same study, development aid recipient countries were found to be at the periphery, that is, not in a position to shape normative preferences or advocate for resources across partnerships. In additional studies, network analyses have been used to examine donor motivation and coordination of development aid for environmental adaptation (Betzold and Weiler, 2016), and the impact of network position on health outcomes in countries which receive development aid for health (Han *et al.*, 2018).

# 2.3 Materials and Methods

This section first describes the development and definitions of the actor typology present in the DAH landscape, followed by details about the dataset and analyses.

# 2.3.1 Actors in the development aid for health landscape

Categorizing actors in the DAH landscape allows us to track macro-level changes in the network structure over time. The typology used to define these categories in the DAH landscape in this study was built upon the previous work described above, most substantially on the schematic developed by (McCoy *et al.*, 2009)), the empirical results from (Hoffman and Cole, 2018), and the framework by (Frenk and Moon, 2013). The typology was shaped with input from literature drawn from organisation and management sciences, and was further refined through empirical analysis of the DAH data described below. As described next, there are four broad categories of entities (Table 1): public, private, civil society, and public-private partnerships.

Туре	Sub-group	
Public	National governments	
rubiic	Multilateral organisations	
Brivata	Individuals	
riivate	Small and medium enterprises, Corporations	
Civil Society Organization (CSO)	Non-governmental organisations (NGOs)	
Civil Society Organisation (CSO)	Public charities and non-profit organisations (NPOs)	
	Global Health Networks	
rubic-riivate rattiersnip (PPP)	Global Health Initiatives (GHIs)	

Table 2-1 Typology of DAH actors

*Public entities* consist of national governments and multilateral organisations comprised of national government member states. National governments fund global health efforts by budgeting aid flows from national treasuries to bilateral development agencies, multilateral institutions, civil society organisations (CSOs), and Public-Private Partnerships (PPPs) (IHME, 2017). One

specific form of aid for health is official development assistance (ODA), which is development aid provided to a list of donor countries, comprised of those which fall below a threshold measured from the World Bank's GNI per capita indicator (OECD, 2021), and tracked by Organisation for Economic Co-operation and Development (OECD). The OECD's Development Assistance Committee (OECD-DAC) is an international forum comprised of the twenty-nine most significant state-level donors, plus the European Union<sup>32</sup>. The past twenty years have seen a proliferation of donor countries which are not members of OECD-DAC, yet contribute significant and substantial development aid for health. Some of these Non-OECD-DAC countries, sometimes referred to as "new donor countries" (Gulrajani and Swiss, 2019) or "emerging donors" (Gore, 2013), have distributed more development aid than OECD-DAC countries, particularly some of the committee's newest members.

Multilateral Organizations are considered in the first instance public institutions due to their mechanisms for accountability, distribution of funds, and historical structure. In global health, multilaterals consist of United Nations organisations (especially the World Health Organisation as the UN's technical body on health), the World Bank entities, the European Union, and Regional Development Banks (specifically the African Development Bank, Asian Development Bank, and the Inter-American Development Bank.)

*Private entities* consist of individuals, small and medium enterprises, and corporations which contribute to development aid for health indirectly via tax contributions to government budgets. In addition, there are a variety of country-specific charitable-giving mechanisms through which direct contributions to can be made to civil society organisations, public-private partnerships, and philanthropic foundations focused on providing development aid for health (McCoy *et al.*, 2009; Reich, 2018). Differing tax regimes and cultural practices between countries encourage differing levels giving from private individuals, families, and private companies. For example, generous publicly-funded subsidies of charitable giving in the United States have led to the proliferation of corporate responsibility programmes and externally-run corporate philanthropies, the latter of which is considered a civil society organisation when established as a philanthropic foundation through an endowment (Reich, 2018).

*Civil Society Organisations* (CSOs) are "non-market and nonstate organisations [pursuing] shared interests in the public domain" (OECD, 2011). Civil Society Organisations are 'the broad spectrum of voluntary associations that are entirely or largely independent of government and that are not primarily motivated by commercial concerns (Najam, 2000), which include trade unions, faith-based organizations, advocacy groups, philanthropic foundations, community groups, think tanks, professional associations (Smith, 2019), and research centres, as well as incountry branches of internationally affiliated organisations (UNDP, 2013). While the term non-governmental organisation (NGO) has often been used interchangeably with CSO, NGOs are considered a subset of CSOs, distinguishable from other CSOs for their specific associations with development cooperation (UNDP, 2013). The WHO described distinct categories of non-state, non-market entities as NGOs, philanthropic foundations, and academic institutions (WHO, 2014).

Philanthropic foundations are a particularly prominent form of CSO in the global health landscape. Foundations are funded solely by endowments and therefore do not raise funds from the public or accept direct funds from governments (Clarke, 2019), which distinguishes them from other forms of CSOs. Foundations do not provide direct services, but rather distribute funding to other entities who may act on behalf of the foundation (Stuckler *et al.*, 2011). They are, however, structured similar to charities to benefit from generous tax schemes, the effects of which are most evident in the United States, home to the largest number of private philanthropic

<sup>&</sup>lt;sup>32</sup> As of January 2021, the members of OECD-DAC are Australia, Austria, Belgium, Canada, Czech Republic, Denmark, European Union, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Italy, Japan, Korea, Luxembourg, The Netherlands, New Zealand, Norway, Poland, Portugal, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, United Kingdom, and the United States (OECD, 2021).

foundations (Reich, 2018). The most common types of foundations working in global health are those established by wealthy families or individuals (eponymous or not) and charitable trusts established by private small and medium enterprises or corporations (Clarke, 2019).

The definitions of Public-Private Partnerships (PPPs) are broad and lack consensus. In the context of global health, PPPs are referred to as Global Health Initiatives (GHIs), Global Health Alliances, Global Health Partnerships, and Global Public Private Partnerships for Health (GPPPHs), though what constitutes each of these does not differ from the broad definitions of PPPs in other sectors (see, for example, domestic infrastructure PPPs in (Casady et al., 2020).) While the name invokes a seemingly balanced civil society-private sector coordinated effort, the proportional representation of civil society, particularly that of recipient countries and patients or community representatives, is small relative to the private sector and donor countries (Storeng and de Bengy Puyvallée, 2018). In global health, these entities often occupy the space of both funding recipients and donors (e.g. GFATM). For the purpose of the typology in this paper, building on the work of (Widdus, 2005; Buse and Tanaka, 2011; Buse et al., 2012), the following definition of PPPs was developed: PPPs consist of institutionalised polylateral collaborative relationships, established with the purpose of specific shared objectives and involving some degree of shared decision-making. In the first instance, entities were categorized as PPPs if they were included in the 100 partnerships listed in (WHO, 2009), and additional entities were included if they met the definition as described.

#### 2.3.2 Development Aid for Health (DAH) data

Financial arrangements in the global health system "relate to how finances flow through health systems, and focus on how systems are financed, types of funding organizations, how to remunerate providers, how products and services are purchased and the incentive structures for consumers (Hoffman and Cole, 2018)." Financial support in the form of development aid for health (DAH) constitutes a specific subgroup of these arrangements within the global health system, and plays an important role in the financing of health systems in low- and lower-middle-income countries (IHME, 2017).

As illustrated in previous work, DAH cannot be captured solely by quantifying the dyadic relationships between donor and recipient countries, but rather as flows of resources from and across a "constellation of actors" (Szlezák *et al.*, 2010) within the wider global health system. The analyses here utilise the DAH data assembled by IHME, first described in (Ravishankar *et al.*, 2009), covering the period from 1990 through 2015. It is important to note here that while IHME itself is a powerful actor with respect to its control of health metrics and influence on decision-making, as described in the introduction and elsewhere (see for example (Shiffman, 2014; Mahajan, 2019; Shiffman and Shawar, 2020)), the organization is not explicitly present in the DAH dataset used here as this analysis is focused specifically on aid.

The data are structured as annual quantified flows of disbursed funds from sources to channels and then to recipient countries. The sources and channels are disaggregated by the names of specific agencies. Agencies may function as sources, channels, and in some cases, both. Only the recipient countries where the funds end up are indicated, not the specific implementing entities, which could include public, private, CSO, or other type of global health actor discussed above. The flows across sources, channels, and recipient countries were further disaggregated by 22 distinct health areas of focus for which the funds were dispersed. These data were cleaned and aggregated first by actor (or agency) within the source, channel, and recipient country categories, then iteratively by the broader categories of global health actors, as outlined above, where relevant. Flows of DAH with unspecified sources, channels, and recipients were not included in the analyses.

#### 2.3.3 Analytical Approach

The flows of DAH between actors constitute an emergent, unplanned network structure which "evolved as a result of a myriad of individual aid allocations decisions driven by a variety of humanitarian, strategic, commercial, and political motives (Han *et al.*, 2018)." As discussed above, analysing the emergent network structure provides insights as to the relationships between actors and the actor's positionality within the structure of development aid for health more broadly. As discussed above, networks are structures with mathematical functions made up of nodes and the links between them, called edges. In terms of the DAH network, the individual agencies are nodes and the financial resources that flow between them are the edges. This network is *directed*, as in each edge indicates the direction of aid flows (from whom, to whom), and *weighted*, as in each edge has an attribute of the amount of aid funding that flowed between two given actors. Figure 1 illustrates these concepts, as well as those of the projections and metrics discussed next, using a simple DAH network example.

The DAH data was projected in two ways: first as a pair of bipartite networks (sources to channels and channels to recipients), then as a unimodal network including all actors. The bipartite graphs, networks with two disjointed sets of nodes with edges, were used to evaluate the network metrics within each of the functional roles, i.e. sources, channels, recipients. By the capturing metrics of actor nodes in their different functions (or modes, in network terms) in the system, we are able to isolate particular characteristics related to being either a source, channel, or recipient, as some actors take on more than one of these roles. Out-degree measures the number of incident outgoing edges from a node. For the directed bipartite network of sources and channels, the out-degree metric for sources captures the number of channels directly funded by a given source. Conversely, in-degree measures the number of incident incoming edges to a node. For the bipartite network of channels and recipient countries, this captures the number of channels directly funded by a given source. Conversely, in-degree measures the number of incident incoming edges to a node. For the bipartite network of channels and recipient countries, this captures the number of channels providing funds to implementing entities within a given country. Degree centrality, which counts the all incident edges connected to a given node, was utilised to provide an indication of the centrality of channels. These metrics were captured annually for years 1990 through 2015.

The DAH data was also projected as a unimodal network (i.e. all of the nodes were of the same type, 'global health actors') to examine system-wide characteristics and actor positionality within the system. As described above, the most relevant metric related to power describes the centrality of a given actor. Previous work on knowledge networks has shown that because more central nodes "tend to have greater access to and control over valuable information flows, they have more power to influence others ((Burt, 1982) in (Phelps et al., 2012))." The same applies to the DAH network, in that the more central nodes will be highly embedded amongst the global health actors and able to exercise power and influence through their control of financial resources. There are at least 100 metrics for calculating the centrality of a node (Oldham et al., 2019). Closeness centrality, conceptually developed by (Bavelas, 1950; Sabidussi, 1966) and defined by (Freeman, 1978), is the reciprocal of peripherality (Boldi and Vigna, 2014). The metric captures the absolute network involvement of a given node by measuring how connected it is to the rest of the nodes in the system, not only the nodes to which it is directly linked. Power in global health, as described by closeness centrality, results from the ties to other actors and also the weight of those ties (i.e. the amount of DAH transferred.). That is, a higher closeness centrality value results from a given actor being more embedded, or linked to the rest of network, and a higher amount of DAH flowing from and through the actor relative to other actors in the network. As shown in the previous network analyses in health and development detailed above, the more control over the quantity and volume of flows an actor has, the more they are able to direct and influence decision-making related to policy and practice in a given system. Previous work on closeness centrality in the international health aid network articulated the theoretical need for a tuning parameter to

account for both the number of ties and the intensity of the ties, and demonstrated the optimisation of the tuning parameter at 0.5 (Han *et al.*, 2018), following on from the closeness centrality defined by (Opsahl *et al.*, 2010), as follows:

$$C_C^{W\alpha}(i) = \left[\sum_j^N d^{W\alpha}(i,j)\right]^{-1}$$

Where d is the shortest distance between node *i* and *j*, *w* is the weighted adjacency matrix (in which  $w_{ij}$  is greater than 0 if node *i* is connected to node *j*, and the value represents the weight of the tie), and  $\alpha$  is the tuning parameter (equal to 0.5.)

#### Figure 2-1 Illustrative example of simple DAH network





This figure shows a generic Development Aid for Health (DAH) network projected as a A bimodal network of sources and channels, B bimodal network of channels and recipients, and C unimodal network of global health actors. Note that in C the nodes are all the same mode ('Global Health Actors'), but include the source (S), Channel (C), and Recipient (R) labels which correspond to the same nodes in A and B. The amount of DAH transferred between entities is represented as the weights of edges, in this diagram as randomly assigned numbers noted above each arrow.

For illustrative purposes, the network metrics can be calculated for components in this simple network. In A, Source 1 has an out-degree of 1, which means that Source 1 provided resources to one channel. In the same panel, Channel 2 has an in-degree of 2, meaning that Channel 2 received resources from two sources. In B, Channel 2 has an out-degree of 1, meaning that it provides resources to two implementing entities within a given recipient country. To examine which channels of DAH are most centrally located between sources and channels, we can look at the degree centrality, which is the sum of all incident edges or DAH flows. In the case of our simple network, Channel 1 has a higher degree centrality of 4 (2 in-degree + 2 out-degree) compared to Channel 2 with a degree centrality of 3 (2 in-degree + 1 outdegree.)

To examine system-wide positionality, we can calculate closeness centrality using the formula described in the text. We observe the following results, by actor node number in C:

Node ID	<b>Closeness centrality</b>
1	1.32
2	3.67
3	1.04
4	2.50
5	0.00
c	0.08

The workflow for the analyses presented here was as follows: Stata SE (version 15.1) was used for data cleaning and management, NetworkX package (version 2.5) in Python (version 3.7) was used for the network analyses, GEPHI (version 0.9.2) was used for network visualisations, and R (version 4.0.2) was used for descriptive analyses and additional data visualisations.

#### 2.4 Results

2.4.1 Changes in the DAH landscape, 1990—2015

The representations of DAH as networks presents a striking visualisation of the systemic changes between 1990 and 2015. Projected in a dual circle layout and ranked by out degree, the inner circle consists of DAH recipient countries and the edge colour represents the source of funding (Figure 2, static and video formats). As reported elsewhere, total funding for global health interventions was found to have increased from approximately USD 7 billion in 1990 to over USD 36 billion in 2015 (IHME, 2017).

#### Figure 2-2 DAH network in 1995, 2002, and 2015\*



Video format:

https://www.dropbox.com/s/thupxg870ntcqmi/Video1%20animation%20of%20Figure%201.mp4?dl=0

This study found that the increase in absolute DAH disbursements was accompanied by a fivefold rise in the number of actors over the same period, with a particularly rapid rate of increase in CSOs between 2005 and 2011 (Figure 3). Over one-third (33.1%, n=1593) of CSO channels provided funding to countries for one single health area, of which two-thirds were dedicated to solely to MDG target areas: HIV/AIDS, malaria, child and maternal health, and nutrition.



Figure 2-3 Total numbers of actors (nodes) and ties between actors (edges) 1990-2015

The proportional distribution of DAH from sources and through channels has also shifted from a landscape largely dominated by public entities to more of a mixed picture, though most markedly across DAH channels (Figure 4).

Figure 2-4 Proportional distribution of DAH from sources and through channels, 1990-2015



In 1990, 94.5% of DAH came from national governments and multilateral sources and 92.4% was allocated through bilateral and multilateral channels. By 2015, while the majority of DAH still came from public sources (81.3% of the total), less than half of DAH (49.9%) was allocated through public channels. The increase in the sheer volume of CSOs discussed above was also paired with an increase in the proportional funding allocated by and through these entities. Also of particular importance was the increase in distribution of DAH through PPPs, driven by the creation of the GFATM and the Global Alliance for Vaccines and Immunizations (GAVI), which combined accounted for 15% of total DAH allocated through channels in 2015.

#### 2.4.2 Changes in power across the DAH landscape, 2000–2015

Aspects of power derived from the control of financial resources were examined through the network metrics in-degree, out-degree, degree centrality, and closeness centrality. The actors were ranked from highest to lowest by metric within the source, channel, and recipient country categories for each year (the top ten in each are shown in Table 2.) OECD-DAC countries were ranked highest in terms of the number of channels they directly funded (outdegree), aside from the second place ranking of the BMGF from 2002 onwards (Table 2.A.) Generally, OECD-DAC countries also had the highest degree centralities of all channels of DAH. The exceptions were (1) the increased activity from family foundations just after the establishment of the MDGs in 2002, and (2) the entry of the GFATM into the top ten in 2015, at which point it had been well-established (Table 2.B.)

Closeness centrality, which incorporates both the direct relationships between actors and the amounts of financial resources (DAH) transferred between actors, describes how quickly a node can reach all other nodes in a network and therefore how well-connected or 'important' a node's position is within the network. The average closeness centralities across all types of global health actors have increased since 1990 due to both the increased number of relationships as the number of actors in the network increased over time and the increased funding moving throughout the network (Figure 5.) The traditional donors, bilateral and multilateral aid agencies, have the highest average closeness centralities (Table 2.C.)

In terms of individual actors, 42 of the 100 entities with the highest measures of closeness centrality are CSOs (see Supplementary Materials.) This is not discernible in the aggregate categories in Figure 5, which shows CSOs as having amongst the lowest average closeness centralities. Many CSOs are set up as cause-specific entities and therefore are more likely to be peripheral actors in the network, only connected through a single donor entity. The number of active CSOs has been above 1000 each year since 2004 (Figure 3), and while the funding has increased, the competition for funding has also increased, resulting in a greater dispersion of funding across the network. Approximately one-third of the highest ranking CSOs are family foundations, most with highly recognisable names and visible presences amongst the general population (Table 3). Two of the highest ranking CSOs are charitable arms of pharmaceutical companies, Merck Company Foundation (ranked at number 10) and Bristol-Meyers Squibb Foundation (ranked at number 15.) The remaining half of the highest ranking CSOs are NPOs/NGOs.

#### Table 2-2 Rankings by DAH network metrics in 1990, 2002, and 2015

	<u> </u>		
Rank	1990	2002	2015
1	USA	USA	USA
2	UNITED KINGDOM	BMGF	BMGF
3	NETHERLANDS	UNITED KINGDOM	SPAIN
4	FRANCE	NETHERLANDS	CANADA
5	SWEDEN	FRANCE	ITALY
6	PORTUGAL	SWEDEN	NORWAY
7	LUXEMBOURG	SPAIN	NETHERLANDS
8	ITALY	LUXEMBOURG	IRELAND
9	GERMANY	IRELAND	FINLAND
10	FINLAND	GERMANY	AUSTRIA

#### A. Out-degree ranking of sources

# B. Degree centrality ranking of channels

channels					
Rank	1990	2002	2015		
1	USA	USA	USA		
2	FINLAND	BMGF	BMGF		
3	NETHERLANDS	FRANCE	CANADA		
4	SWEDEN	NORWAY	ITALY		
5	SWITZERLAND	UNITED KINGDOM	SPAIN		
6	AUSTRALIA	DAVID AND LUCILE	NORWAY		
		PACKARD			
		FOUNDATION			
7	ITALY	SWEDEN	JAPAN		
8	CANADA	FORD FOUNDATION	GERMANY		
9	NORWAY	CANADA	FRANCE		
10	FRANCE	GERMANY	GFATM		

# C. Closeness centrality ranking across all actors

Rank	1990	2002	2015
1	USA	USA	USA
2	FRANCE	GERMANY	UNITED KINGDOM
3	JAPAN	FRANCE	GFATM
4	ITALY	UNITED KINGDOM	BMGF
5	SWEDEN	WORLD BANK IDA	FRANCE
6	NETHERLANDS	ITALY	CANADA
7	GERMANY	NORWAY	GERMANY
8	CANADA	SPAIN	JAPAN
9	UNITED KINGDOM	CANADA	NORWAY
10	FINLAND	NETHERLANDS	NETHERLANDS

BMGF, Bill and Melinda Gates Foundation; GFATM, Global Fund to Fight AIDS, Tuberculosis and Malaria; USA, United States of America; World Bank IDA, World Bank International Development Association

Rank amongst CSOs	Rank amongst all actors	Entity name	Туре
1	13	BMGF	Family Foundation
2	28	PRODUCT RED	NPO/NGO
3	38	POPULATION SERVICES INTERNATIONAL	NPO/NGO
4	39	FORD FOUNDATION	Family Foundation
5	43	JOHN SNOW INTERNATIONAL	NPO/NGO
6	45	ROCKEFELLER FOUNDATION	Family Foundation
7	46	DAVID AND LUCILE PACKARD FOUNDATION	Family Foundation
8	48	FHI 360	NPO/NGO
9	49	UNITED NATIONS FOUNDATION	Public Charity
10	50	MERCK COMPANY FOUNDATION	Corporate Foundation
11	53	JOHN D. AND CATHERINE T. MACARTHUR FOUNDATION	Family Foundation
12	56	MANAGEMENT SCIENCES FOR HEALTH	NPO/NGO
13	57	CHAI	NPO/NGO
14	58	JHPIEGO	NPO/NGO
15	59	BRISTOL-MYERS SQUIBB FOUNDATION, INC	Corporate Foundation
16	61	DAMIEN FOUNDATION	NPO/NGO
17	64	INTRAHEALTH INTERNATIONAL	NPO/NGO
18	66	W. K. KELLOGG FOUNDATION	Family Foundation
19	67	CHINA MEDICAL BOARD, INC	NPO/NGO
20	70	PACT INC	NPO/NGO
21	71	WILLIAM AND FLORA HEWLETT FOUNDATION	Family Foundation
22	72	OPEN SOCIETY FUND	Family Foundation
23	74	COMIC RELIEF	NPO/NGO
24	76	MAC AIDS FUND	Public Charity
25	77	KNCV TUBERCULOSIS FOUNDATION	NPO/NGO

#### Table 2-3 Top 25 Civil Society Organizations (CSOs) in terms of closeness centrality, 1990-2015

BMGF, Bill and Melinda Gates Foundation; CHAI, Clinton Health Access Initiative; JHPIEGO, Johns Hopkins Program for International Education in Gynecology and Obstetrics

#### 2.5 Discussion

The landscape of global health actors shifted dramatically between 1990 and 2015, as underscored by those involved in disbursements of development assistance for health (DAH). Throughout the MDG era the system became denser, as the numbers of actors and relationships between actors increased substantially. During this same period funding became more dispersed and less concentrated in flows from large bilateral and multilateral organisations.

Amongst the public entities, the United States government, through its bilateral aid agencies, remains a singular force in DAH, having maintained the most central position across all network metrics reported here across all years. Though through a combination of the massive influx of new funding sources and a decrease in public spending, the majority control of financial resources in the DAH network receded from public entities and gave way to a vast array of civil society organisations (CSOs) and public-private partnerships (PPPs). The most prominent of these were the BMGF and GFATM, which were found to have risen to the third and fourth most central, important positions within the DAH network by 2015. As a PPP, GFATM occupies the positions of both donor and funding recipient, the latter of which necessitates a degree of accountability to the organisation's largest donors to meet fundraising goals for its continued viability.

Since the year 2000, thousands of non-governmental organisations (NGOs) and nonprofit organisations (NPOs) were created to facilitate cause-specific initiatives with the intention of contributing to progress towards the MDG targets. The substantial increase in CSO actors was in response to the space created by the perceived inefficiencies of more traditional donors, i.e. multilateral actors, to meet the disease-specific MDGs (Clinton and Sridhar, 2017), compounded the increasingly common use of NGOs for development activities by national governments, multilaterals, and PPPs (Doyle and Patel, 2008; KFF, 2014, 2015). While NGOs are perceived by some to be more agile and flexible, the sheer quantity of these relatively new NGOs and other CSOs has diminished the space for coordination and, at times, encumbered the system with fragmentation to the point of ineffectiveness (Spicer *et al.*, 2020).

While many definitions of global health, including the one employed in this study, invoke a dynamic of transnational partnership and exchange, especially between high income countries and low/lower-middle income countries, it is not necessarily representative of the DAH system as observed here. Present throughout the entire time period examined, but visually most evident in 1990 due to the sheer volume of edges in later years, were the contributions of the recipient countries to multilateral organisations (represented by the white edges in Figure 2, both the static and video formats.) In most cases, these were non-OECD-DAC countries fulfilling voluntary pledges and assessed contributions to multilateral organisations. In later years, this was also attributable to an influx of funding from lower-middle income countries to public-private private partnerships. Relatedly, over time, we can observe too the transition of countries from recipients to donors or hybrid donor-recipients, as in the cases of Brazil, India, and China, the latter of which was highlighted by Micah et al 2019. These countries have contributed more total DAH than some of the newest OECD-DAC countries, namely the Czech Republic and Poland. This illustrates the complex, dynamic nature of DAH underpinning the financial arrangements in global health, which does not comport with perceptions of the system as a flow of resources from richer to poorer countries nor the definitions of global health as partnerships without reference to power asymmetries.

While for most of its existence, global (or international) health was guided by the normative and formal functions of international and bilateral relationships, the contribution of greater resources to health-related programming gave private actors an increasingly important role in the system. Total funding for global health interventions has increased from approximately USD 7 billion in 1990 to over USD 36 billion in 2015, with an increase in proportionate contributions by corporations and private foundations from 8% in 1990 to an

annual average of 22% since the year 2000 (IHME, 2017). While this increase in funding certainly increases the possibility of improving the health of the world's population, there are concerns regarding transparency and accountability to the recipient organizations, intended beneficiaries, and the effects of private actors on rest of the system. Despite the altruistic rhetoric, private entities, especially family and corporate foundations, are only accountable to their executive boards, not to populations of people, national governments, or international organizations (McGoey, 2016). These actors are able to prioritize, withdraw, or withhold funding at any time, which increases the power of their support in an unquantifiable way.

Here underscores the importance of analyses of power in global health and the application of Bourdieu's capitals framework. Once actors who hold power derived from economic capital have been identified, we have a framework to explore the impacts of these asymmetries. For example, the charitable arms of pharmaceutical companies were found to be amongst the most powerful CSOs in terms of network centrality. Aside from specific cases, pharmaceutical solutions to global health issues have been shown to be problematic and unsustainable (see for example Parker and Allen, 2014; McGoey, 2016.) Yet biomedical technologies delivered through vertical interventions persist, and continue to receive the majority of financial resources across global health interventions (IHME, 2016). Some of these solutions have been designed and implemented without the meaningful input from the recipient populations or their representatives, and led to unethical activities on the part of the actor (McGoey et al., 2011) and sometimes violent backlash from the recipients (Hastings, 2016). Of course the involvement of pharmaceutical companies in the DAH network is not the only reason for this, but their prominent roles in the system and dynamics with other important actors influence the global health agenda and priority-setting. One recent example of particular importance is the reneged open-source promise related to the Oxford University COVID-19 vaccine, the intellectual property rights of vaccines whose development was largely backed by public funds, and their impact on the COVAX and other means of equitable access to the vaccine (Twohey and Kulish, 2020; Cheney, 2021; Kashyap et al., 2021).

In terms of limitations, the results presented here rely on the quality and breadth of the data. Contributions by private individuals were not included in the analysis because those included in IHME's DAH dataset were not presented as having been collected in a systematically robust way. Most public charities solicit funds from private individuals, who in turn may influence arrangements in the DAH network. Importantly then, these results should be viewed as restricted to actor organizations, not inclusive of the power single individuals may exert. It is also important to re-emphasize that power derived from financial resources is not absolute or singular. While financial ties are explicit expressions of dynamic power arrangements, implicit forms of power, such as the development of health metrics for decision-making, may hold equal or greater weight in determining the direction and impacts of the global health system. Finally, it should be stressed that IHME, who produced the dataset used in these analyses, do themselves hold a significant position of power in the global health landscape. This exemplifies the limitations in our ability to interpret the results and underscores that the work presented here has contributed only a partial view. That is, that power is not singular or absolute in its source or presentation, but embedded in the composition of, and relationships between, its origins.

#### 2.6 Conclusion

The establishment of the MDGs, with three of the eight goals explicitly targeting health, DAH became an important political tool and symbol. These goals were meant to serve as apolitical objectives around which everyone working in development could coalesce (McCoy *et al.*, 2009). Similar to this rhetoric surrounding the broad goal of poverty reduction, the narrative around DAH has been apolitical in nature, where even questioning aid disbursements has been "obstructed by the moral oratory of 'saving lives' and 'fighting disease' (McCoy and Singh, 2014)." To what extent then is it appropriate for global health actors to improve their own positions or enrich themselves from their involvement in the governance, financial, and delivery arrangements of the system? And further, what then are the implications when these same actors accumulate substantial capital, or positions of power, within global health?

It quickly becomes apparent how understanding power dynamics in global health is necessary to tackle health inequities (Marmot *et al.*, 2008) and enhances "our ability to promote transparency, accountability and fairness (Sriram *et al.*, 2018)." To this end, this study contributed an updated, comprehensive typology of global health actors involved in development assistance for health, and analyses of the emergent network structure of development assistance for health from 1990 through 2015. The analysis of power using network metrics provided multidimensional insights as to the importance of actors in the system and changes in their positions leading up to, and through, the MDG era.

From here, this work can provide background on the utility of network analysis to observe power in global health. Adding the network structures of cultural, symbolic, and social capitals to the one of economic capital presented here would provide a more complete view of the global health system. Further analyses linking the impact of power in DAH on funding decisions and the achievement of health targets are ongoing, as is an examination of the dynamic roles of non-OECD-DAC countries in the DAH network. The extent to which these analyses can interrogate the meaning of 'effectiveness' in cost effectiveness analysis is similarly being explored. Power asymmetries impede our ability to fully realise health and wellness for all. They underscore the most important discussions happening today in global health, and elsewhere, related to economic and other inequities, climate, decolonisation, racism and diversity -- especially in light of the ongoing COVID-19 pandemic as described by Abimbola *et al.* (2021), AlKhaldi *et al.* (2021), Hassan *et al.* (2021), and Kashyap *et al.* 2021. It is therefore important for more widespread scholarship regarding power in global health, especially beyond case studies, to be undertaken and integrated more regularly into discussions of the financial, delivery, and governance arrangements within the system.

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# 2.8 Supplementary Materials

#### 2.8.1 Closeness centrality results

Power in global health can take on many forms. To the extent that power can be described as derived from the distribution of financial resources, we have observed the emergent network structure of development aid for health (DAH) transfers between global health actors. The metric, closeness centrality, captures the absolute network involvement of a given global health actor by measuring how connected it is to the rest of the actors in the system, including those to which it is only indirectly linked. The magnitude of closeness centrality is based on the ties to other actors and also the weight of those ties (i.e. the amount of DAH transferred.) Table S1 contains the global health actors with the highest 100 average closeness centrality measures for the years 1990 through 2015.

Donk	Actor	Actor turo	Actor turo sub group	Average Closeness
капк	Actor	Actor type	Actor type sub-group	centrality
1	UNITED STATES OF AMERICA	PUBLIC	OECD DAC COUNTRIES	1120.99
2	UNITED KINGDOM	PUBLIC	OECD DAC COUNTRIES	451.34
3	FRANCE	PUBLIC	OECD DAC COUNTRIES	448.13
4	GERMANY	PUBLIC	OECD DAC COUNTRIES	432.93
5	JAPAN	PUBLIC	OECD DAC COUNTRIES	427.96
6	NETHERLANDS	PUBLIC	OECD DAC COUNTRIES	389.52
7	CANADA	PUBLIC	OECD DAC COUNTRIES	379.42
8	NORWAY	PUBLIC	OECD DAC COUNTRIES	346.40
9	SWEDEN	PUBLIC	OECD DAC COUNTRIES	344.68
10	ITALY	PUBLIC	OECD DAC COUNTRIES	322.37
11	GFATM	PPPs	GHIs	319.21
12	SPAIN	PUBLIC	OECD DAC COUNTRIES	304.74
13	BMGF	CSOs	CSOs	299.55
14	DENMARK	PUBLIC	OECD DAC COUNTRIES	283.21
15	BELGIUM	PUBLIC	OECD DAC COUNTRIES	276.63
16	AUSTRALIA	PUBLIC	OECD DAC COUNTRIES	276.27
17	World Bank IDA	MULTILATERALS	WORLD BANK	269.74
18	World Bank IBRD	MULTILATERALS	WORLD BANK	260.86
19	IRELAND	PUBLIC	OECD DAC COUNTRIES	207.74
20	SWITZERLAND	PUBLIC	OECD DAC COUNTRIES	202.02
21	FINLAND	PUBLIC	OECD DAC COUNTRIES	200.74
22	AUSTRIA	PUBLIC	OECD DAC COUNTRIES	184.90
23	EC	MULTILATERALS	EC	179.53
24	GAVI	PPPs	GHIs	168.52
25	KOREA	PUBLIC	OECD DAC COUNTRIES	165.10

Table S1. Actors with highest 100 average closeness centrality measures, 1990-2015

			NON OECD DAC	
26	RUSSIA	PUBLIC	COUNTRIES	156.59
27	LUXEMBOURG	PUBLIC	OECD DAC COUNTRIES	146.93
28	PRODUCT RED	CSOs	CSOs	142.61
29	PORTUGAL	PUBLIC	OECD DAC COUNTRIES	133.02
30	GREECE	PUBLIC	OECD DAC COUNTRIES	120.52
			NON OECD DAC	
31	SAUDI ARABIA	PUBLIC	COUNTRIES	114.82
32	IDB	MULTILATERALS	REG DEV BANKS	105.58
33	CHINA	PUBLIC	COUNTRIES	103.65
			NON OECD DAC	
34	POLAND	PUBLIC	COUNTRIES	95.17
35	ASDB	MULTILATERALS	REG DEV BANKS	94.14
36	NEW ZEALAND	PUBLIC	OECD DAC COUNTRIES	88.78
37	CHEVRON CORPORATION	PRIVATE	PRIVATE COMPANIES	85.12
	POPULATION SERVICES			
38	INTERNATIONAL	CSOs	CSOs	76.55
39	FORD FOUNDATION	CSOs		76.46
40	THAILAND	PUBLIC	COUNTRIES	72 64
41	HUNGARY	PUBLIC		70.79
12	AEDB		REG DEV BANKS	62 30
42				61 70
43	JOHN SNOW INTERNATIONAL	0.005	NON OECD DAC	01.79
44	LIECHTENSTEIN	PUBLIC	COUNTRIES	60.79
45	ROCKEFELLER FOUNDATION	CSOs	CSOs	59.23
	DAVID AND LUCILE PACKARD			
46	FOUNDATION	CSOs		56.66
47	INDIA	PUBLIC	COUNTRIES	56.62
48	FHI 360	CSOs	CSOs	55.73
49	UNITED NATIONS FOUNDATION	CSOs	CSOs	55.59
50		CSOs	CSOs	55 55
			NON OECD DAC	55.55
51	KUWAIT	PUBLIC	COUNTRIES	55.36
52		DUDUC	NON OECD DAC	52.22
52		PUBLIC	COUNTRIES	53.23
53	MACARTHUR FOUNDATION	CSOs	CSOs	52.14
54	WHO	MULTILATERALS	UN	50.97
55	UNITAID	PPPs	GHIs	49.07
	MANAGEMENT SCIENCES FOR			
56	HEALTH	CSOs	CSOs	46.75
57	СНАІ	CSOs	CSOs	45.43
58	JHPIEGO	CSOs	CSOs	45.33
E0	BRISTOL-MYERS SQUIBB	CSOc	CSOc	40.00
23				42.32
60	ICELAND	PUBLIC	OECD DAC COUNTRIES	40.75

61	FONDATION DAMIEN - FONDAM	CSOs	CSOs	39.62
62	SLOVENIA	PUBLIC	OECD DAC COUNTRIES	38.86
63	TAKEDA PHARMACEUTICAL	PRIVATE	PRIVATE COMPANIES	38.69
64	INTRAHEALTH INTERNATIONAL	CSOs	CSOs	35.49
65	BRAZIL	PUBLIC	NON OECD DAC COUNTRIES	34.99
66	W. K. KELLOGG FOUNDATION	CSOs	CSOs	34.60
67	CHINA MEDICAL BOARD, INC	CSOs	CSOs	34.22
68	UNICEF	MULTILATERALS	UN	34.07
69	UNFPA	MULTILATERALS	UN	34.03
70	PACT INC	CSOs	CSOs	33.57
71	WILLIAM AND FLORA HEWLETT FOUNDATION	CSOs	CSOs	33.36
72	OPEN SOCIETY FUND	CSOs	CSOs	32.89
70			NON OECD DAC	21.02
73		PUBLIC		31.92
74				31.40
75		PUBLIC		30.35
/6	KNCV TUBERCULOSIS	CSUS		30.33
77	FOUNDATION	CSOs	CSOs	30.10
78	SUSAN THOMPSON BUFFETT FOUNDATION	CSOs	CSOs	30.05
79	CARE INTERNATIONAL	CSOs	CSOs	29.79
80	LEVI STRAUSS FOUNDATION	CSOs	CSOs	28.96
81	MEDTRONIC COMMUNITIES FOUNDATION	CSOs	CSOs	28.95
82	MEDECINS SANS FRONTIERES	CSOs	CSOs	28.69
83	WORLD VISION	CSOs	CSOs	28.16
84	IDOL GIVES BACK	CSOs	CSOs	27.80
85	NAMIBIA	PUBLIC	NON OECD DAC COUNTRIES	27.43
86	COCA-COLA FOUNDATION, INC	CSOs	CSOs	27.39
87	SINGAPORE	PUBLIC	NON OECD DAC COUNTRIES	26.43
88	PRINCIPAL REPAYMENTS	MULTILATERALS	WORLD BANK	25.94
89	CZECH REPUBLIC	PUBLIC	OECD DAC COUNTRIES	25.11
90	RED CROSS	CSOs	CSOs	23.92
91	ALCOA FOUNDATION	CSOs	CSOs	23.82
07	TIMKEN FOUNDATION OF	CSOs	CSOc	)) E0
92		<u> </u>		23.30
95		<u> </u>		22.70
94			NON OECD DAC	22.33
95	TURKEY	PUBLIC	COUNTRIES	22.21
96	CATHOLIC RELIEF SERVICES	CSOs	CSOs	21.86

	ROCKEFELLER BROTHERS FUND,			
97	INC	CSOs	CSOs	21.58
			NON OECD DAC	
98	CHILE	PUBLIC	COUNTRIES	21.23
	DORIS DUKE CHARITABLE			
99	FOUNDATION	CSOs	CSOs	20.41
	SOCIETY FOR FAMILY HEALTH			
100	(NIGERIA)	CSOs	CSOs	20.17

AFDB, African Development Bank; BMGF, Bill and Melinda Gates Foundation; CHAI, Clinton Health Access Initiative; CSOs, Civil Society Organizations; EC, European Commission; GAVI, Global Alliance Vaccine Initiative; GFATM, Global Fund to Fight AIDS, Tuberculosis, and Malaria; GHIs, Global Health Initiatives; IDB, Inter-American Development Bank; OECD DAC, Organisation for Economic Co-operation and Development's Development Assistance Committee; PPPs, Public-Private Partnerships; UAE, United Arab Emirates; UN, United Nations

# 3 Shifting the dynamics: implementation of locally-driven, mixed-methods modelling to inform schistosomiasis control and elimination activities (Paper 2)

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# Shifting the dynamics: implementation of locally-driven, mixed-methods modelling to inform schistosomiasis control and elimination activities

## Abstract

## Introduction

The integration of more diverse perspectives into the development of evidence for decisionmaking has been elusive, despite years of rhetoric to the contrary. This has led to cycles of population-based health interventions which have not delivered the promised results. The WHO most recently set a target for schistosomiasis elimination by 2030 and called for cross-cutting approaches to be driven by endemic countries themselves. The extent to which elimination is feasible within the timeframe has been a subject of debate.

## Methods

Systems maps were developed through participatory modelling activities with individuals working on schistosomiasis control and elimination activities from the village through national levels in Uganda. These maps were first synthesised, then used to frame the form and content of subsequent mathematical modelling activities, and finally explicitly informed model parameter specifications for simulations, using the open source SCHISTOX model, driven by the participants.

## Results

Based on the outputs of the participatory modelling, the simulation activities centred around reductions in water contact. The results of the simulations showed that mass drug administration, at either the current or target levels of coverage, combined with water contact reduction activities, achieved morbidity control in high prevalence *S. mansoni* settings, while both morbidity control and elimination were achieved in high prevalence *S. haematobium* settings within the ten-year time period.

## Conclusion

The combination of participatory systems mapping and individual-based modelling was a rich strategy which explicitly integrated the perspectives of national and subnational policymakers and practitioners into the development of evidence. This strategy can serve as a method by which individuals who have not been traditionally included in modelling activities, and do not hold positions or work in traditional centres of power, may be heard and truly integrated into the development of evidence for decision-making in global health.

# **Key Questions**

# What is already known?

The elimination of schistosomiasis as a public health programme has been shown to be feasible, as evidenced by previous case studies and predictive modelling estimates. However, the continued prioritisation of mass drug administration, with the minimal integration and lack of widespread financial support for alternative interventions, is not supported by this evidence. Further, there remains a disconnect between the rhetoric of country-driven, locally

based solutions to global health problems, which have been shown to significantly improve impacts, and the reality of its widespread implementation.

## What are the new findings?

In this study, we used participatory modelling to shape and inform mathematical modelling, demonstrating one of the possible strategies to integrate a wider range of perspectives in the form of individuals directly involved in the policy, oversight, and implementation of control and elimination activities within endemic countries. We conducted participatory systems mapping workshops with individuals at the village, district, and national levels of the Ugandan Ministry of Health, then used these outputs to select and inform the parameters of an open-source individual-based model. The results of this approach showed that achieving morbidity control and elimination were achievable within most recent timeframe set forth by the World Health Organization, once priority was given to complementary interventions.

# What do the new findings imply?

Incorporating the perspectives of individuals embedded in the biological and social systems of locations with endemic schistosomiasis has important, positive impacts on the development of evidence to support policy and practice. As has been suggested by previous evidence, and supported by this study, intervention strategies need to be tailored to local contexts, supported by a reorientation in the development of evidence for decision-making.

## 3.1 Introduction

As described by the World Health Organization's Director of the Department of Neglected Tropical Diseases (NTDs), the newest strategy to control and eliminate neglected tropical diseases by 2030 (the "NTD Road Map to 2030" (WHO, 2020)) was "built on the principle of impact at country level through cross-cutting approaches, owned and driven by countries themselves, and augmented by coordinated support from partners" (Malecela and Ducker, 2021). Similar comments have been made specifically about the NTD, schistosomiasis, for which the primary interventions are mass deworming activities, referred to as preventative chemotherapy (PC) or mass drug administration (MDA), which are the distributions of deworming medicines to populations or sub-populations in defined geographic areas without individual diagnosis. Policymakers and practitioners have described the need to move from a top-down approach focused solely on MDA to integrated and adaptive strategies which are responsive to specific settings and populations (Parker and Allen, 2014; Secor, 2014; Tchuem Tchuenté *et al.*, 2017; Mazigo, 2019). These discussions are supported by empirical evidence in countries where schistosomiasis elimination has occurred, yet none of which achieved success through mass deworming strategies alone.

In addition to the lack of effectiveness in achieving elimination, meta-analyses have shown that mass deworming interventions targeting schistosomiasis are largely ineffective at improving child health outcomes (Welch et al., 2017; Taylor-Robinson et al., 2019). These results are complemented by modelling studies that have shown the current recommendations for MDA are not predicted to achieve the WHO targets of morbidity control or elimination as a public health problem within the specified timelines (Li et al., 2019; Toor et al., 2020). This is especially pronounced in high prevalence settings, where achieving targets with MDA alone is not likely unless the intervention coverage is increased to 85% in school-age children (SACs) and 40% of individuals over the age of 15 years (Toor et al., 2018). The practical implementation of such changes would be challenging given the current target of 75% SAC coverage remains elusive in most locations (WHO, 2020). The inclusion of additional interventions, such as snail (vector) management and WASH activities, have been predicted to reach the targets within the timeframe specified in the NTD Road Map to 2030 (Li et al., 2019), yet remain as secondary or optional components to the MDA-focused agendas of many donors, policymakers, and researchers. In addition, once the targets are reached, there remain uncertainties about how feasible it will be to maintain low prevalence levels in some areas without continued rounds of PC, potentially in perpetuity (Ayabina et al., 2021).

This perpetuation of biomedical solutions to complex infectious disease problems delivered through vertical programmes, despite evidence favouring more holistic approaches, has been well-documented and critiqued (Atun *et al.*, 2008; WHO, 2009). These interventions have been largely devised outside of the recipient localities and are often implemented without the genuine input from relevant public authorities and intended beneficiaries (Packard, 2016). This is compounded by the disconnect between the development of evidence to justify and support intervention implementation and the actual evidence needs of policymakers and practitioners in endemic countries for decision-making regarding control and elimination activities (Burchett *et al.*, 2015). Together these processes undermine the domestic ownership of health issues and solutions because they position the decision-making power around prioritization, service delivery, and evaluation largely outside of the countries themselves (Bruen and Brugha, 2014; Gill and Benatar, 2016). And, ultimately, this runs antithetical to the principles espoused in the most recent NTD Road Map to 2030.

To shift these dynamics, it is vital to integrate more diverse perspectives, particularly from those embedded within the endemic settings. Not only will this enhance country ownership, but will also improve the design, delivery, and, ultimately, the impact of interventions. Schistosomiasis as a complex disease problem is embedded in space-specific social, economic, biological, and environmental systems. The dynamic relationships between these systems determine the prevalence of the disease and the effectiveness of interventions, which are not captured in linear theories of change or reductionist methods of evaluation. Individuals who themselves are embedded in these systems can provide critical insights as to these relationships and the potential impacts of interventions over time. Mass deworming activities, in particular, are often implemented with complementary components, such as WASH or nutrition activities — all of which influence each other to produce a summative effect different from that of the individual components (Nikolay *et al.*, 2015). In addition, population-based interventions generally should be viewed as dynamic, longitudinal processes, as interactions with local ecologies and social systems affect the interventions and intervention settings over time (Galea *et al.*, 2010; Petticrew, 2015). These features configure nonlinear relationships, especially feedback loops and phase transitions, which are not accounted for in the prevalent deterministic, linear models of change (Galea *et al.*, 2010; Petticrew *et al.*, 2010).

This study aimed to develop evidence for decision-making in response to the needs of policymakers and practitioners from the Ugandan Ministry of Health, while incorporating the complexity of schistosomiasis transmission and control activities. This was accomplished by (1) capturing their perspectives on schistosomiasis transmission using qualitative participatory modelling, and (2) using the participatory modelling outputs to inform mathematical model simulations in response to the evidence needs. Participatory methods have been previously used to inform health policy, practice, and evaluation, most notably in relation to non-communicable diseases (Finegood *et al.*, 2010) and accompanying risk factors (Friel *et al.*, 2017), but has not been linked explicitly to modelling work and the development of evidence for decision-making in this way or context. Similar variations of this protocol used for this study have been previously described in the context of energy policy (Barbrook-Johnson and Penn, 2021) and ecosystem management (Mehryar *et al.*, 2019), but not implemented outside of higher income countries in the context of neglected tropical diseases.

## 3.2 Methods

Various types of participatory modelling have been used to generate shared conceptual depictions of complex health issues, following on from the prominent work on poverty reduction and development led by the World Bank and research, such as Robert Chamber's work on Participatory Rural Appraisal, through the late 20th century (Chambers, 2006). Systems mapping is a type of participatory modelling, used to elicit and quantify diverse perspectives from a variety of actors on causal relationships within complex systems. The process ends with a 'systems map', a diagram of explicit factors, causally linked to one another, which visually depicts a defined 'system' from the perspective of participating discussants (Barbrook-Johnson and Penn, 2021); examples of similar outputs include causal loop diagrams and stock-and-flow diagrams. More recently, systems mapping has been embraced by those working on computational modelling and simulations as a way to inform their models with 'real world' information vis-a-vis the outputs of "purposeful learning processes for action that engage the implicit and explicit knowledge of stakeholders to create formalized and shared representations of reality" (Voinov et al., 2018). Depending on the aims and context, systems maps can be used to guide, inform, and even be used as the framework for simulations and other modelling activities. In health, systems maps have previously been used in calls for applying a systems epidemiology framework to schistosomiasis (Krauth et al., 2019). In this study, systems maps produced using the Participatory Systems Mapping (PSM) method with individuals working on schistosomiasis in Uganda framed the form and content of subsequent modelling activities and explicitly informed model parameter specifications.

## 3.2.1 Participants

Individuals working on schistosomiasis control and elimination activities from the national, district, and village levels within the Ugandan health system were invited to participate in workshops in October of 2019. The aim was to implement a process which captured their perspectives and then incorporate these into the development of evidence for decision-making which was directly responsive to their needs. Thirty-three individuals from the national, district, and village levels participated in two participatory systems mapping workshops over three days. The participants were purposively invited to the workshop in consultation and coordination with the Uganda Ministry of Health Vector Control Division and the Uganda-UK Health Alliance. Individuals were selected from low, moderate, and high transmission settings, with the aim of capturing diverse perspectives and encouraging discussions across transmission settings. Those individuals from the national level were from Ministry of Health departmental headquarters and two non-governmental organisations (NGOs) involved in schistosomiasis control activities. Individuals from the district level included District Vector Control Officers (DVCOs) and District Health Officers (DHOs) within the Ministry of Health (MoH) organisational structure. Individuals from the village level were members of village health teams (VHTs), volunteer community health workers also organised within the MoH. One workshop with national and district level representatives took place in Kampala, and the second workshop with members of village health teams took place in Jinja. Participants were reimbursed or provided with transportation, accommodation, and sustenance to facilitate their participation.

## 3.2.2 Participatory Systems Mapping (PSM) workshops

The workshops included presentations on the fundamentals of modelling and evidence related to schistosomiasis, as well as small and large group discussions on schistosomiasis control and elimination strategies and evaluation of the PSM outputs. In addition, participants were provided background on how systems maps could be used to define the parameters of simulation activities. The participatory systems mapping exercises followed the process described by Barbook-Johnson and Penn from the Centre for Evaluating Complexity Across the Nexus (CECAN) (Barbrook-Johnson and Penn, 2021). After being provided with background and instructions on PSM, small groups of four to eight participants were formed based on health system level, to ease potential pressures of speaking up in the presence of superiors.

The PSM was managed in each group by one or two facilitators and a note-taker. To begin the exercise, each group was given the prompt 'schistosomiasis transmission' and instructed to individually brainstorm factors which directly or indirectly impact transmission. These were then brought together and linked causally through group debate and consensus over course of a day. The systems maps were initially built using erasable paper, markers, and sticky notes. Digitised versions of the systems maps were presented to the participants for validation, and the digital versions were corrected accordingly.

Subsequent large group discussions used the systems maps as tools to describe the impact of specific factors represented in the systems maps, and describe how interventions might be designed and implemented to influence key points in the system to drive down schistosomiasis transmission. The maps were also used as a point of departure to evaluate the potential causes for the lack of effectiveness of current interventions, in particular MDA, on producing long-term, sustained reductions in schistosomiasis transmission.

## 3.2.3 Generation of the aggregated systems map

To incorporate the group maps into a full systems map, the factors from each group were combined and standardised to a minimal extent (e.g., "Children playing/swimming" and

"Children playing in water" were standardised to "Playing/swimming") for a master list of factors described by the participants as directly or indirectly related to schistosomiasis transmission (see Supplementary Materials Section 1.) Each group map was then reimplemented with the standardised factor names as two-dimensional adjacency matrices, with cell values ( $\alpha_{i,j}$ ) equal to +1 (positive relationship), -1 (negative relationship), or 0 (no relationship) from the row factor (*i*) to the column factor (*j*). Factors from the master list not included in a given group map were added to the corresponding adjacency matrix (with  $\alpha_{i,j}=0$ ) as needed for a conformable set of matrices. Matrix addition was used to combine the four matrices, with the resultant  $\alpha_{i,j}$  values (ranging from -4 to +4) representative of the generalised importance of each factor, captured by frequency with which each relationship was mentioned across the systems maps.

The full adjacency matrix was exported as a weighted edge list and projected as the full systems map. Structural analysis of the full map considered network centrality measures to identify the factors of greatest interest (Papageorgiou *et al.*, 2020). This method of network analysis was chosen a priori as part of the study protocol to reduce researcher bias in the identification of factors of interest, and also with the intention to use the same method in subsequent research comparing systems maps over time and between countries. These were considered along with the outcomes of the small and large group discussions to define the purpose of the subsequent model simulations and inform the model parameter specifications. Following the workshops, the participants provided feedback on the summaries of the activities and discussions to ensure that the notes accurately reflected the content, and verified the final digitised versions of the systems maps. Additional inputs from participants were included through individual discussions as the modelling process progressed, with respect to their time commitments through 2020.

## 3.2.4 Model and Simulation Overview

In terms of appropriate methods for incorporating complexity, individual-based modelling is able to accommodate the stochastic, non-linear, and dynamic interactions between humans and the environment in the transmission cycle of schistosomiasis. In addition, and of importance for the purposes of this study, it is scalable (from a village to a national setting), adaptable across contexts, flexible in the types of information that can be included, and inclusive in the ways that outputs can be communicated. The SCHISTOX model employed in this study is an individualbased simulation model developed by Graham et al (2021). In addition to the suitability of its stochastic framework and inclusion of both S. mansoni and S. haematobium species, the SCHISTOX model has the distinct advantage in its development as an open-source repository on GitHub (Graham, 2021), which can be run in Julia or through an R wrapper. This latter point is particularly important in that it allows for more straightforward communication with workshop participants, as they are able to see and work with the actual coding, when compared to other stochastic models of schistosomiasis transmission, which were reported as being seen by participants as "black boxes." Model parameters, categorised as human population, parasite population, transmission, or control, can be explicitly specified based on a given context and available information. Given the prevalence of both S. haematobium and S. mansoni across Uganda, models were run to include the relevant parameter specifications adapted for both species. Parameters were defined by Graham et al's SCHISTOX publication (Graham et al., 2021), the SCHISTOX model documentation on GitHub (last accessed October 2021) (Graham, 2021), personal correspondence with the model developers, and in consultation with workshop participants. As discussed next, the primary focus of the simulations presented here was to observe how changes in the population water contact parameter would impact the prevalence, with specific reference to the WHO target timelines, while holding the other initialisation

parameter values constant. All parameter specifications used in this study can be found in Supplementary Materials Section 2.

To initialise the simulations, each species-specific model was run for 100 years under high prevalence scenarios to establish epidemiological equilibrium within the population. The aim of the simulations followed the results of the PSM workshops and subsequent discussions with participants. In particular, participants were interested in the potential impacts of limiting water contact and had suggested a variety of context- and place-specific interventions. Some of these interventions included providing gum boots to rice farmers and fisher-folk, clothes washing stations, and bathing shelters (see Supplementary Materials Section 4, Theme 2 for additional details from participants related water contact.) Given the aim to provide generalised guidance to these diverse situations, exploratory age-specific water contact was simulated over a series of proportional reductions which could then be applied in local contexts and decisionmakers to scale preferred interventions.

To provide guidance on the potential impact of intervention combinations, four scenarios were considered in high prevalence *S. mansoni* and *S. haematobium* settings. Reduction in water contact was considered alongside MDA implementation. MDA coverage for school-age children was simulated at two levels in accordance with the current WHO and national guidelines: (1) the most recent reported median coverage for high prevalence districts (46%, range) (ESPEN 2021), and (2) the recommended target coverage of 75% (WHO, 2020). The reported median coverage for high prevalence districts in Uganda was selected to provide a relevant reference point, relative to the recommended target coverage, for district and sub-district decision-makers. The simulations were run for ten years in the SCHISTOX R interface.

## 3.2.5 Patient and Public Involvement

There were no funds or time available for patient or public involvement in this study. Additional research based on this study involving individuals with schistosomiasis is being developed. However, we are cognizant of the effects of the ongoing COVID-19 pandemic in the areas where we work and are putting our efforts into the pressing needs of the health workers and patients ahead of a research agenda.

## 3.3 Results

The systems maps produced through PSM presented complex, dynamic perspectives on the transmission of schistosomiasis across Uganda. The participants identified key points of potential intervention as centred around water contact from economic, household, hygiene, and leisure activities. The aggregate systems map (Figure 1) shows five factors directly influencing schistosomiasis transmission: open defecation/urination, ingestion of the schistosomiasis drug praziquantel, quality/standard of schistosomiasis drugs (drug efficacy), population of snail vectors, and contact with infested water. The factors identified as directly or indirectly effecting schistosomiasis transmission were across eight categories: individual behaviours, beliefs and knowledge, health system components and activities, environmental/ecological, schistosomiasis treatment/drugs, WASH, water contact activities, and governance/politics. The small group maps can be found in Supplementary Materials Section 3. The key discussion points which emerged from the small and large group discussions are summarised in Table 1 and Supplementary Materials Section 4.

No.	Key discussion point	Specific examples
1	Water contact is an especially important transmission/potential control point which allows for substantial flexibility in the design of interventions and control of implementation components at the local level.	Specific control points were economic activities (fishing, rice farming, and snail harvesting), household activities (washing, fetching water), and hygiene activities (bathing, latrine use)
2	The only group level focused on MDA implementation was comprised of members of village health teams (VHTs); the district and national level groups mentioned the intervention, but not in detail.	As the group directly responsible for MDA implementation, the VHTs detailed material support (bags to carry medicines, fuel, salaries) as factors influencing MDA implementation
3	Individuals from all groups discussed the lack of available treatment in communities outside of MDA implementation periods.	The lack of treatment availability in health facilities leads to the inability to provide proper case management with the absence of drugs in lower level health facilities or with VHTs
4	Communication related to schistosomiasis transmission and interventions needs to be improved between the national, district, and village levels.	There was a disconnect in the dissemination of updated, relevant and useful materials from the national to the subnational levels, specifically these concerns were the need for translation into local languages and the provision of hard copy formats.
5	The system for collecting data related to schistosomiasis is inefficient and ineffective for routine use and facilitating responses.	Data collection and feedback is a patchwork of reliability and completely dependent on the individual data collector at the community level and the aggregator at the district level.

Table 3-1 Key discussion points and examples from Participatory Systems Mapping workshop and follow-up

To further analyse the structure of the aggregate systems map, network centrality metrics were determined for each of the factors. In line with the small and large group discussions, the factors with the highest degree centrality, that is those with the highest number of incident links from and to other factors, were "contact with infested water" and "open defecation and urination" (see Supplementary Materials Section 5 for all network centrality metrics.) This suggests that these are vital intervention points in the system of schistosomiasis transmission from the perspectives of the workshop participants.

As discussed above, following on from the outputs of the participatory modelling and analysis of the aggregate map, the simulation activities centred around reductions in water contact. As an exploratory step, simulated reductions in the age-specific water contact in relation to the initialisation parameters were tested. Results showed that decreasing contact with infected water by 75% across all ages in high *S. mansoni* prevalence settings, while holding all else equal, achieved morbidity control within 20 years and achieved elimination as a public health problem within 30 years. In high *S. haematobium* settings, water contact reductions of 75% achieved morbidity control within 15 years and elimination within 20 years. (All of the water contact exploratory simulation results can be found in Supplementary Materials Section 6.)

Further simulations were used to compare the impact of water contact reductions with current and target MDA coverage levels on the prevalence of schistosomiasis, individually and in combination (Figure 2.) The simulation results showed that employing MDA for school age children (SACs) as the sole intervention, at both the current median coverage level in high prevalence districts in Uganda (46%), and the policy-recommended target of 75% coverage, did not achieve either morbidity control or elimination within the ten-year time period. The results showed that combining water contact reduction interventions at 75% with the current (46%) or target (75%) MDA coverage reached the most recent WHO's NTD Road Map to 2030 targets of morbidity control and elimination in both *S. mansoni* and *S. haematobium* settings within ten years. While the simulations indicated that morbidity control and elimination could be achieved, as these indicators pertain to high intensity infections, it should be noted that population prevalence did not achieve 5% or 1% targets in settings with either species within ten years (Figure 2.)

### Figure 3-1 Aggregated systems map





legend for abm diagram 12apr21.drawio

#### Systems Mapping workshop and follow-up



#### A. Heavy burden prevalence S. mansoni setting





#### C. Population prevalence S. mansoni setting

#### D. Population prevalence *S. haematobium* setting



Note: H2O contact interventions, implementation of water contact reduction interventions to decrease contact by 75%; Current MDA, most recent reported median coverage of School Age Children (SACs) for high prevalence districts in Uganda (46%); Target MDA, recommended target coverage of SACs in high prevalence districts of 75%; these results were not adjusted for diagnostic sensitivity.

## 3.4 Discussion

This study used participatory systems mapping (PSM) to elicit and depict the perspectives of Ugandan policymakers and practitioners on factors related to schistosomiasis transmission and interventions. Focus group discussions and follow-up interviews provided additional information and insights as to their evidence needs and guided the subsequent modelling activities. These outputs framed individual-based modelling simulations and were incorporated into the model parameter specifications. Simulations were used to predict the impacts of water contact reductions in communities of high *S. haematobium* and *S. mansoni* prevalence settings. The combination of participatory systems mapping and individual-based modelling was a rich strategy which explicitly integrated the perspectives of national and subnational policymakers and practitioners into the development of evidence for decision-making related to schistosomiasis control and elimination activities.

The visualisations of the schistosomiasis transmission system were produced by national, district, and village-level policymakers and practitioners involved in schistosomiasis control and elimination activities. The systems maps indicated causal effects and the directionality of these effects (positive or negative) by linking factors where relationships were perceived to exist. The digitised versions of the maps served as depersonalised expressions of consensus by small groups that facilitated conversations in the large group about difficult topics, related in particular to resources, data, and the lack of sustained reductions in prevalence after years of deworming interventions. These discussions may not have otherwise taken place openly given the social dynamics between district-level and national-level participants. Feedback from participants indicated that they hoped to use the systems maps to advocate for resources they deemed necessary from within the Uganda and amongst international donors and aid agencies, as the maps were viewed as leverage in a system of top-down decision-making around schistosomiasis control activities. Participatory systems mapping encouraged critical thinking and provided the space to develop potential solutions based on lived and professional experiences. From the systems maps, it was clear that participants at the national, district, and village levels were most focused on factors that increase or decrease infested water contact, a key intervention point in the schistosomiasis transmission cycle. This perspective was used to guide the model simulation activities.

The SCHISTOX individual-based model by Graham et al (2021) was employed to simulate the impacts of age-specific reductions in water contact under various scenarios. The results showed that employing MDA alone, at either the current or target levels of SAC coverage, did not result in achieving the most recent NTD Road Map to 2030 targets of morbidity control or elimination in high prevalence settings within ten years. However, when combined with water contact reduction activities, morbidity control was reached in *S. mansoni* settings and morbidity control and elimination were achieved in *S. haematobium* settings within the same ten-year time period. These outcomes were modelled in the context of high prevalence levels and may not be generalisable to low or moderate prevalence settings.

There were several important insights from this study relevant to the broader context of the NTD Road Map to 2030 and the global strategies for achieving schistosomiasis morbidity control and elimination. The participatory systems mapping supported critiques about mass deworming strategies as vertical, top-down interventions (Tchuem Tchuenté *et al.*, 2017; Mazigo, 2019). The simulations provided further evidence that MDA alone will not achieve the prevalence reduction targets (Li *et al.*, 2019; Toor *et al.*, 2020). Individuals from village health teams (VHTs) were the only group to specifically discuss the implementation of MDA in relation to schistosomiasis transmission, most likely because they were directly responsible for carrying out these activities. The lack of access to treatment for routine care within the communities,

leading to the inability to provide adequate case management, were important gaps highlighted in the context discussions about MDA.

Interventions to reduce exposure to infected water were not included in the WHO's NTD Road Map to 2030, despite being the reported driver to elimination of schistosomiasis in previous case studies in the same document. In this study, water contact was described as the key potential intervention point in the schistosomiasis transmission cycle by participants and reduction in water contact was shown in simulations to be an important component leading to decreased prevalence and eventual elimination. Previous empirical work by Knopp et al showed that behavioural and educational interventions were not as effective at reducing schistosomiasis prevalence as MDA alone or as integrated components (Knopp *et al.*, 2019), although, as has been discussed elsewhere (Mazigo, 2019), the integrated components may not have been implemented widely enough to generalise the findings.

There is clearly still a need to better understand the feasibility and costs of water contact reduction interventions. In most places with a high prevalence of schistosomiasis infections, contact with local water bodies underpins the social, economic, and hygiene activities of daily life. Therefore, any adaptations to these activities would need to be developed and led from within communities in order to achieve meaningful reductions in water contact. The degree to which this is feasible, and the extent of the impact, is entirely context-specific and dependent on holistic approaches to funding and implementation. In addition, a bigger push toward community-wide MDA in all relevant high-prevalence areas, improvements in diagnostics, the prospects of a vaccine, and a host of other innovative technologies will undoubtedly play a role in moving toward the elimination of schistosomiasis as a public health problem.

It is also important to acknowledge the challenges with implementing participatory modelling and the potential issues with its outputs. Clearly the biggest limitation of the work presented here is that participatory modelling activities are very resource intensive, both in time and money. Prior to the implementation of the activities, it requires relationship building to foster credibility and buy-in from participants. In terms of outputs, fundamentally, the systems maps are abstractions of reality. These are negotiated representations of individual perspectives which do not 'objectively' nor entirely capture the system which results in schistosomiasis transmission. In this way, actually, the outputs of participatory modelling are akin to the outputs of mathematical modelling: both are inherently biased by the composition of individuals whose inputs drive and shape these processes. One of our broader aims of this work was to explore how we might explicitly use these biases to allow for locally fostered approaches to evidence for decisionmaking.

## 3.5 Conclusion

The WHO's NTD Road Map to 2030 calls for a country-led process supported by partners. If this is meant beyond rhetoric, partner organisations need to engage with policymakers and practitioners in endemic countries, not only as the recipients of evidence for decision-making or facilitators of interventions produced outside the communities,

but as individuals capable of driving these processes. This study demonstrates one of many possible strategies to integrate a wider range of perspectives in the form of individuals directly involved in the policy, oversight, and implementation of schistosomiasis control and elimination strategies within endemic countries. Inclusivity and the flexibility to allow innovation to be driven by a more diverse set of voices and experiences will push the sustainable reduction in the burden of schistosomiasis by 2030.

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## Contributors

CAF, MP, SK, BO, NO, TA implemented the study and provided interpretations of the data. CAF guided the conceptualisation and investigation, wrote the first draft of the Article, and guided the writing, review, and editing. All authors contributed to drafting the work or revising it critically for important intellectual content, and all authors have read and approved the final version. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The funder of the study had no role in the study design, data collection, data analysis, data interpretation, or writing of the report. The authors had full access to all the data in the study and accept responsibility for the decision to submit for publication.

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## **Declaration of interests**

We declare no competing interests.

## Ethics approval

Ethical clearance and permission for the relevant components of this study were granted from the London School of Economics and Political Science Research Ethics Committee (reference number 000914) and the Uganda National Council for Science and Technology (Research Registration Number HS1285ES). Written informed consent was obtained from all workshop participants.

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# 3.7 Supplementary materials

Factors from group systems maps (PSM exercise) Group map Standardised factor		Factor Type	
Bachelors or unmarried			
bathing in contaminated			
water	VHT	Bathing in water bodies	Behaviours
Bathing in natural water		0	
sources	National	Bathing in water bodies	Behaviours
Bathing in water	District1	Bathing in water bodies	Behaviours
Belief that lake/river water is pure and cleansing	National	Water immersion rituals	Behaviours
Children playing in water	District1	Playing and swimming	Behaviours
Children playing/swimming	District2	Playing and swimming	Behaviours
Children playing/swimming in contaminated water	VHT	Playing and swimming	Behaviours
Community mobilisation to participate in health related issues	District2	Community mobilisation for SCH activities	Behaviours
Compliance to pzq	District1	Proportion of population ingest SCH drugs (PZQ)	Behaviours
Going for stool examination	District1	People seek care for SCH	Behaviours
Leisure activities/swimming	National	Plaving and swimming	Behaviours
MDA coverage (neonle taking	Nutional	Proportion of population ingest	
nills)	National	SCH drugs (PZO)	Behaviours
Mothers take children for		Mothers take children for	
deworming	VHT	deworming	Behaviours
People seek care for sch			
symptoms	District2	People seek care for SCH	Behaviours
People seek consultation for			
sch symptoms	VHT	People seek care for SCH	Behaviours
		Proportion of population ingest	
People take sch drugs	VHT	SCH drugs (PZQ)	Behaviours
		Proportion of population ingest	
People taking PZQ	National	SCH drugs (PZQ)	Behaviours
Refugees or migrants bathing			
in contaminated water	VHI	Bathing in water bodies	Behaviours
School attendance	VHT	School attendance	Behaviours
Taking sch tx	District1	Proportion of population ingest SCH drugs (PZQ)	Behaviours
	District2	Proportion of population ingest	Dehevieure
Uptake of sch meds	District2	SCH drugs (PZQ)	Benaviours
wasning in natural water	National	Washing in water bodies	Poboviours
Water immercien initiation	National	washing in water bodies	Benaviours
rituals including immersive			
hantism	National	Water immersion rituals	Behaviours
Adequate health edu about	National	Adequate knowledge about SCH in	benaviours
sch	District1	communities	Beliefs and Knowledge
	2.00.002	Adequate health education in the	
Adequate health education	National	communities	Beliefs and Knowledge
Adequate knowledge on sch		Adequate knowledge about SCH in	<u> </u>
transmission	District1	communities	Beliefs and Knowledge
Adequate sch knowledge in		Adequate knowledge about SCH in	
the community	VHT	communities	Beliefs and Knowledge

Table 3-2 Participatory systems mapping full list of factors and standardisations

Attitude about taking the sch			
meds	District1	Fear of side effects	Beliefs and Knowledge
Awareness about sch in		Adequate knowledge about SCH in	
communities	District1	communities	Beliefs and Knowledge
Belief that feces deposited in			
the water will increase fish		Belief that faeces deposited in H2O	
catch	National	increase fish stock	Beliefs and Knowledge
Belief that pregnant women		Belief that pregnant women should	
should not use latrine	National	not use latrines	Beliefs and Knowledge
Cultural beliefs about			
outdoor defecation - esp		Belief that pregnant women should	
regarding pregnant women	District2	not use latrines	Beliefs and Knowledge
	<b>A 1 1 1 1</b>		
Fear of side effects	District1	Fear of side effects	Beliefs and Knowledge
Husbands refuse wives to		Proportion of Husbands refuse	
swallow meds	District1	wives to swallow SCH drugs	Beliefs and Knowledge
Incorrect myths about sch or		Prevalence of Myths about SCH and	
sch meds	VHI	SCH meds	Beliefs and Knowledge
Knowledge about sch in the		Adequate knowledge about SCH in	
community	District2	communities	Beliefs and Knowledge
Knowledge of benefits of		Knowledge of benefits of latrine	
latrine use	National	use	Beliefs and Knowledge
Latrine beliefs (pregnant		Belief that pregnant women should	
woman loses child)	District1	not use latrines	Beliefs and Knowledge
Religious sector dont believe		Prevalence of Myths about SCH and	
in modern meds	District1	SCH meds	Beliefs and Knowledge
Sch education for VHTs and		Adequate knowledge about SCH in	
religious leaders	VHT	communities	Beliefs and Knowledge
		Proportion Fishing without	
Fishing activities	VHT	protective gear	Economic
Fishing in infested waters		Proportion Fishing without	
without protective gear	National	protective gear	Economic
Fishing without protective		Proportion Fishing without	
gear	District2	protective gear	Economic
Full time boat use for		Proportion Fishing without	
economic activities	National	protective gear	Economic
		Snail harvesting without protective	
Harvesting snails	District1	gear	Economic
Logging without protective		Proportion logging without	
gear	National	protective gear	Economic
Migration to district for		Migration to district for economic	
economic purposes	District2	purposes	Economic
Mongering without		Proportion Fishing without	
protective gear	District2	protective gear	Economic
-		Proportion rice farming without	
Rice farming activities	VHT	protective gear	Economic
Rice growing/harvesting		Proportion rice farming without	
without protective gear	National	protective gear	Economic
Snail harvesting as an		Snail harvesting without protective	
economic activity	National	gear	Economic
Snail harvesting without		Snail harvesting without protective	
protective gear	District2	gear	Economic
		Snail harvesting without protective	
value/price of snail shells	District1	gear	Economic
Availability of snails that are			
Infected	National	Shall vector population	Environmental/Ecological
Presence of snail vectors	District2	Snail vector population	Environmental/Ecological
Adequate infrastructure for		Infrastructure to avoid H2O,	
avoiding water - esp bridges	National	bridges	Environmental/Ecological
			-

Adequate			
infrastructure/bridges for	infrastructure/bridges for Infrastructure to avoid H2O,		
crossing water	District1	bridges	Environmental/Ecological
Living near water bodies	National	Households located near water bodies	Environmental/Ecological
Proper maintenance of water dams	National	Proper maintenance of H2O dams	Environmental/Ecological
			, , ,
Advocacy about sch at the		Advocacy about SCH at the district	
district and national level	District2	and national level	Governance and Politics
Crackdown on lliegal fishing	National	Enforcement of lilegal fishing laws	Governance and Politics
Funding for sch activities	District2	Funding for SCH activities	Governance and Politics
Introduction and		Introduction and enforcement of	
Enforcement of local bi-laws	VHT	local bi-laws	Governance and Politics
Political will to deal with sch		Political will/leadership related to	
at the LC1-5 level	District2	SCH and WASH	Governance and Politics
		Political will/leadership related to	
Political will/leadership	VHT	SCH and WASH	Governance and Politics
Presence and Enforcement of		Introduction and enforcement of	
community bylaws	District2	local bi-laws	Governance and Politics
Private sector support	District2	Funding for SCH activities	Governance and Politics
Access of VHTs to fisher folk			
areas	District1	Proper implementation of MDA	Health System
		Accuracy of SCH-related data	
Accurate data on sch	District1	reporting	Health System
Adequate and responsive			
health system surveillance			
system	District2	Adequate response to data	Health System
Adequate diagnostic/lab			
capacity	District1	Adequate diagnostic/lab capacity	Health System
Adequate logistics (time and			
transport) for drug			
distribution	District1	Proper implementation of MDA	Health System
Adequate tech staff for sch			
programme	District1	Proper implementation of MDA	Health System
Advocacy and mobilization		Health worker mobilisation for SCH	
within the districts	National	activities	Health System
Appropriate quantity of PZQ	D: 1 : 14		
for MDA	District1	Proper implementation of MDA	Health System
Available transport to sub	VUIT	Dranar implementation of MDA	Liggith System
	VIII	Proper implementation of MDA	Health System
district store	VHT	Proper implementation of MDA	Health System
Community acceptance of	VIII		The and the system
VHTs	District1	Proper implementation of MDA	Health System
VIIIS	District		The art of system
Correct/adequate training for			
administering tx (during mda)	VHT	Proper implementation of MDA	Health System
Delays in funding and meds			
for MDA	District1	Proper implementation of MDA	Health System
Diagnostic capacity at health			<i>i</i> -
facilities - lab/clinician skills			
and equipment	District2	Adequate diagnostic/lab capacity	Health System
Drug stock at contro	Л	Proper implementation of MDA	Hoalth System
Drug stock at district store	VHT	Proper implementation of MDA	Health System
Talattian follo	Distail 14	Accuracy of SCH-related data	Line altebra Count
Faisification of data	DISTRICT	reporting	Health System

	Food availability at time of		Food availability at time of SCU	
	take w mode	District2	Food availability at time of SCH	Health System
-	Human resources for health	DISTINCT	Human resources for health at the	Health System
	at the district level	District2	district level	Health System
	Irregular MDA	District1	Proper implementation of MDA	Health System
	M&E related control efforts	51.1.1.0		
_	related to sch	District2	Accuracy of M&E of SCH	Health System
	No dose poles or weight	N/UT		Lie althe Granta an
_	Scales	VHI	Proper implementation of MDA	Health System
	(national lovel) and denors	District1	Broper implementation of MDA	Hoalth System
_		DISTICT	Propertion of SCH cases with	Treatth System
	Proper case management	District2	proper case management	Health System
-	Respect for VHT in the	DISTINCE	proper case management	Theaten System
	community	VHT	Proper implementation of MDA	Health System
_	Timely and accurate sch		Accuracy of SCH-related data	
	surveillance data	District2	reporting	Health System
-	Unmanaged sch cases	2.000.002	Proportion of SCH cases with	
	(human reservoir)	District2	proper case management	Health System
	VHT giving the wrong dose			
	(too low)	VHT	Proper implementation of MDA	Health System
	VHT is able to pick drugs from			
	the parish level	VHT	Proper implementation of MDA	Health System
		N/UT		
_	VH1 motivation	VHI	Proper implementation of MDA	Health System
	VHT salary	VHT	Proper implementation of MDA	Health System
	VHTs find people at home			
	during MDA	VHT	Proper implementation of MDA	Health System
	VHTs have adequate storage			
	for drugs	VHT	Proper implementation of MDA	Health System
	VHTs have adequate			
	transport	VHT	Proper implementation of MDA	Health System
	VHTs have carrying bags for			
_	drugs	VHT	Proper implementation of MDA	Health System
	VHTs have stock of drugs	VHT	Proper implementation of MDA	Health System
	VHTs have time to distribute		- · · · · · · · · · · ·	
_	drugs during MDA	VHT	Proper implementation of MDA	Health System
	VHTs reach people's homes			
_	during MDA	VHI	Proper implementation of MDA	Health System
	Schistosomiasis transmission	District1	Schistosomiasis transmission	Outcome
	Schistosomiasis transmission	District2	Schistosomiasis transmission	Outcome
	Schistosomiasis transmission	National	Schistosomiasis transmission	Outcome
	Schistosomiasis transmission	VHT	Schistosomiasis transmission	Outcome
-			Access to SCH drugs outside of	
	Access to sch meds	District2	MDA	Treatment
_	Availability of PZO in health		Access to SCH drugs outside of	
	facilities	District2	MDA	Treatment
F			Availability of drug formulation for	
l	Availability of sch tx for U5s	District1	U5s	Treatment
ľ	·		Availability of drug formulation for	
l	Drug formulation for U5s	District2	U5s	Treatment
Γ	Effectiveness of quality or			
L	standard of drugs	VHT	SCH drug effectiveness/quality	Treatment
l			Access to SCH drugs outside of	
L	Missing PZQ	National	MDA	Treatment
1	Price of PZQ	District2	Price of SCH drugs	Treatment
L_	1.		0-	

PZQ is not considered an	D: 1 : 12	Access to SCH drugs outside of	<b>-</b>
essential drug	District2	MDA Proportion of population ingest	Treatment
Sch drug coverage	District1	SCH drugs (PZQ)	Treatment
Sch drugs available at health		Access to SCH drugs outside of	
facilities	VHT	MDA	Treatment
U5s taking sch meds	District1	Availability of drug formulation for U5s	Treatment
Access to potable water	District2	Access to potable water	WASH
Availability of bathing shelters	VHT	Availability of bathing shelters	WASH
Availability of boreholes	District1	Availability of latrines	WASH
Availability of latrines	District1	Availability of latrines	WASH
Availability of pit latrines	District2	Availability of latrines	WASH
Availability of potable water	VHT	Access to potable water	WASH
Availability of notable water	District1	Access to notable water	WASH
Cannot dig minimum 15' requirement for latrine (time,		Lack space for nit latrings	WASH
			WASH
Lack of boreholes	VHT	Availability of latrines	WASH
Latrine availability	National	Availability of latrines	WASH
Latrine usage	District1	Latrine use	WASH
Latrine use	National	Latrine use	WASH
Open defecating in water/stream	District1	Open defecation/urination	WASH
Open defecation	District2	Open defecation/urination	WASH
Open defecation in water	VHT	Open defecation/urination	WASH
Open urination/defecation	National	Open defection (urination	MACH
People obtain water from	INALIONAL	Open derecation/unnation	WASH
open source	VHT	Access to potable water	WASH
Poor texture for building pit	District2	Lack chock for hit latrings	WASH
Poor texture of soil at landing			WASH
sites to dig latrines	District1	Lack specs for pit latrines	WASH
toilet use	District2	Latrine use	WASH
Availability and use of gum boots			
Availability and use of	VHT	Availability and use of protective gear for water work	Water Contact
protective gear - gum boots,	VHT	Availability and use of protective gear for water work	Water Contact
	VHT	Availability and use of protective gear for water work Availability and use of protective	Water Contact
gloves, overalls	VHT	Availability and use of protective gear for water work Availability and use of protective gear for water work	Water Contact Water Contact
gioves, overalls Availability of protective gear	VHT National	Availability and use of protective gear for water work Availability and use of protective gear for water work Availability and use of protective	Water Contact Water Contact
gioves, overalls Availability of protective gear for work in water	VHT National District1	Availability and use of protective gear for water work Availability and use of protective gear for water work Availability and use of protective gear for water work	Water Contact Water Contact Water Contact
Availability of protective gear for work in water Contact with infected water	VHT National District1 District1	Availability and use of protective gear for water work Availability and use of protective gear for water work Availability and use of protective gear for water work Contact with infested H2O	Water Contact Water Contact Water Contact Water Contact
Availability of protective gear for work in water Contact with infected water Contact with infested waters	VHT National District1 District1 National	Availability and use of protective gear for water work Availability and use of protective gear for water work Availability and use of protective gear for water work Contact with infested H2O Contact with infested H2O	Water Contact Water Contact Water Contact Water Contact Water Contact
Availability of protective gear for work in water Contact with infected water Contact with infested waters Enter contaminated water	VHT National District1 District1 National VHT	Availability and use of protective gear for water work Availability and use of protective gear for water work Availability and use of protective gear for water work Contact with infested H2O Contact with infested H2O Contact with infested H2O	Water Contact Water Contact Water Contact Water Contact Water Contact Water Contact
Availability of protective gear for work in water Contact with infected water Contact with infested waters Enter contaminated water Exposure to infested water	VHT National District1 District1 National VHT District2	Availability and use of protective gear for water work Availability and use of protective gear for water work Availability and use of protective gear for water work Contact with infested H2O Contact with infested H2O Contact with infested H2O Contact with infested H2O	Water Contact Water Contact Water Contact Water Contact Water Contact Water Contact Water Contact Water Contact
gioves, overalls Availability of protective gear for work in water Contact with infected water Contact with infested waters Enter contaminated water Exposure to infested water	VHT National District1 District1 National VHT District2	Availability and use of protective gear for water work Availability and use of protective gear for water work Availability and use of protective gear for water work Contact with infested H2O Contact with infested H2O Contact with infested H2O Contact with infested H2O Availability and use of protective	Water Contact Water Contact Water Contact Water Contact Water Contact Water Contact Water Contact Water Contact
gioves, overalls Availability of protective gear for work in water Contact with infected water Contact with infested waters Enter contaminated water Exposure to infested water Fisher folk not using protective gear	VHT National District1 District1 National VHT District2 District1	Availability and use of protective gear for water workAvailability and use of protective gear for water workAvailability and use of protective gear for water workContact with infested H2OContact with infested H2OAvailability and use of protective gear for water work	Water Contact

Rice and yam farmers not		Availability and use of protective	
using protective gear	District1	gear for water work	Water Contact
Use of personal protective		Availability and use of protective	
gear	District2	gear for water work	Water Contact

## 3.7.1 Mathematical modelling inputs

The primary purpose of the simulation results presented in this paper was to observe how variations (decreases in particular) in the population water contact parameter would impact the prevalence, while holding the other initialisation parameter values constant. The parameters were informed by four sources: (1) Graham et al's SCHISTOX publication<sup>33</sup>, (2) the SCHISTOX model documentation on GitHub<sup>34</sup>, (3) personal correspondence with the model developers, and (4) in consultation with workshop participants. Consultation with the workshop participants included written and verbal communication, both during the workshop and after the workshop as the parameters were specified. These communications continued through July 2021, and are ongoing as additional components of the project continue. In some cases, participants agreed that a value described in the SCHISTOX parameterisation documentation adequately reflected their contexts for the purposes of the simulation. In others cases, individual input, followed by group negotiation and consensus, determined the input value. All of the parameters were put up for discussion and confirmation by the participants, though only the ones which generated comments, and the extent of the input, are noted in the Table S2 below.

Parameter	Initial value/specification	Source
N (population)	750	Input from workshop participants on the average most relevant population size
Time step	10	Parameterization documentation <sup>2</sup>
N communities	1	Parameterization documentation <sup>2</sup> and input from workshop participants
Density dependent fecundity	0.0007 (S. mansoni); 0.0006 (S. haematobium)	Parameterization documentation <sup>2</sup> and personal correspondence with the model developers
Average worm lifespan	5.7 years (S. mansoni); 4 years for (S. haematobium)	Graham et al's SCHISTOX publication <sup>1</sup>
Maximum age in the population (years)	100	Confirmed by workshop participants as the most appropriate for their purposes
Miracidia maturity	24 (S. mansoni); 21 (S. haemotobium)	Graham et al's SCHISTOX publication <sup>1</sup> and parameterization documentation <sup>2</sup>
Contact rate	0.1	Parameterization documentation <sup>2</sup> and personal

Table 3-3 Parameter specifications

 <sup>&</sup>lt;sup>33</sup> Graham M, Ayabina D, Lucas TCD, *et al.* SCHISTOX: An individual based model for the epidemiology and control of schistosomiasis. *Infectious Disease Modelling* 2021
 <sup>34</sup> Graham M. Schistoxpkg.jl. 2021 <u>https://github.com/mattg3004/Schistoxpkg.jl</u>. (last accessed October 2021)

		correspondence with the
		model developers
Max fecundity	50	Parameterization
		documentation <sup>2</sup> and personal
		correspondence with the
		model developers; the max
		fecundity and max fecundity
		contact rate product (below)
		were set based on an
		investigation into the system
		behaviour in varving these
		parameters for the model
		simulation to reach
		equilibrium at a high
		population prevalence (>50)
Max fecundity contact rate product	1/15	Parameterization
	1,10	documentation <sup>2</sup> and personal
		correspondence with the
		model developers: the max
		fecundity and max fecundity
		contact rate product (above)
		were set based on an
		investigation into the system
		heboviour in varying these
		parameters for the model
		simulation to roach
		simulation to reach
		equilibrium at a flight
Ago contact rates	a(0.0008_0.4563_0.4434	Population prevalence (>50)
Age contact rates	C(0.0998, 0.4503, 0.4424, 0.0015)	Parameterization
	0.0013)	documentation and personal
		correspondence with the
		model developers; these
		rates are normalised to 1
	(4.0.45.400)	across the array
Ages for contacts	c(4, 9, 15, 100)	Parameterization
		documentation <sup>2</sup> and
		confirmed by workshop
		participants as the most
		appropriate for their
		purposes
MDA adherence	0.9	Parameterization
		documentation <sup>2</sup> and
		confirmed by workshop
		participants as adequately
		reflecting their contexts in
		general; although it should
		be noted that the village-
		level participants were
		especially interested in the
		impacts of varying this

		parameter and that work is
		ongoing
MDA access	0.9	Parameterization
		documentation <sup>2</sup> and
		confirmed by workshop
		participants as adequately
		reflecting their contexts in
		general: as with MDA
		adherence (above) while it
		was agreed that this
		narameter would be kent
		defined as in the
		noremotorization
		parameterization
		documentation for the
		purposes of this simulation,
		the village-level participants
		were particularly interested
		in observing the impacts of
		varying this parameter
Factor for altering the contact rate for	1	Parameterization
females		documentation <sup>2</sup>
Factor for altering the contact rate for males	1	Parameterization
		documentation <sup>2</sup>
Proportion of cercariae which are able to	1	Graham et al's SCHISTOX
infect humans		publication <sup>1</sup> and
		parameterization
		documentation <sup>2</sup>
Aggregation for predisposition of individuals	0.24	Parameterization
to uptake larvae		documentation <sup>2</sup>
Proportion of cercariae that survive from	1/2	Graham et al's SCHISTOX
one time point to the next	_,_	publication <sup>1</sup> and
		parameterization
		documentation <sup>2</sup>
Proportion of miracidia that survive from	1/2	Graham et al's SCHISTOX
and time point to the port	1/2	publication <sup>1</sup> and
one time point to the next		
		parameterization
death areh hu ana		Devenue to visation
death prob by age	C(0.0656, 0.0093, 0.003, 0.0	Parameterization
	0.0023, 0.0027, 0.0038,	documentation
	0.0044, 0.0048, 0.0053,	
	0.0065, 0.0088, 0.0106,	
	0.0144, 0.021, 0.0333, 0.0529,	
	0.0851, 0.1366, 0.2183,	
	0.2998 , 0.3698, 1)	
ages for death	c(1, 5, 10, 15, 20, 25, 30, 35,	Parameterization
	40, 45, 50, 55, 60, 65, 70, 75,	documentation <sup>2</sup>
	80, 85, 90, 95, 100, 110)	
vaccine effectiveness	0.95	Graham et al's SCHISTOX
		publication <sup>1</sup> and
		parameterization
		documentation <sup>2</sup>

drug effectiveness	0.863 (S. mansoni); 0.94 (S. haematobium)	Parameterization documentation <sup>2</sup>
Specified age structure	c(8639, 9082, 6424, 5074, 4425, 3847, 3628, 3062, 2436, 1770, 1868, 1066, 743, 518, 355, 144)	Parameterization documentation <sup>2</sup>
Ages per index	5	Parameterization documentation <sup>2</sup>
Heavy burden threshold	400 eggs/1 gram faeces (S. mansoni); 50 eggs/10mL urine (S. haematobium)	Graham et al's SCHISTOX publication <sup>1</sup> and parameterization documentation <sup>2</sup>
Rate acquired immunity	0	Parameterization documentation <sup>2</sup>
Human larvae maturity time (in days)	30	Parameterization documentation <sup>2</sup>
Input ages	c(4, 9, 15, 100)	Parameterization documentation <sup>2</sup> and confirmed by workshop participants as the most appropriate for their purposes
Input contact rates	c(0.032, 0.610, 1, 0.06)	Parameterization documentation <sup>2</sup>
scenario	"high adult"	Parameterization documentation <sup>2</sup> and confirmed by workshop participants as adequate for the purposes of these specific simulation activities

## Participatory systems mapping results

Figure 3-3 Small group participatory systems maps: National level







Figure 3-5 Small group participatory systems maps: District level 2



Key → →

- Positive relationship
- Negative relationship

Figure 3-6 Small group participatory systems maps: Village level



Key Negative relationship Positive relationship 3.7.2 Excerpts of commentary from workshop participants on schistosomiasis transmission and control

# Reasons schistosomiasis transmission continues after all these years of mass drug administration

- These people are fishing communities and so their fishing habits continue to be the same despite years of MDA. They continue to enter in the lake for fishing and other related activities, and therefore there's continuous infection and re-infection with schisto and other worms. This observation is in line with arguments that MDA alone isn't sufficient to control or eliminate schisto in endemic areas. As it is, MDA mainly focuses on treatment of people believed to be at risk of infection but does little to prevent people from being infected at least for now, there's little or rather no evidence suggesting so.
- The behavioural change activities on schisto control is very low and seasonal, that's, it's only that time and period when there's MDA that the community gets to hear something related to schisto control. In other words, there's an uncoordinated behavioural change programs with regard to control of schisto. In so doing, key messages about how to break the lifecycle of schisto are often forgotten along the way.
- There's variation in sanitation standards in [district anonymised] and its surrounding areas. The soil textures in majority of landing sites in Uganda is sandy and so it's very difficult to dig and have long lasting pit latrines but even so, the fewer latrines dug are normally washed away during rainy seasons. So people resort to open defecation in the bush, around water streams and so on.
- Also, MDA coverage in the community is low. Most times, MDA program focuses on • treatment of school going children with little attention to treating the whole community, and where the community is considered for treatment, the method of administering the drugs is not effective. The VHTs normally deploy two methods during MDA: first, is the door to door method where a VHT moves from household to household to administer drugs. This method has the following challenges. a) It is possible that a VHT may not find a single person in a household. In this case the VHT takes note of that HH for purpose of revisiting it. However, most times they (VHTs) don't revisit such HHs. b) After recording on drug register books, VHT administers drugs to HH members present and leave drugs for those missing. Here too, it comes difficult for VHTs to know whether or not the drugs would be delivered and swallowed. c) Due to fear of side effects, a family may decide not to take drugs at all. Second, is the administration of drugs in a central place. Here, VHT informs the community/village members about administration of drugs in a central place within the village. Also, considering distance and of nature of people's activities, fewer people may come for the drugs. In short, all these methods if not done with caution, have lots of unresolved issues about drug coverage, drug uptake and breaking the lifecycles of the disease.

## Actions/Interventions to minimise contact with infested water

• There should be intensive and consistent education and behavioural change programs on schistomiasis control in the District/region. Physical engagement with fishing folks at landing sites and local FM radio stations should be consistently used to disseminate schisto control measures to the community. Also, posters clearly showing lifecycles of schisto should be erected in communities and messages translated in local languages like [language anonymised].

- There should be consistent and continuous sensitisation about hygiene and proper use of latrine, and where possible, the District, Sub-county, Parish and village leaders should all be involved in the dissemination of info and monitoring of compliance. Leaders mentioned therein can design Latrine Assessment Tools for purposes of showing both the coverage and use of latrines in the community. This way, HHs with sub-standard latrines can be identified and encouraged to improve, while those already cautioned but are not ready to improve after a period of time per say 1 or 2 months can be summoned by the LC I court systems and punished for breaching minimum living standards.
- Encourage fishermen and rice growers to procure affordable water resistant gargets like gumboots so that even when they are fishing/cultivating, contact with infested water can be reduced.
- Lobby for safe water projects in the communities, like boreholes, spring water. Currently, [NGO anonymised] Field Office, is implementing a multibillion tape water project in [district anonymised] District. This project, if implemented well will help improve on the safe water coverage in the District and reduce the frequency mothers and children get into contact with infested water for domestic and other purposes.
- Install water treatment plants or equipments at landing sites so that infested water can be purified before being deemed safe for domestic use.
- Design specific programs, for example, registration and procurement of special gumboots for fishermen and rice growers so as to limit their level of exposure to schisto and other worms.
- Come up with projects that can help increase latrine coverage in the community. [NGO anonymised] for example has been constructing latrines/toilets in public places like schools, landing sites, health centres, and the organisation has been applauded for improving on sanitation and human waste disposal that would otherwise exacerbate transmission of schisto and other intestinal worms in the community.
- There should be continuous sensitisation and behavioural change activities so that the whole community gets equated with the lifecycle of schisto and how they can actively participate in eradicating it.
- Initiate and design a project that will enable fishing community diversify and engage in other welfare activities like poultry, piggery, bee keeping and so on.

# 3.7.3 Network analysis results

Table 3-4 Network centrality metrics from full map

Factors	Indegree	Outdegree	Degree Centrality
Contact with infested H2O	25	4	29
Open defecation/urination	13	4	17
Schistosomiasis transmission	17	0	17
Adequate knowledge about SCH in communities	2	12	14
Latrine use	8	3	11
Proportion Fishing without protective gear	6	5	11
Snail harvesting without protective gear	4	7	11
Access to SCH drugs outside of MDA	6	4	10
Availability of latrines	3	6	9
Proportion of population ingest SCH drugs (PZQ)	8	1	9
Proportion of population ingest SCH drugs (PZQ)	8	1	9
Availability and use of protective gear for water work	1	7	8
People seek care for SCH	4	3	7
Playing and swimming	3	4	7
Access to potable water	2	4	6
Bathing in water bodies	3	3	6
Belief that pregnant women should not use latrines	0	6	6
Proportion of SCH cases with proper case management	4	2	6
Adequate diagnostic/lab capacity	3	2	5
Proper implementation of MDA	1	4	5
Proportion of Husbands refuse wives to swallow SCH drugs	4	1	5
Accuracy of SCH-related data reporting	2	2	4
Availability of drug formulation for U5s	2	2	4
Introduction and enforcement of local bi-laws	2	2	4
Political will/leadership related to SCH and WASH	0	4	4
Proportion rice farming without protective gear	1	3	4
SCH drug effectiveness/quality	3	1	4
Snail vector population	2	2	4
Water immersion rituals	2	2	4
Adequate health education in the communities	0	3	3
Adequate response to data	2	1	3
Advocacy about SCH at the district and national level	1	2	3
Community mobilisation for SCH activities	2	1	3
Funding for SCH activities	1	2	3
Households located near water bodies	0	3	3
Knowledge of benefits of latrine use	1	2	3
Lack specs for pit latrines	0	3	3
Migration to district for economic purposes	0	3	3

Mothers take children for deworming	2	1	3
Proportion logging without protective gear	1	2	3
Accuracy of M&E of SCH	1	1	2
Belief that faeces deposited in H2O increase fish stock	1	1	2
Enforcement of illegal fishing laws	0	2	2
Fear of side effects	1	1	2
Human resources for health at the district level	1	1	2
Infrastructure to avoid H2O, bridges	0	2	2
Prevalence of Myths about SCH and SCH meds	1	1	2
Price of SCH drugs	0	2	2
Washing in water bodies	1	1	2
Availability of bathing shelters	0	1	1
Food availability at time of SCH drug administration	0	1	1
Health worker mobilisation for SCH activities	0	1	1
Proper maintenance of H2O dams	0	1	1
School attendance	0	1	1

## 3.7.4 Water contact simulation scenario results

Figure 3-7 Water contact simulation scenario – High prevalence S. mansoni settings

## A. Population prevalence



B. Heavy burden population prevalence



Note: Morbidity control, less than 5%; Elimination, as a public health problem, less than 1% prevalence ; 25%, 50%, 75%, 90%, reduction in infested water contact
Figure 3-8 Water contact simulation scenario – High prevalence S. haematobium settings

# A. Population prevalence



B. Heavy burden population prevalence





# 4 Revisiting the plan to 'rescue the bottom billion': An assessment of the costs and effectiveness associated with schistosomiasis control activities (Paper 3)

# Abstract

This study builds on previous work regarding the effectiveness of mass drug administration (MDA) compared to water, sanitation, and hygiene (WASH) activities and combination interventions aimed at the control and elimination of schistosomiasis in Uganda. The widely promoted narrative that these programmes are the 'cheapest' and 'easiest' way to 'rescue the bottom billion' is challenged by presenting a cost effectiveness analysis which compares multiple intervention and costing scenarios. This analysis uses the outcomes of the participatory systems mapping workshops to guide the scope of the evaluation, and employs the same method from previous work of individual-based simulations to capture the health benefits across intervention scenarios. The results indicated that the most cost effective scenario is a system of implementation reliant on volunteers from within communities and donated drugs. As anticipated, when all else is held equal, including these costs results in lower cost effectiveness ratios relative to other interventions. Further, the results bring into question the purpose of continuing interventions which are not predicted to achieve the desired targets within the 30-year time horizon. There are potential opportunities for intervention implementation which is more aligned with the aims of equitable, country-led sustainable development.

# 4.1 Background

Through the 1990s and early 2000s, there was a renewed push for the control and elimination of neglected tropical diseases (NTDs), the impacts of which were identified as primary reinforcements of poverty amongst the world's poorest people (World Health Organization. Division of Control of Tropical Diseases, 1992; WHA, 2001; World Bank, 2003; Fenwick *et al.*, 2005) . Policy-makers, academics, and pharmaceutical companies devised to alleviate the lack of education, diminished work productivity, long-term health care costs, and child mortality of these so-called 'bottom billion' through mass drug administration (MDA) campaigns (Hotez, 2009; Hotez and Thompson, 2009; Hotez *et al.*, 2009). Amongst these campaigns, those targeting schistosomiasis (often along with soil-transmitted helminths) through school-based deworming programmes are of particular prominence. Schistosomiasis is caused by parasitic blood flukes transmitted via contaminated fresh water sources. Globally, an estimated 236.6 million people aged five years and older across 51 endemic countries are at risk of schistosomiasis infection (WHO). Ninety percent of schistosomiasis burden is in sub-Saharan Africa, primarily caused by *Schistosoma mansoni* (intestinal schistosomiasis) and *Schistosoma haematobium* (urinary schistosomiasis) species (Deol *et al.*, 2019; WHO).

The efforts to control and eliminate schistosomiasis through MDA have been recognized in the achievement of a Guinness World Record for 'the most medication donated in 24 hours' by pharmaceutical companies (Stephenson, 2017) and a Nobel Prize which included work on the long-term labour impacts by academic economists (WHO, 2021). These programmes have been proclaimed as the largest public health programmes to have ever been implemented and the cheapest way to 'rescue' the populations who suffer the burdens of these worms (Hotez et al., 2009). More than two decades since the publication of guidance documents and the approval of a World Health Assembly resolution on mass drug administration for schistosomiasis and soiltransmitted helminths (WHA, 2001), the elimination of schistosomiasis as a public health problem and interruption of transmission have not been realised (WHO, 2020). Economic evaluations of schistosomiasis interventions have formed the basis for MDA advocacy for at least the past twenty years. The intervention has long been considered a "best buy" in global health (see for examples World Bank, 2003; Hall and Horton, 2009; Ahuja et al., 2015; Sean, 2016; SCI Foundation), which is often referring to the relatively low estimated cost per health unit (e.g. Disability Adjusted Life Year (DALY)) averted. These claims have not gone unchallenged and have been the subject of some controversies. At least one prominent analysis, which was frequently cited for a period of time, was later discovered to have misprinted decimal place for the cost per DALY (US\$3.36-6.92 instead of \$336-692 (Hotez et al., 2006)). In addition, debates known as the 'Worm Wars' have brought questions about whether there actually are any significant health impacts from MDA to the forefront (Majid *et al.*, 2019). Since these debates, several mathematical modelling studies and meta-analyses of previous studies have shown that MDA will not achieve the desired impacts within the specified time periods (Welch et al., 2017; Toor et al., 2018, 2020; Li et al., 2019; Taylor-Robinson et al., 2019; Ayabina et al., 2021). These results question the basis for continuing the with the same strategies and the same focus, and invoke the need for new insights to be considered.

This broadly describes the inspiration for this study, which grew out of previous work aimed at developing locally relevant and responsive evidence for decision-making (Fergus *et al.*, 2022). The purpose was to incorporate different voices and perspective into the decision-making processes surrounding the implementation of health interventions, in this case the development of evidence. We used a form of participatory modelling, called participatory systems mapping (Barbrook-Johnson and Penn, 2021), to elicit the perspectives of health workers related to schistosomiasis control and elimination. Individuals from the national, district, and sub-national levels of the Ugandan health system were gathered for a series of workshops in 2019. The output of the process was a series of systems maps depicting direct and indirect factors related to schistosomiasis transmission. Following small and large group discussions and individual interviews, the maps were refined and digitized (see (Fergus *et al.*, 2022) for digitized map outputs.)

The *a priori* assumption was that this project would capture the variation in MDA implementation components, and describe how these components were shaped by social-economic-political processes in which they were devised and implemented. However, it was clear from the workshops at the national and district levels that the participants were not interested in discussing the components of MDA implementation. In fact, they viewed it as a strategy about which all decisions were made outside of their purview. On the one hand they were told that this strategy was required to improve the health and well-being of their populations, yet the availability of resources and implementation could be sporadic and lacklustre. In addition, the high reinfection rates and continued prevalence after all of these years of efforts did not instil confidence about the effectiveness of the programme nor the usefulness of their time spent on MDA activities.

These sentiments were especially poignant amongst the village-level participants, who, unlike their district and national level counterparts, did discuss MDA implementation at length. These individuals were volunteers on Village Health Teams (VHTs) who were paid very small monthly stipends in exchange for delivering health programmes within their communities, one of the most time consuming which was MDA. They described the lack of resources provided to them to effectively and efficiently deliver the programme, and the extent to which they input their own time and financial resources toward MDA implementation. They were also concerned about the high rates of reinfection and continued high prevalence levels of schistosomiasis due to the interactions between community members and local water bodies. As with the district and national level systems maps, sanitation, hygiene, and the availability of clean water were highlighted as key factors related to schistosomiasis transmission. The participants were eager to discuss the various WASH interventions which would be most effective in their specific areas and were able to indicate the potential effect of these activities via the systems maps.

Given that one of the aims of the project was to be responsive to the evidence needs of decision-makers, the results of the participatory modelling informed and guided the implementation of subsequent mathematical modelling simulations assessing the impacts of MDA programmes, water contact reduction interventions, and a combination of the two. This study follows on from these analyses to present an economic evaluation of intervention scenarios. This paper continues on with a description of the transmission model, which was used to observe the impacts of intervention scenarios on schistosomiasis prevalence. Then the methods used to gather and assess costs and cost effectiveness are described. Finally, the results of these analyses are observed using two assessment methods. First, a more standard comparison of cost effectiveness ratios, as cost per infection averted using predefined WASH intervention costs, is shown. This is followed by a series of critical cost estimates, where water contact reduction activities are assessed by providing the costs per person needed to achieve equivalent cost effectiveness ratios of MDA scenarios. This latter method allows for a flexibility and adaptability in terms of localising the available evidence when compared to the more standard comparison of cost effectiveness ratios.

# 4.2 Methods

# 4.2.1 Transmission model

Based on the stochastic, non-linear, and dynamic interactions between humans and the environment in the transmission cycle of schistosomiasis, an individual-based simulation model, SCHISTOX, developed by Graham et al (2021), was employed in this study. In addition to its structural and framework suitability, the SCHISTOX model has the distinct advantage in its

development as an open-source repository on GitHub (Graham, 2021), which can be run in Julia or through an R wrapper. This latter point is particularly important in that we would be able to use it in workshop settings (such as those described in Fergus et al 2020 (Fergus *et al.*, 2022)), where participants would be able to see and work with the actual coding and make adjustments to their particular settings. Model parameters, categorised as human population, parasite population, transmission, or control, were explicitly specified based on Ugandan-specific information, where available, and otherwise based on published data from other settings. Given its widespread prevalence, the models included the relevant parameter specifications adapted to *Schistoma mansoni* species. All parameter specifications used in this study can be found in the Supplementary Materials, Section 1. To initialise the simulations, each species-specific model was run for 100 years under high prevalence scenarios to establish epidemiological equilibrium within the population. In line with the cost effectiveness horizon, the simulations were run for thirty years.

### 4.2.2 Interventions

As discussed above, the purpose of this study was to provide comparative cost estimates of different intervention scenarios aimed at the control and elimination of schistosomiasis. The first type of intervention was the current recommendation of mass drug administration (MDA). In this study, three MDA scenarios were simulated. MDA coverage of school-age children was simulated at two levels to reflect the most recent estimates of coverage in Uganda (i.e. the status quo) and in accordance with the current WHO and Uganda Ministry of Health guidelines: (1) the most recent reported median coverage for high prevalence districts (46%) (ESPEN), and (2) the recommended target coverage of 75% (WHO, 2020). As described in (Fergus *et al.*, 2022) the reported median coverage for high prevalence districts in Uganda was selected to provide a relevant reference point, relative to the recommended target coverage, for district and sub-district decision-makers.

In terms of water contact reduction activities, I took an outcomes-based approach, where the desired impact served as the starting point (here a population-level reduction in water contact of 75% was used) and worked backward from there to identify appropriate interventions. This allows for a level of generalizability, and potential transferability, that is less available when starting from the intervention perspective. The intention is for place- and time-based specific regarding intervention components can be tailored to specific populations. The outcomes of the systems maps indicated that water sanitation and hygiene interventions were of particular interest (see (Fergus *et al.*, 2022), Supplementary Materials.) Of the potential points of influence related to WASH activities, 5 out of 6 were specifically related to improved water sources and improved toilets. An overview of the intervention scenarios are presented in Table 1. The specific water contact reduction interventions considered are discussed below in the costing section.

Table 4-1 Overview of intervention scenarios

Туре	Intervention (description)	Target population	Coverage
Water contact reduction	Water	Entire community	100%
Water contact reduction	Sanitation	Entire community	100%
Water contact reduction	Water+Sanitation	Entire community	100%
MDA	School-based MDA	School-aged children	46% (current coverage)
MDA	School-based MDA	School-aged children	75% (target coverage)
MDA	Community	Population aged 5+ years	75% school-aged children; 40% adults
Combination	School-based MDA+Water+Sanitation	School-aged children and entire community	75% (target coverage) for MDA; 100% for WASH
Combination	School-based MDA+Water	School-aged children and entire community	75% (target coverage) for MDA; 100% for water
Combination	School-based MDA+Sanitation	School-aged children and entire community	75% (target coverage) for MDA; 100% for sanitation
Combination	Community+Water+Sanitation	Population aged 5+ years and entire community	75% (target coverage) for MDA; 100% for WASH
Combination	Community+Water	Population aged 5+ years and entire community	75% (target coverage) for MDA; 100% for water
Combination	Community+Sanitation	Population aged 5+ years and entire community	75% (target coverage) for MDA; 100% for sanitation

Note: MDA, Mass drug administration

### 4.2.3 Cost and cost effectiveness

The costs and health benefits were quantified for each of the intervention scenarios described above. To quantify the health impacts of intervention scenarios, the numbers of days with schistosomiasis infection were counted for each individual under simulated implementation conditions. These were summed and converted to infection-years, then compared to the relative baseline of infection-years from a counterfactual scenario simulation with no interventions. The same analyses were conducted for high intensity infections for comparison.

The cost of MDA is necessarily determined by the price of praziquantel and the cost of delivery strategies. MDA delivery strategies are subject to economies of scale, and therefore costs are responsive to the size of the target population (Turner et al., 2016, 2018). The delivery costs were estimated using the WHO regression tool (Fitzpatrick et al., 2016), which predicts placebased per-person cost estimates via meta-regression of published studies. The parameter values used to estimate the delivery costs are outlined in Table 2. For the scenarios where volunteers were used, the economic costs of MDA delivery were increased by 15% per person targeted to account for the opportunity costs of time for those who deliver the drugs, as estimated by (Turner et al., 2019) and used previously for a similar purpose by (Collyer et al., 2019). The costs of praziquantel were based on previously published estimates of the market value (Collyer et al., 2019) or viewed as donations by pharmaceutical companies (Turner et al., 2020), dependent on whether the resource value or the actual expenditure was being considered. The financial and economic costs of MDA implementation are outlined in Table 3. These estimates were scaled to the size of the target population, not the number of individuals who were treated, to reflect the programme planning costs, e.g. the costs of the scenario with the most recent coverage estimates for school-based deworming (46%) reflect the target population of 75%.

Table 4-2 Parameter values used	ed to estimate MDA delivery costs
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Parameter	Value	
National or subnational programme	Subnational	
Number of diseases integrated	1	
Number of rounds per year	1	
Year of implementation	3	
GDP per capita (US\$)	882.028	
Population density	228 per square kilometer	
Volunteers used	Both considered	
Coverage rate	75% SAC (School-based); 75% SAC + 40% adults (Community-based)	

Note: the population density and GDP per capita were sourced from World Bank Database [36] for the year 2020.

A. Economic costs			
Delivery mode (target populations)	Delivery cost point estimates (95% CI)	PZQ costs	
School-based delivery (SACs)			
Volunteers	2.95 (1.52-4.36)	$2.5 \times US$0.08 per SAC$	
Paid workers	8.97 (4.09-14.43)	2.5 x 05\$0.06 per 5/10	
Community delivery (SACs and adults)			
Volunteers	1.25 (0.74-1.66)	2.5 x US\$0.08 per SAC +	
Paid workers	3.79 (2.00-5.47)	3.5 x US\$0.08 per adult	
B. Financial costs			
Delivery mode (target populations)	Delivery cost point estimates (95% CI)	PZQ costs	
School-based delivery (SACs)			
Volunteers	1.23 (0.66-1.76)	Donated	
Paid workers	3.72 (1.74-5.89)	Donated	
Community delivery (SACs and adults)			
1			
Volunteers	1.04 (0.62-1.32)	Donated	

Table 4-3 Economic and financial costs of MDA implementation (delivery and medication costs)

Note: MDA, mass drug administration; SAC, school-aged children

The costs, design, and implementation of effective WASH interventions are place-, time-, and demographically-specific. The WASH needs of communities are diverse, and as humans, our social-economic-biological ties to water and sanitation practices vary. As discussed previously, the purpose of this analysis is to provide insights as to how reductions in water contact interventions via WASH interventions might compare to the current recommended interventions, the status quo, and whether a combination of MDA and water reduction interventions are feasible in terms of cost. Since the costs of WASH interventions are subject to much heterogeneity, two analytical approaches were employed to provide different, potentially useful, perspectives. The first approach considered costs for improved water supply and improved sanitation, which had been compiled by the WHO and UNDP (WHO and UNDP, 2007) and updated to reflect 2020 prices and Uganda-specific costing (World Bank, 2020). For the second approach, the critical costs of a generalised water contact reduction intervention (which achieved 75% reduction in water contact) which achieved the same cost effectiveness as MDA were determined. This is the annual cost per person that could be spent on any alternative intervention(s) which reduce water contact by 75% and avert the same number of schistosomiasis cases as the specified MDA implementation strategy. This method has previously been used to determine the critical costs for various vaccine schedules for schistosomiasis (Collver et al., 2019).

In the context of this outcomes-based approach to assessing water contact reduction, there is a lot of leeway in terms of how interventions might be costed. It would be rather straightforward to cherry-pick low or high costs to fit a certain narrative. I conducted a review of published literature, including other literature reviews, and cost data. In the end, the regional-level costs published by the WHO and UNDP (WHO and UNDP, 2007) provided conservative estimates within the bounds of very localised costs published in locations similar to the one being simulated in this study (Sijbesma and Christoffers, 2009; Salari *et al.*, 2020). Much like the intervention effectiveness estimates, future work should include workshop participants using

their own place- and time-specific costing data to assess the cost effectiveness of interventions. Thus, to cost the WASH activities, three intervention types were considered: improved water supply, improved sanitation, and both improved water supply and sanitation. The median, low, and high costs of potential WASH activities (see Table 4 for annual per person costs) were updated to reflect 2020 prices using the World Bank GDP deflator (World Bank, 2020), and inclusive of annual upkeep, maintenance, and/or repair as needed on the basis of the intervention.

Improved water supply	Annual cost per person
Standpost	2.4
Borehole	1.7
Dug well	1.55
Rain water	3.62
Improved sanitation	Annual cost per person
Septic tank	9.75
VIP	6.21
Simple pit latrine	4.88

Table 4-4 Costs of WASH interventions

Note: Costs as indicated by [37] and updated to reflect 2020 US\$ prices

Intervention cost effectiveness was quantified by the years of infection averted per US\$1 spent. These analyses were conducted for a 30-year time horizon. Results for a nested time period of the initial ten years are also presented to assess the impact of interventions and costs of the global 10-year targets for elimination and control (WHO, 2020). Where relevant, costs were no longer included for years following population-level transmission interruption (0% population prevalence with no subsequent resurgence.) These evaluations were performed from a health provider perspective and include an annual discount rate of 3% for both costs and health effects, per WHO recommendation (WHO *et al.*, 2003).

Two approaches were used to evaluate the cost effectiveness of the intervention scenarios described above. Cost effectiveness ratios (CERs), calculated as \$US per infection averted, were used to compare interventions. In the first instance, two cost effectiveness thresholds were defined by benchmark CER ranges based on (1) the current recommendation of school-based MDA with a target of 75% of school aged children and (2) the most recent coverage estimates of school-based MDA in Uganda of 46% of school aged children. As proposed by Weinstein and Zeckhauser (1973) and more recently described by Marseille *et al.* (2014) and Eichler *et al.* (2004), using benchmark thresholds, as opposed to pre-defined thresholds based on per capita GDP, provides more locally relevant evidence for decision-making related to resource allocation. The second evaluation strategy utilised the league table approach, where the intervention scenarios are ranked in accordance to their CERs (Haddix *et al.*, 2002; Marseille *et al.*, 2014). For the purposes of this study, the benchmark thresholds and league table methods accommodated the data availability constraints related to both health outcomes and costing of interventions.

# 4.3 Results

# 4.3.1 Intervention effectiveness

Figure 1 shows the predicted prevalence estimates and intervals which contain 95% of predicted estimates from simulation runs for the 30-year. The adult and school-aged children prevalence estimates are shown in pink and green, respectively. The prevalence estimates of all infections and high intensity infections are shown on the left and right, respectively. The results related to intervention effectiveness were similar to those presented in the previous paper (Fergus *et al.*, 2022). Specifically, and perhaps unsurprisingly, Figure 1 shows that water contact reduction of 75% (A) and mass drug administration alone (rows A, B, C, and E) were not predicted to be as effective as combinations of the two (rows D and F.) Perhaps unsurprisingly community-based MDA covering 75% SAC and 40% of adults plus 75% water contact reduction had the steepest and most sustained reduction in schistosomiasis prevalence.

There are two targets often cited related to schistosomiasis, one is the interruption of transmission (defined as zero incident cases) and the other is elimination as a public health problem (EPHP, defined as reaching <5% prevalence of high intensity infections amongst school aged children) (WHO, 2020). Table 5 shows the month that these targets would be achieved within the 30 year time horizon, from the modelled estimates in Figure 1. The current MDA coverage estimates were not predicted to reach either EPHP or interruption of transmission withing the specified time period. School-based MDA with a coverage of 75% SAC plus water contact reduction of 75% was the only scenario predicted to achieve both EPHP and interruption of transmission, when the 95% intervals were also considered. Three of the scenarios were predicted to achieve EPHP within the 10-year (120-month) target timeframe, community-based MDA alone, community-based MDA plus 75% water contact reduction, and school-based MDA with SAC coverage of 75% plus 75% water contact reduction. Both of the combination interventions achieved the target in about half the number of months compared to community-based MDA alone.

Figure 4-1 Intervention effectiveness assessed by schistosomiasis infection prevalence (left) and high intensity infection prevalence (right), vertical blue dotted lines indicate the WHO's target 10-year time period for elimination and control of schistosomiasis



### A. Water contact reduction of 75%





C. School-based MDA, SAC coverage of 75%



— Adult — SAC

180 Months D. School-based MDA, SAC coverage of 75%, plus water contact reduction of 75%



# F. Community MDA plus water contact reduction of 75%



Note: MDA, mass drug administration

Scenario	EPHP	Interruption of transmission
Water contact reduction 75%	307 (233-NR)	NR (NR-NR)
MDA SAC 46%	NR (265-NR)	NR (NR-NR)
MDA SAC 75%	337 (325-350)	NR (NR-NR)
MDA SAC 75% + Water contact reduction 75%	37 (37-38)	306 (296-313)
MDA Community	73 (49-121)	NR (278-NR)
MDA Community + Water contact reduction 75%	37 (31-37)	NR (210-NR)

Table 4-5 Time (in months) predicted to achieve schistosomiasis targets of elimination as a public health problem (EPHP) and interruption of transmission

Note: Community, community-based coverage of school-aged children (75%) and adults (40%); EPHP, elimination as a public health problem (<5% prevalence of high intensity infections amongst school-aged children); Interruption of transmission (0% population prevalence); MDA, mass drug administration; NR, target not reached; SAC, school-based coverage of school-aged children.

# 4.4 Cost effectiveness

Cost effectiveness threshold ranges were benchmarked by the current recommended, schoolbased coverage of 75% of school aged children, with the low and high ends of the range based on whether volunteers or paid workers were used to implement the programme, respectively. For the first assessment, infections averted per US\$1 were determined for each intervention scenario in comparison with benchmark thresholds (Figure 2, thresholds are indicated by grey dotted lines in both A and B.) None of the scenarios had a higher cost effectiveness measurement than the recommended school-based MDA which reached (not only targeted) 75% of school aged children using volunteers for implementation. However, community-based MDA alone and community-based MDA plus water improvement interventions did fall within the threshold range, meaning that these interventions were more cost-effective compared to the recommended scenario when paid workers were used for its implementation. The scenarios which represented the current coverage levels in Uganda were amongst the least favourable in terms of cost-effectiveness. To underscore this point, infections years averted per US\$1 spent was 20% higher when paid workers were employed to implement community-wide MDA plus both water and sanitation improvements compared to volunteers being utilised to implement school-based MDA which achieved the current 46% coverage of school-aged children.

The league table comparison of cost effectiveness presented in Table 6 ranks the interventions by cost of \$US1 per infection averted. The purpose of providing the cost effectiveness comparisons in a league table format is to allow decision-makers to compare the costs of interventions against their budgetary restrictions, starting with the cheapest scenario and then moving down the table, adding components or coverage levels as the budget allows. This assumes, by logic, that each successive intervention is becoming incrementally more comprehensive and with that the measure of health benefit also increases. As shown in Table 6, the intervention scenarios assessed in this study include several which cost more, yet see lower health benefits. This is highlighted by the scenarios of the current MDA coverage levels amongst school aged children. (46%), which were both around average annual cost per target population, yet had the lowest predicted annual cases averted. The other issue which had a substantial impact on cost effectiveness was the use of volunteers. It is clear that, all else held equal, not paying workers to implement an intervention is more cost effective than paying workers. The incremental cost effectiveness of paying workers instead of using volunteers was \$US 0.21 for school-based MDA, \$US 0.24 for community-wide MDA, and \$US 0.08 for the combination community-wide MDA plus WASH interventions per infection averted.



Figure 4-2 Infection years averted per US\$1 cost, comparisons with benchmark threshold range based on current recommended intervention (dashed lines) of 75% SAC coverage via school-based MDA in two formats, (A) spider plot and (B) lollipop plot

Note: \* indicates volunteers (not paid workers) were used to implement MDA delivery; dotted lines on both A and B represent the CE threshold range for 75% coverage of SAC via school-based MDA using volunteers (max) and paid workers (min); SAC 46%/75%, school based mass drug administration for school aged

children with corresponding coverage levels; Community, community level mass drug administration with 75% coverage of school aged children and 40% coverage of adults; Water, improved water interventions; Sanitation, improved sanitation systems.

Table 4-6	League	table	of cost	effectiveness
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		Annual cost per	Annual no. of		\$1 per	Infections averted	\$1 per infection	
		person in target	infections averted	Thousand \$ per	infection	within target	averted by target	Volunteers
Туре	Intervention (description)	population	(1000s)	1000 people	averted	timeframe (10 years)	deadline (10 years)	used?
MDA	SAC 75%*	3.16	126	13.66	0.11	12.00	0.50	Yes
MDA	Community*	2.99	161	22.98	0.14	23.75	0.42	Yes
Combination	Community*+Water	5.51	213	32.14	0.15	43.42	0.74	Yes
Combination	Community+Water	10.58	213	49.06	0.23	43.42	1.13	No
MDA	SAC 75%	9.17	126	39.69	0.32	12.00	1.45	No
Combination	Community*+Sanitation	10.63	213	76.93	0.36	43.42	1.77	Yes
MDA	Community	8.06	161	61.57	0.38	23.75	1.14	No
Combination	Community+Sanitation	15.70	213	93.85	0.44	43.42	2.16	No
Combination	SAC 75% + Water	5.68	145	64.00	0.44	15.84	1.77	Yes
Combination	Community*+Water+Sanitation	13.15	213	99.00	0.46	43.42	2.28	Yes
Combination	Community+Water+Sanitation	18.22	213	115.92	0.54	43.42	2.67	No
Combination	SAC 75%+Water	11.69	145	90.04	0.62	15.84	2.49	No
MDA	SAC 46%*	3.16	21	13.66	0.66	3.04	1.97	Yes
Water contact reduction	Water	2.52	47	50.35	1.07	5.89	3.75	No
Combination	SAC 75%* + Sanitation	10.79	145	166.17	1.14	15.84	4.60	Yes
Combination	SAC 75%+Sanitation	16.81	145	192.20	1.32	15.84	5.32	No
Combination	SAC 75%*+Water+Sanitation	13.32	145	216.52	1.49	15.84	5.99	Yes
Combination	SAC 75%+Water+Sanitation	19.33	145	242.55	1.67	15.84	6.71	No
MDA	SAC 46%	9.17	21	39.69	1.91	3.04	5.72	No
Water contact reduction	Sanitation	7.64	47	152.52	3.25	5.89	11.36	No
Water contact reduction	Water+Sanitation	10.16	47	202.87	4.33	5.89	15.11	No

Note: Green indicates the cost effectiveness threshold range based on school-based MDA with 75% SAC coverage; Purple indicates the current median coverage level of SACs in Uganda for school-based MDA; SAC 46%/75%, school based mass drug administration for school aged children with corresponding coverage levels; Community, community level mass drug administration with 75% coverage of school aged children and 40% coverage of adults; Water, improved water interventions; Sanitation, improved sanitation systems.

# 4.4.1 Critical cost of water contact reduction interventions

The second economic assessment method was to develop critical cost estimates where the water contact reduction intervention would meet the same cost effectiveness as a given MDA implementation strategy. This allows for interventions to be considered under the specific and local budget restraints and be adapted to the social and economic activities related to water contact, and is therefore not strictly limited to WASH interventions as discussed in the section above. The critical costs per person (shown in Figure 2), or amount that would need to be spent per target population to achieve the same cost effectiveness as MDA, ranged from \$5.10 to \$17.92 per person in the target population. Given how high these estimates are, even on the lower end when compared to MDA implementation which used volunteers, water contact reduction interventions might be viewed as cost prohibitive.



Figure 4-3 Critical cost of water contact reduction interventions to achieve the same cost effectiveness ratio as a given MDA implementation strategy

Note: Community, community level mass drug administration with 75% coverage of school aged children and 40% coverage of adults; Paid workers, delivery costs included the cost for pay individuals to deliver MDA; School-based, school based mass drug administration for school aged children with 75% coverage level; Volunteers, delivery costs considered that individuals were not compensated as volunteers to deliver MDA.

# 4.5 Discussion

This study presented cost effectiveness assessments of several intervention scenarios aimed at the control and elimination of schistosomiasis in Uganda. The scope was driven by previous work which combined participatory and computational modelling to develop evidence for decision-making, aimed to be inclusive and responsive to the perspectives of health workers. To this end, water contact reduction interventions were compared to school-based and communitywide MDA. In the first instance, the interventions were defined as WASH activities and costed accordingly. In the second, critical cost estimates where water contact reduction interventions had the same cost effectiveness as MDA scenarios were developed. In terms of intervention effectiveness, all of the scenarios, except the current MDA coverage level, achieved elimination of schistosomiasis as a public health problem (EPHP) within the thirty-year time horizon. Three of the six scenarios achieved EPHP within WHO's 10-year target timeline: school-based MDA at 75% SAC coverage plus water contact reduction of 75%, and community-wide MDA, both with and without the additional water contact reduction activities. These three scenarios also achieved interruption of transmission within the thirty-year time horizon, when the lower bound of months taken to achieve zero cases is taken into account. As would be expected, the addition of water contact reduction interventions to community-wide MDA decreased the amount of time it was predicted to take to achieve transmission interruption and EPHP. The achievement of these targets was not taken into account as to whether the interventions would be included in the cost effectiveness analyses.

In terms of overall cost effectiveness, none of the interventions exceeded the upper end of the benchmark thresholds, determined by the cost effectiveness of the current recommended intervention, school-based MDA at 75% SAC coverage, using volunteers for implementation. However, when only interventions which employed paid workers were considered, community-based MDA plus improved water source interventions was considered the most cost effective, exceeding the lower end of the benchmark threshold. When the critical costs of water contact reduction interventions relative to MDA were considered, these ranged from an annual US\$5.10-US\$17.92 per person.

In terms of the current coverage level of MDA in Uganda, as modelled in this study, not only will it not achieve the prevalence reduction targets discussed above, it was found to be amongst the least cost effective scenarios. While it should be noted that this is due to the gap between costing for the target of 75% and achieving only 46% coverage, this also highlights the cost of missing targets related population coverage. Missing targets can happen for a number of reasons. Based on the workshop participants we worked with and their systems maps, this could be the result of lack of personal resources they use to support the logistics of implementation (such as transport or fuel costs to obtain or distribute tablets). There were also concerns raised related to their motivation without financial compensation.

To this point, the bottom line is that it will always be less cost effective to pay individuals to deliver interventions. Even though this study showed that, all else held equal, not paying workers to implement MDA is more cost effective than paying workers, that does not mean that this is an appropriate, equitable, or sustainable strategy. This work supports previous studies which showed that the use of volunteers is one of the significant indicators of per person MDA implementation costs (Turner *et al.*, 2020) and that there exists a significant opportunity cost when volunteers are used (Turner *et al.*, 2019).

There are several limitations to this study. Even though the purpose was to develop conservative and more generalised cost effectiveness estimates, the cost data could be improved through additional financial assessments of the current situation in Uganda. Travel restrictions, as well as time and financial restraints, have limited my ability to move forward with these activities. To maximise utility, it would be important that both the transmission model and costing of interventions were specified to the conditions in a sample of locations. Further, the interventions under consideration should be drawn from participatory processes to respond to the specific contexts where the results can be readily applied, such as the systems mapping workshops described elsewhere (Fergus et al., 2022). In terms of comparability, the cost effectiveness ratios are only relevant in the context of schistosomiasis. A subsequent cost-utility analysis, i.e. by converting infections to DALYs or QALYs, would allow for comparisons across health issues and potential interventions. In addition, while the impact of MDA is largely restricted to schistosomiasis and related sequelae, the impact of WASH interventions is more widespread. Diarrhoeal diseases, for example, are the second highest cause of child mortality globally, and WASH interventions play a significant role in preventing these infections (Grimes et al., 2015; WHO, 2021). Including these wider impacts would make the cost effectiveness assessment more comprehensive. In addition, this analysis did not consider other important innovative technologies and interventions that may be introduced over the thirty-year time horizon, including improvements in diagnostics that will likely play a role in moving toward the control and elimination of schistosomiasis.

From a system-wide perspective, there are many factors that go into decision-making surrounding the implementation of interventions. Most global health interventions are responsive to economic and political changes and priorities, as well as the production of new evidence and technologies. However, the implementation of MDA seems to be stickier than most. On a global level, the target of 75% coverage of school aged children has remained the same since the World Health Assembly 2001 Resolution (WHA54.19) updated over time to reflect a new 10-year time period. The information used to support the continuation of MDA programmes is often developed ex post facto and used to support narrative-, rather than evidence-, based decision-making, which can be a reasonable approach when implemented transparently and without alternatives. The results presented here indicate that MDA in its current form will not achieve the targets regarding the schistosomiasis burden established by the global community. These results broadly describe potential opportunities for interventions and considerations for cost effectiveness which are more aligned with the aims of country-led and sustainable development, as described by the UN's Sustainable Development Goals and the WHO's Roadmap for Neglected Tropical Diseases.

While it can be assumed that the advocates for the continued widespread use of the same MDA implementation strategies to "rescue the bottom billion" do sincerely intend to alleviate the burden of schistosomiasis, there are questions as why this singular strategy with the same targets has not been revisited in a way that has affected meaningful adaptation. This study joins several modelling studies and meta-analyses (Welch et al., 2017; Taylor-Robinson et al., 2019) which continue to show that this strategy will not achieve the targets within the desired time period (Toor et al., 2018, 2020; Li et al., 2019), and there is the possibility of the need to continue the current levels of MDA in perpetuity to maintain low prevalence levels (Ayabina et al., 2021). These prospects do not align with the goals of sustainable development. The degree to which the current iteration of MDA is reliant on the volunteer time from within the communities of implementation to achieve its promoted level of cost effectiveness, as shown in this study and elsewhere (Turner et al., 2019, 2020), challenges its contribution to alleviating poverty when opportunity costs are considered. Just over 100 years ago, the mass deworming campaigns targeting the rural poor across the American South were disbanded due, in part, from the assessment that WASH activities were necessary to achieve sustained control and elimination (Ettling, 1981). We are in a much different position now, especially with effective and non-toxic medications and technological improvements. Therefore it is clearly time to reassess and adapt the aims and guidance regarding MDA at the global level in a way that leads to sustained reductions in schistosomiasis and poverty more broadly.

# 4.6 References

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# 4.7 Supplementary Materials

# 4.7.1 Simulation inputs

The primary purpose of the simulation results presented in this paper was to compare how the impact on schistosomiasis prevalence from a decrease in the population water contact parameter would compare to mass drug administration implementation strategies and combination interventions, while holding the other initialisation parameter values constant. The parameters were informed by four sources: (1) Graham et al's SCHISTOX publication<sup>35</sup>, (2) the SCHISTOX model documentation on GitHub<sup>36</sup>, (3) personal correspondence with the model developers, and (4) results from consultations with workshop participants described in Fergus et al's participatory modelling publication<sup>37</sup>. Consultation with the workshop participants included written and verbal communication, both during the workshop and after the workshop as the parameters were specified. These communications continued through July 2021, and are ongoing as additional components of the project continue. In some cases, participants agreed that a value described in the SCHISTOX parameterisation documentation adequately reflected their contexts for the purposes of the simulation. In others cases, individual input, followed by group negotiation and consensus, determined the input value. All of the parameters were put up for discussion and confirmation by the participants, though only the ones which generated comments, and the extent of the input, are noted in the Table S2 below.

Parameter	Initial	Source
	value/specification	
N (population)	750	Input from workshop participants on the
		average most relevant population size
		(described in Fergus et al <sup>3</sup> )
Time step	10	Parameterization documentation <sup>2</sup>
N communities	1	Parameterization documentation <sup>2</sup> and
		input from workshop participants
		(described in Fergus et al <sup>3</sup> )
Density dependent	0.0007 (S. mansoni); 0.0006	Parameterization documentation <sup>2</sup> and
fecundity	(S. haematobium)	personal correspondence with the model
		developers
Average worm	5.7 years (S. mansoni); 4	Graham et al's SCHISTOX publication <sup>1</sup>
lifespan	years for (S. haematobium)	
Maximum age in the	100	Confirmed by workshop participants as
population (years)		the most appropriate for their purposes
		(described in Fergus et al <sup>3</sup> )
Miracidia maturity	24 (S. mansoni); 21 (S.	Graham et al's SCHISTOX publication <sup>1</sup>
	haemotobium)	and parameterization documentation <sup>2</sup>

Table 4-7 Parameter specifications

<sup>&</sup>lt;sup>35</sup> Graham M, Ayabina D, Lucas TCD, et al. SCHISTOX: An individual based model for the epidemiology and control of schistosomiasis. Infections Disease Modelling 2021

<sup>&</sup>lt;sup>36</sup> Graham M. Schistoxpkg;jl. 2021 <u>https://github.com/mattg3004/Schistoxpkg.jl</u>. (last accessed October 2021)

<sup>&</sup>lt;sup>37</sup> Fergus CA, Ozunga B, Okumu N, Parker M, Kamurari S, Allen T. Shifting the dynamics: implementation of locally driven, mixed-methods modelling to inform schistosomiasis control and elimination activities. BMJ Glob Health. 2022 Feb;7(2):e007113. doi: 10.1136/bmjgh-2021-007113. PMID: 35110273; PMCID: PMC8811568.

Contact rate	0.1	Parameterization documentation <sup>2</sup> and personal correspondence with the model
		developers
Max fecundity	50	Parameterization documentation <sup>2</sup> and
		personal correspondence with the model
		developers; the max fecundity and max
		fecundity contact rate product (below)
		were set based on an investigation into
		the system behaviour in varying these
		parameters for the model simulation to
		reach aquilibrium at a high population
		reach equilibrium at a high population
		prevalence (>50)
Max fecundity	1/15	Parameterization documentation <sup>2</sup> and
contact rate product		personal correspondence with the model
		developers; the max fecundity and max
		fecundity contact rate product (above)
		were set based on an investigation into
		the system behaviour in varying these
		parameters for the model simulation to
		reach equilibrium at a high population
		prevalence (>50)
	-(0,0008,0,45(2,0,4424	Demonstration 1 monstration <sup>2</sup> and
Age contact rates	C(0.0998, 0.4505, 0.4424, 0.0045)	Parameterization documentation and
	0.0015)	personal correspondence with the model
		developers; these rates are normalised to
		1 across the array
Ages for contacts	c(4, 9, 15, 100)	Parameterization documentation <sup>2</sup> and
		confirmed by workshop participants as
		the most appropriate for their purposes
		(described in Fergus et al <sup>3</sup> )
MDA adherence	0.9	Parameterization documentation <sup>2</sup> and
		confirmed by workshop participants as
		adequately reflecting their contexts in
		general; although it should be noted that
		the village-level participants were
		especially interested in the impacts of
		varying this parameter and that work is
		ongoing (described in Fergus et $a^{13}$ )
MDA access	0.0	Darameterization documentation <sup>2</sup> and
MDM access	0.9	apprend by workshop participants as
		commed by workshop participants as
		adequately reflecting their contexts in
		general; as with MDA adherence (above),
		while it was agreed that this parameter
		would be kept defined as in the
		parameterization documentation for the
		purposes of this simulation, the village-
		level participants were particularly
		interested in observing the impacts of
		varying this parameter (described in
		Fergus et al <sup>3</sup> )

Factor for altering the contact rate for	1	Parameterization documentation <sup>2</sup>
females		
Factor for altering	1	Parameterization documentation <sup>2</sup>
the contact rate for		
males		
Proportion of	1	Graham et al's SCHISTOX publication <sup>1</sup>
cercariae which are		and parameterization documentation <sup>2</sup>
able to infect		
humans		
Aggregation for	0.24	Parameterization documentation <sup>2</sup>
nredisposition of	0.21	
individuals to		
matelia lamaa		
Drage atting of	1/2	Carbon et alle SCHISTON authoritien
	1/2	Granam et al 8 SCHISTOX publication
cercariae that		and parameterization documentation
survive from one		
time point to the		
next		
Proportion of	1/2	Graham et al's SCHISTOX publication
miracidia that		and parameterization documentation <sup>2</sup>
survive from one		
time point to the		
next		
death prob by age	c(0.0656, 0.0093, 0.003,	Parameterization documentation <sup>2</sup>
	0.0023, 0.0027, 0.0038,	
	0.0044, 0.0048, 0.0053,	
	0.0065, 0.0088, 0.0106,	
	0.0144, 0.021, 0.0333,	
	0.0529, 0.0851, 0.1366,	
	0.2183, 0.2998, 0.3698, 1)	
ages for death	c(1, 5, 10, 15, 20, 25, 30,	Parameterization documentation <sup>2</sup>
	35, 40, 45, 50, 55, 60, 65,	
	70, 75, 80, 85, 90, 95, 100,	
	110)	
vaccine	0.95	Graham et al's SCHISTOX publication <sup>1</sup>
effectiveness		and parameterization documentation <sup>2</sup>
drug effectiveness	0.863 (S. mansoni); 0.94 (S.	Parameterization documentation <sup>2</sup>
	haematobium)	
Specified age	c(8639, 9082, 6424, 5074,	Parameterization documentation <sup>2</sup>
structure	4425, 3847, 3628, 3062,	
	2436, 1770, 1868, 1066,	
	743, 518, 355, 144)	
Ages per index	5	Parameterization documentation <sup>2</sup>
Heavy burden	400  eggs/1  gram faeces  (S.	Graham et al's SCHISTOX publication <sup>1</sup>
threshold	mansoni); 50 eggs/10mL	and parameterization documentation <sup>2</sup>
	urine (S. haematobium)	
Rate acquired	0	Parameterization documentation <sup>2</sup>
immunity		

Human larvae maturity time (in	30	Parameterization documentation <sup>2</sup>
days)		
Input ages	c(4, 9, 15, 100)	Parameterization documentation <sup>2</sup> and confirmed by workshop participants as the most appropriate for their purposes (described in Fergus et al <sup>3</sup> )
Input contact rates	c(0.032, 0.610, 1, 0.06)	Parameterization documentation <sup>2</sup>
scenario	"high adult"	Parameterization documentation <sup>2</sup> and confirmed by workshop participants as adequate for the purposes of these specific simulation activities (described in Fergus et al <sup>3</sup> )



# 5. Opportunities and disconnects in the use of primary research on schistosomiasis and soil-transmitted helminths for policy and practice: results from a survey of researchers (Paper 4)

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# Abstract

Even with efforts to facilitate use of evidence in health policy and practice, limited attention has been paid to researchers' perspectives on use of their research in informing public health policy and practice at local, national, and global levels. We conducted a systematic literature search to identify published primary research related to schistosomiasis or soil-transmitted helminths, or both. We then surveyed corresponding authors. Results indicate differences by locations of authors and in conduct of research, especially for research conducted in low- and middle-income countries. Our findings exemplify disparities in research leadership discussed elsewhere. Researchers' perspectives on the use of their work suggest limited opportunities and 'disconnects' that hinder their engagement with policy and other decision-making processes. These findings highlight a need for additional efforts to address structural barriers and enable engagement between researchers and decision-makers.

Key messages:

- Communication of evidence from researchers to policymakers has potential to improve population health, but researchers have broad concerns about their limited opportunities for engagement.
- Substantial structural and perceived barriers remain for researchers who wish to transform their findings into relevant policies and influencing practice.

# Keywords

Evidence and decision-making, health policy, schistosomiasis, soil-transmitted helminths

# 5.1 Introduction

In recent decades, recognition that policy informed by evidence can improve health outcomes has prompted increased interest among public health practitioners, researchers, and policymakers to assure that more research and scientific knowledge will inform policy and practice (Orton *et al.*, 2011). Considerable efforts made to facilitate improvements in evidence-based public health policy and practice date back to at least the early 1970s, but several substantive questions remain (Oliver *et al.*, 2014b). Much scholarship addresses applied methods for: "bridging the gap" between research and policy (Caplan, 1979), models of research uptake by decision-makers (Weiss, 1979), and, more recently, on knowledge translation or brokerage (Sebba, 2007). The process of 'research production to use' by policymakers and practitioners is active and non-linear. Thus, it is important to understand the roles and characteristics of the parties involved, as well as the processes. Researchers have conducted substantive research on the perspectives and actions of policy-makers and practitioners (Orton *et al.*, 2011; Oliver *et al.*, 2014a), but scant research exists about the institutions and perspectives of researchers who produce potentially relevant evidence for decision-making.

The use of research outputs as evidence to inform decision-making is an outcome of complex and nuanced interactions among policy-makers, researchers, and practitioners (Oliver and de Vocht, 2017). Unanswered questions remain about researchers' direct engagement with health policy and practice decision-making processes. While dissemination strategies and conclusions from research publications often include direct statements of potential policy relevance, a systematic review on the use of research evidence described policymakers' perceptions of research outputs as lacking relevance or transferability for their purposes (Orton *et al.*, 2011). At the same time, global and national policy documents, particularly those outlining clinical and population-based public health recommendations, tend to refer to published research findings supported by citations of published peer-reviewed literature. This positions individuals who conduct primary research as integral to the process of research use for policy and practice, yet few studies have examined researchers' perspectives about the use and usefulness of their work for such purposes (see for example (Campbell *et al.*, 2009; Holmes *et al.*, 2012; Sibley *et al.*, 2017)).

In locations where certain types of diseases are prevalent, such as the neglected tropical diseases (NTDs), local research funding, infrastructure, and capacity are often lacking (Davies and Mullan, 2016) – even as those in the policy and practice spheres have broadly promoted the benefits of such localised work for improving health and for development. Research led by individuals from low- and middle-income countries (LMICs) has produced relevant and translatable outputs to support local health interventions and policies (Beran *et al.*, 2017). The realisation of LMIC researchers in leadership roles, however, remains limited, at least as evidenced by the distribution of principle investigators, advisory roles, and first authorship - positions, which are held primarily by researchers from high-income countries (HICs) (Keiser *et al.*, 2004; Jacobsen, 2009; Chersich *et al.*, 2016; Kelaher *et al.*, 2016; Rees *et al.*, 2017; Mweemba *et al.*, 2019). LMIC researchers face barriers to research involvement, dissemination, and influence, often imposed and perpetuated by institutional structures and how research is funded in HICs (Wight *et al.*, 2014; Chersich *et al.*, 2016; Davies and Mullan, 2016; Mweemba *et al.*, 2019; Murunga *et al.*, 2020).

Previous studies on research production and researcher engagement with policy and practice have emerged from a variety of geographic locations and sub-fields of public health (Burchett *et al.*, 2013, 2015; Huckel Schneider *et al.*, 2016; Luna Puerta *et al.*, 2019; Rees *et al.*, 2019), yet none have explicitly examined these issues in relation to NTDs. NTDs largely affect people in LMICs who live in remote, marginalised areas with poor access to resources. This study focused on the NTDs, schistosomiasis and soil-transmitted helminths (STHs) as topics of particular interest to

health policymakers, practitioners, and researchers since the mid-1800s. For more than a century, public health authorities have attempted to control these parasitic diseases by implementing various 'deworming' interventions, most often referred to as Mass Drug Administration (MDA) or Preventative Chemotherapy (PC). Recently, development analysts have described these interventions as amongst the world's largest public health programmes (Bundy et al., 2017) to "rescue the bottom billion" (Hotez et al., 2009). This assertion, however, lacks broad consensus (Majid et al., 2019): over the past twenty years, works of schistosomiasis and STH researchers have contributed to a contentious debate about whether the available evidence actually supports mass deworming strategies (Majid et al., 2019). This debate, often called the 'Worm Wars', revolves around a handful of epidemiological and economic studies that show differing results using the same data (28). A plethora of other research has yielded potentially relevant evidence for public health policy and practice. Given that schistosomiasis and STH inflict tremendous burden and disability on more than one billion people annually, affecting the health, economic and education opportunities for individuals on all continents except Antarctica, it is vital that all potential evidence for decision-making be considered to support the control and elimination of these diseases.

To date, no one has examined systematically where and by whom this work has been produced. This study aims to provide insights on these sources and to illustrate how researchers view their own work in relation to development of health policies and their implementation. Our findings highlight opportunities – as well as 'disconnects' between primary research and its use in informing and transforming public health policy for schistosomiasis and STH control. We analyse: 1) leadership of research, based on corresponding authorship and publication characteristics; 2) communication channels between primary researchers and policy processes; and, 3) researcher perceptions about challenges in transforming research evidence into policy.

# 5.2 Methods

We surveyed corresponding authors from articles published on schistosomiasis or STHs, or both, to explore researchers' perceptions on use of their work in developing policy and influencing practice. To construct the sampling frame, we conducted a systematic literature search to identify articles that reported primary data collection related to schistosomiasis or STHs, or both. We invited corresponding authors of the publications to participate in an online survey, following previous studies using similar methods (Burchett *et al.*, 2013; Rees *et al.*, 2019).

## 5.2.1 Sampling frame

An intention behind assignment and order of authorship of peer-reviewed publications is to indicate contribution, responsibility, and credit for published research (Baerlocher *et al.*, 2007; Strange, 2008; Smith and Williams-Jones, 2012; Avula and Avula, 2015). Norms and standards of authorship assignment, however, vary substantially across disciplines (for examples, see (Weeks *et al.*, 2004; Baerlocher *et al.*, 2007; Henriksen, 2016)), and remain subject to controversy and debate (Marušić *et al.*, 2004; Strange, 2008; Johal *et al.*, 2017). Corresponding authorship indicates a form of leadership and ownership of the published work, however loosely defined. Designation of a corresponding author is a publication requirement across all disciplines and journals, but no such requirement applies to first and last authorship assignments. Multi-author studies are far more common in some fields (biomedical research) than others (anthropological research), although researchers from both fields study schistosomiasis and STHs. For these reasons, we included only one author from each publication in our sampling frame, the corresponding author.

On 10 July 2019 we conducted a systematic literature search of EMBASE, PubMed, and Web of Science to identify published articles reporting primary data related to human

schistosomiasis and/or STHs. We included English language articles from the previous five years, without geographic limitation (for full search terms, please see the Supplementary Materials). A check on the initial search (prior to any screening and removal of duplicates) in Web of Science showed that limiting the search to English language captured the vast majority of articles published on schistosomiasis (98%) and STH (96%).

The search produced 12,060 articles from the three databases. We compiled these results in Zotero reference manager software. After removal of duplicates and title screening, three researchers reviewed the remaining 1,413 articles for inclusion using the following criteria:

- 1. Published 10 July 2014 through 10 July 2019;
- 2. Reported results from primary data collection (clinical, population- or laboratory-based) of human schistosomiasis or at least one of the STHs infecting humans, or both;
- 3. Study conducted in a country with ongoing transmission of schistosomiasis or STHs, or both.

The inclusion criteria, limited to the previous five years, captured views of contemporary researchers actively working in these fields of study. Email addresses in scientific databases become invalid (or "stale") over time: estimates show approximately 2% of all contact emails do so each year (Rodriguez-Esteban *et al.*, 2019), and up to half within five years of publication (Wren *et al.*, 2006).

We compared results of the screenings and resolved discrepancies by unanimous decision. We extracted the corresponding author's name, contact details, institutional affiliations, journal title, year of publication, and research study locations from each article and entered these into a database. We screened author contact details and eliminated duplications. Where no email addresses appeared in the published article (n=16), we sought contact details through internet search engines, institution website searches, and professional social media and citation accounts (such as ResearchGate, GoogleScholar profiles.)

The sampling frame and results are limited by inclusion only of corresponding authors; researchers from LMICs often appear in the middle of author lists, even when the first and last ('lead') authors are from HICs (Rees *et al.*, 2019). Having recognized different disciplinary norms on authorship, we use corresponding authorship as a symbol of leadership for each specific piece of work and in the overall analysis. Thus, this sampling frame still allowed us to gain insights about the leadership of research and its dissemination.

# 5.2.2 Survey Content

We developed a questionnaire on researcher perspectives, consisting of 43 multiple choice, ranking, rating, and open-ended free text questions, based on previous research in health policy-making (Hanney *et al.*, 2003; Buse *et al.*, 2012), health policy documents (Haynes *et al.*, 2015), evidence uses and preferences of health policy-makers and practitioners (Jacob *et al.*, 2017), and researcher characteristics (see Supplementary Materials for the full questionnaire.) Participants could clarify their selections or provide examples in free text comment boxes. For rating questions, we employed three-point Likert scales to determine sentiment direction and highlight non-neutral responses (Colton and Covert, 2015). We piloted the survey with seven individuals at varied levels of professional experience (from two to 40 years) and institutional affiliations. We revised the survey based on pilot feedback.

### 5.2.3 Survey Implementation

We implemented the survey using Qualtrics survey software (Qualtrics, Provo, UT, USA, Version 10/2019). We invited researchers to participate via email in October 2019 through November 2019. We sent email reminders to non-respondents at one and four weeks after initiation. The survey did not require participants to complete every answer. We considered a

survey completed after a participant progressed from each question to the next to reach a final acknowledgement screen.

# 5.2.4 Data analysis

We added the following additional data to the search results database to examine where and from whom the publications originated: countries of institutional affiliation, location of research, journal impact factor (IF) for the publication year, and the publisher and publisher location, as reported by SCImago Journal and Country Rank (SCImago). To examine how distribution of research aligned with the burden of disease, we included the country-level prevalence estimates of schistosomiasis and STHs (Global Burden of Disease estimates (Global Burden of Disease Collaborative Network, 2018)) for each location, along with each country's global rank for the prevalence estimates (with 1 as the highest burden estimate.)

The research team conducted descriptive analyses using the number of completed survey responses for each question as the denominator. Results were stratified by location of researcher, field of research, years of professional experience. We reviewed free text responses and analysed those manually. We conducted all other analyses and data visualisations using Microsoft Excel (version 16.34), Python (version 3.3), or R (version 4.0.2).

# 5.3 Results

### 5.3.1 Systematic Search Results

The systematic search yielded 545 publications that met the inclusion criteria (Table 1; see Supplementary Materials for flow diagram). While most publications (98.4%, n=536/545) reported a focus of research in one country, nine included results of primary research from up to five countries, resulting in 565 research focus country observations across a total of 72 countries (Table 1.) When matched with the estimated disease prevalence (from (Global Burden of Disease Collaborative Network, 2018)), countries of focus for the majority of research publications were not always those with highest prevalence levels (Table 2). This suggests that other factors determined decisions about where to focus these research programmes.

### Table 5-1 Characteristics of systematic review results

Characteristic	Percent (n)
Research location (by WHO Region) (n=565)	
African	67.43 (381)
Americas	9.03 (51)
Eastern Mediterranean	2.48 (14)
European	0.35 (2)
South-East Asian	9.56 (54)
Western Pacific	11.15 (63)
Research location (by World Bank income group) (n=565)	•
HIC	1.42 (8)
UMC	11.50 (65)
LMIC	49.20 (278)
LIC	37.88 (214)
Author affiliation location (by WHO Region) (n=572)	
African	30.24 (173)
Americas	19.93 (114)
Eastern Mediterranean	1.92 (11)
European	30.77 (176)
South-East Asian	3.67 (21)
Western Pacific	13.46 (77)
Author affiliation location (by World Bank income group) (n=572)	
HIC	54.20 (310)
UMC	7.87 (45)
LMIC	21.85 (125)
LIC	16.08 (92)
Journal publisher location (by WHO Region) (n=545)	
African	2.57 (14)
Americas	40.73 (222)
Eastern Mediterranean	2.57 (14)
European	48.99 (267)
South-East Asian	3.30 (18)
Western Pacific	1.83 (10)
Journal publisher location (by World Bank income group) (n=545)	
HIC	89.54 (488)
UMC	2.94 (16)
LMIC	5.87 (32)
LIC	1.65 (9)
Journal Impact Factor (n=545)	Metric
Mean	3.17
Minimum	0.00
25th percentile	2.00
Median	2.71
75th percentile	3.57
Maximum	44.86

Most corresponding authors (95.4%, n=520/545) reported institutional affiliations from one country; 25 corresponding authors reported institutional affiliations from up to three countries, resulting in 572 institutional affiliation observations (Table 1). We found the frequencies of corresponding author affiliations to be highest from the United States (n=79), United Kingdom (n=69), Switzerland (n=40), Ethiopia (n=39), and Australia (n=32).

Matching each country of institutional affiliation to each country of research focus resulted in 592 institutional affiliation-research focus pairs. The pairs with the most match frequencies included Ethiopia-Ethiopia (n=39), Kenya-Kenya (n=29), United States-Kenya (n=23), and United Kingdom-Uganda (n=22). Aggregated at the regional level (as designated by the World Health Organization (World Health Organization)), the highest numbers of publications within each region came from those with corresponding authors with institutional affiliation and research focus using World Bank income categories (World Bank, 2020), we found that most of the publications with research focused on low-middle income countries (LMCs) and low income countries (LICs) included corresponding authors with affiliations from high income countries (HICs) (55.5% and 57.3%, respectively) (Figure 1B.) This is driven by the

grouping of institutional affiliation frequencies from the high-income countries of the United States, United Kingdom, Switzerland, and Australia, as noted above.

To examine the potential opportunity to influence, we matched the impact factors (IFs) of the journals that published the articles to the year of each article's publication date. The average IF across all publications was 3.17 (Table 1.) Researchers published sixteen articles in journals with IFs of zero, indicating that the journal had not been cited in two years or had been publishing for less than two years. When grouped by countries of corresponding author institutional affiliations by WHO region, articles from corresponding authors with European institutional affiliations appeared in journals with the highest average IF (3.996), followed by journals having published articles from corresponding authors with affiliations from the Americas (with an average IF of 3.267), although significant differences were not detected between these averages (Figure 2).



Figure 5-1 Distribution of publications by (A) income groups of institutional affiliations and research focus, and (B) regions of institutional affiliation and research focus

Note: Income group classifications by the World Bank (WB) (47) as HIC, high income countries; UMC, upper middle-income countries; LMC, lower middle income countries; LIC, lower income countries. Regional classifications by the World Health Organization (WHO) (46) as AFR, Africa Region; AMR, Region of the Americas; EMR, Eastern Mediterranean Region; EUR, European Region; SEAR, Southeast Asia Region; WPR, Western Pacific Region.



Figure 5-2 Journal impact factors for publications, by regions of corresponding author affiliations

Note: Regional classifications by the World Health Organization (WHO) (46) as AFR, Africa Region; AMR, Region of the Americas; EMR, Eastern Mediterranean Region; EUR, European Region; SEAR, Southeast Asia Region; WPR, Western Pacific Region.
### 5.3.2 Survey results

In total, we located 467 valid email addresses (85.7% of the 545 articles included, see Supplementary Materials for flow diagram) and used them to invite authors to participate in the electronic survey. The response rate was 27% (n=125); this approximated rates using similar methods (Burchett et al., 2013; Rees et al., 2019). Most (94.4%) respondents had five or more years of professional experience, with over one-quarter (28.8%) having had more than 20 years (Table 3.) Over 90% of respondents had published more than one peer-reviewed journal article on schistosomiasis, STHs, or both; this may reflect the duration of their careers. Academic institutions employed most respondents (67.2%) with government entities as the next most frequent employer (22.1%). Over half of respondents reported their field of research as population or public health, followed by natural or lab-based sciences, clinical research, and social sciences other than population or public health. Respondents reported humanities least frequently. As for disease focus, 55.8% of researchers reported working on both schistosomiasis and STHs, 26.3% on only STHs, and 17.9% on only schistosomiasis.

Just under one-third of corresponding authors who replied to the survey maintained a regular base in the African region; over two-thirds reported their research focus to be on African countries. In comparison, 28.9% of corresponding authors reported being based in Europe, with less than 2% reporting that their research had a European country focus (Table 3).

Nearly two-thirds of those conducting natural science research and half of those conducting clinical research lived in the countries where they conducted the research. Fewer than half (43.5%) of those conducting population or public health research and approximately one-quarter (23.1%) of those conducting social science research reported living in the country of

their research focus. None who reported working on humanities research lived in the country of research focus, but the study included only two such responses.

Table 5-2 Characteristics of survey respondents

Characteristic	Percent (n)
Years of professional experience (n=125)	
<5	5.6 (7)
5 to 10	33.6 (42)
11 to 20	32.0 (40)
> 20	28.8 (36)
Peer-reviewed journal publication history (n=120)	
> 5 articles on SCH/STH	59.2 (71)
2 to 5 articles on SCH/STH	32.5 (39)
1 article on SCH/STH	8.3 (10)
Current employer (by organisation type) (n=122)	
Academic institution	67.2 (82)
Government/Ministry of Health	22.1 (27)
International NGO	4.9 (6)
Domestic NGO	1.6 (2)
Independent consultant	1.6 (2)
Private industry	1.6 (2)
Multilateral institution (UN, World Bank)	0.8 (1)
Location of the researcher (by WHO region) (n=121)	
African	32.2 (39)
European	28.9 (35)
Americas	20.7 (25)
Western Pacific	9.9 (12)
Eastern Mediterranean	5.0 (6)
South-East Asian	3.3 (4)
Location of research focus (by WHO region) (n=121)	
African	66.9 (81)
Western Pacific	13.2 (16)
South-East Asian	11.6 (14)
Americas	4.1 (5)
Eastern Mediterranean	2.5 (3)
European	1.65 (2)
Field of research (n=121)	
Population/public health	52.0 (62)
Natural sciences	19.8 (24)
Clinical	16.5 (20)
Social sciences (other than population/public health)	10.7 (13)
Humanities	1.7 (2)

### 5.3.3 Researcher engagement and perceived relevance

Most respondents reported that they had been involved in some capacity with policy activities at the local (or study site) (71%), national (61%), or global (66%) levels (Table 4.) Seventy-two percent reported they had contributed directly to specific policy activities. When asked to specify these activities, respondents selected policy evaluation (23.3%), implementation activities (21.1%), policy briefs (18.9%), policy formulation (18.9%), and policy agenda setting (17.8%). Free-text comments on the informal activities in which corresponding authors reportedly participated demonstrated that they had been involved in a wide-range of activities that directly or indirectly could inform local, national, and global policy – from dissemination of research findings to local health authorities and national government ministries, to participation in WHO technical advisory groups.

Table 5-3 Percentage of respondents who reported they were ever or never involved in policy activities at the local, national, and global levels, by WHO region of author location

		All reg	gions	AF	R	AN	/IR	EM	R	EU	IR	SEA	R	WF	<b>P</b> R
Policy level	Involvement	%	n	%	n	%	n	%	n	%	n	%	n	%	n
Local	Ever involved	79%	77	100%	32	43%	13		nr	82%	18	100%	2	100%	12
LUCAI	Never involved	21%	21	0%	0	57%	17		nr	18%	4	0%	0	0%	0
Netional	Ever involved	61%	61	69%	22	50%	15	100%	2	50%	11	100%	2	75%	9
National	Never involved	39%	39	31%	10	50%	15	0%	0	50%	11	0%	0	25%	3
Global	Ever involved	66%	66	63%	20	73%	22	100%	2	55%	12	100%	2	67%	8
	Never involved	34%	34	38%	12	27%	8	0%	0	45%	10	0%	0	33%	4

Note: nr, no responses to this question

While respondents reported broad engagement with policy activities at relatively high rates, there was a 'disconnect' for their engagement with policymakers. The majority of respondents believed their research to be relevant to developing global policy (72%) and national policy (78%), yet fewer than half (45%) reported having discussed their research with policymakers directly, at either level, with a similar distribution after disaggregating the results by the home location of researchers. Free-text comments on this question came largely from corresponding authors who had discussed their research findings with WHO representatives – both formally at meetings and in working groups, and informally with colleagues working for the WHO – suggesting use of direct links with the WHO. Also, it was mainly the WHO among international organisations with which they reported contact.

Of those who believed their research to be relevant, but who had not discussed it with policymakers, the most frequently mentioned reason was lack of opportunities to shape policy at either national (44%) or global levels (57%). Despite the potential lack of direct engagement or knowledge transfer opportunities, over 80% of respondents reported that their work had been quoted or referenced in global or national policy documents, or both, with reviews and reports the most prevalent form of document cited (Figure 3.)

Overwhelmingly, respondents reported they viewed their research as relevant to implementation or delivery of health interventions or services. When asked to specify the generalisability or transferability, nearly three-quarters (71.4%, n=85/119) believed their research to be relevant beyond the specific study sites, with the majority (57.1%, n=68/119) reporting their research to be of relevance in any location endemic for schistosomiasis or STHs, or both. Approximately one-quarter of respondents across all fields of research reported relevance of their research to health interventions beyond those specifically targeting these diseases, except

those conducting social science research, where a higher percentage (42.1%, n=8/19) reported relevance of their research beyond schistosomiasis, STHs, or both.

When asked to list the top three challenges in transforming research outputs into tangible policy or practice, most responses included reference to funding-policy-research relationships. The key themes which emerged from the open-text answers were: 1) misalignments between the aims, objectives, and presentation of findings in research compared to those in policy; 2) lack of communication channels and dialogue between researchers and policy-makers; and 3) perceived constraints within the policy process itself. Prevalent examples from this third theme included the low uptake of research results, the dominance of certain groups of researchers or institutions, a lack of openness to findings which challenged current strategies, and the influence of donor organizations on policy processes.



Figure 5-3 Percent of corresponding authors reporting citation or reference in specific types of policy documents at the national and global level

### 5.3.4 Whose goals and priorities determine research agendas and policies?

We asked respondents to select whether the priorities and goals of specific entities 'always', 'sometimes', or 'never' determine research agendas, and global- and national-level policies related to schistosomiasis, STHs, or both. Responses show a perception that priorities of funders, donor organisations, the United Nations (UN), national governments, academic institutions, local priorities, and non-governmental organisations all play roles in determining research agendas (Figure 4). Results are similar for global and national policies. When focusing on those entities that 'always' determine research agendas (see Figure 4), respondents perceived that the funders of research and donor organisations involved in the health or disease area exerted the strongest influence in determining research agendas. In contrast, for global policies, respondents perceived the United Nations (UN) Sustainable Development Goals (SDGs) to have the strongest influence, with more respondents stating that the UN (following the SDGs) 'always' determines policy agendas. For entities that determine national priorities, respondents most often reported it was national governments that 'always' determine national policy agendas. As for entities that 'never' determine agendas and policies, the majority of respondents reported that local priorities 'never' determine global priorities and that academic institutions 'never' determine global or national policies.



Figure 5-4. Corresponding author perspectives on whose goals and priorities determine research agendas

### 5.4 Discussion

Publications reporting primary research on schistosomiasis, STH, or both make a prominent contribution to the evidence available to support policies and practices to control these diseases. Yet the characteristics and perspectives of the researchers and institutions that produce the research have not been systematically examined. This study contributes to debates on research-policy dynamics by presenting results of a systematic literature search and survey on researchers' perspectives on uptake and use of their research in local, national, and global policy. Our findings highlight opportunities as well as counterproductive disconnects between primary research and its use in informing and transforming public health policy for controlling these diseases. It shows this through three interrelated concerns: 1) leadership of research symbolised by corresponding authorship characteristics; 2) communication channels between primary researchers and policy processes; and 3) perceptions of misalignment of aims, objectives, and dissemination of research with policy and agenda setting processes.

Over the past fifteen years we have seen increasing attention to the 'translation' of research findings into knowledge that can be implemented, particularly findings in health policy and systems research (HPSR) in high and low income countries (Almeida and Báscolo, 2006). Recognition of structural disparities (Keiser et al., 2004; Jacobsen, 2009; Chersich et al., 2016; Kelaher et al., 2016; Rees et al., 2017; Mweemba et al., 2019) have led to calls for more leadership of research by those in countries where research is conducted and where it is hoped it will influence decision- and policy-making (Davies and Mullan, 2016; Beran et al., 2017). In terms of the results presented here, the analysis of publication characteristics resulted in a more nuanced portrayal of these disparities, particularly about researchers' home locations, places where they conduct research and where they publish. The highest numbers of publications within each region had corresponding authors with institutional affiliations from the given region. When analysed by country-level income categories we see that most of the publications with research on LMICs included corresponding authors with affiliations from HICs (most often the United States, United Kingdom, Switzerland, and Australia). Similarly, as to potential influence of research, we found authors based in European and American institutions to have published in a greater number of higher than average IF journals than those in other regions. Impact can and should be measured beyond citation frequency, yet the IF measure exemplifies the disparities faced by LMIC-based researchers, as cited elsewhere (Wight et al., 2014; Chersich et al., 2016; Davies and Mullan, 2016; Mweemba et al., 2019; Murunga et al., 2020).

Journal publication characteristics do not in themselves tell us about the use and uptake of evidence in informing and transforming policy. Previous work has cited chasms between research and policy priorities and decision-making needs, including time scales, presentation and interpretation of results, and different types of pressures from different stakeholders (Orton et al., 2011). Our survey reflects some of those tensions and illustrates concerns about misalignment between academic research aims, objectives and presentation of findings - and policy aims, processes, and needs. Interestingly, a review of researcher and decision-maker perceptions in LMICs on Evidence-Informed Policy-making platforms suggested that separation of research and policymakers "is not as rigid" in LMICs as frameworks from HICs might suggest because many policy-makers in LMICs have experience conducting research prior to their current roles. The authors point to a more important role of informal relationships and personal interactions in lower income settings (Shroff et al., 2015). Our analysis shows that, of the corresponding authors who responded to our survey, the majority use formal and informal channels to some extent to present their research findings to decision-makers at local, national, and global levels. Even so, there remains a perceived lack of opportunities and of channels for engaging with policymakers in an actual process of using the evidence to inform policy, and for learning how their research has shaped policy.

Structural barriers inhibit use of diverse types of research evidence available for informing decision-making and policy processes. Schistosomiasis and STH affect populations living in areas of LMICs associated with poverty and social, economic, political and geographic marginalisation (Hotez *et al.*, 2009). Despite this acknowledgement of social and structural determinants of health, the vast majority of research emanated from biomedical fields, with much less representation of social sciences in the recent body of research we studied. This bias implies limitations in types of information from research available to decision- and policy-makers (Allotey *et al.*, 2010).

The vast majority of survey respondents reported that their research was relevant to both policy and practice, and transferable anywhere that is endemic for schistosomiasis or STH. However, an opportunity gap clearly remains, despite concerted efforts by the WHO and others to establish networks and platforms to improve engagement between researchers and policymakers (World Health Organization). Respondents in our survey noted an ongoing lack of opportunity for communication and dialogue between the two groups. These findings suggest that substantial structural and perceived barriers remain for researchers who wish to transform their findings into relevant policies and influencing practice.

### Limitations

Since we limited the systematic review to English language publications, the results do not reflect articles and authors published in non-English language journals. We estimated that English language journals accounted for over 95% of the systematic literature search results prior to placing the language restriction. Given that the burdens of schistosomiasis and STHs are high in many non-English speaking countries, the degree to which the authors' institutional affiliations match the research location may be under-represented in our sample compared to the complete corpus of published literature on schistosomiasis, STH, or both. Similarly, limiting the sampling frame to corresponding authors reflects only a sub-group of individuals having conducted research on schistosomiasis, STHs, or both. Although a narrow definition of the sample population has certain advantages, the results are not representative of all researchers working in the field. As discussed above, researchers from LMICs often appear in the middle of author lists, and their experiences in research and with policy and practice are likely systematically different than those presented in this paper. Further work should be conducted to capture such perspectives.

### 5.5 Conclusion

Our findings contribute to debates in global health on research-policy engagement in public health. We illustrated ongoing structural disparities in research leadership. We found broad concern about opportunities and about disconnects that limit engagement between researchers and decision-makers for use of primary research in policy and decision-making processes. Previous work on the research to policy process has been largely focused on the perspectives and activities of policymakers and practitioners. While it is important to understand the utilisation of research by these actors, to ultimately improve this process, it is also imperative to explore the perspectives and activities of those producing the research. Thus, we suggest further exploration of researchers' perspectives, and their interactions with policy and practice, to shape and advance the use of evidence-informed policy in public health, which will ultimately improve population health.

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- 5.7 Supplementary materials
- 5.7.1 Systematic review search terms

A systematic literature search of EMBASE, PubMed, and Web of Science was conducted on 10 July, 2019 to identify published articles reporting on primary data collection related to schistosomiasis and STHs using the following searches:

## 1. (TS=(schistosom\* OR bilharzia\*)) AND LANGUAGE: (English)

- Timespan=Last 5 years
- (TS=(helmint\* OR "Ancylostoma duodenale" OR "Necator americanus" OR Ascaris OR "Enterobius vermicularis" OR trichuris OR Strongyloid\* OR hookworm\* OR roundworm\* OR pinworm\* OR whipworm\*)) AND LANGUAGE: (English) Timespan=Last 5 years
- 5.7.2 Survey questionnaire
- 1. Please select the best description of your current employment status:



- 2. How many years professional experience do you have?
  - Less than five years (1)
  - 5 to 10 years (2)
  - 11 to 20 years (3)
  - O More than 20 years (4)
- 3. What is your current job title?
- 4. Which type of organisation do you currently work in?

Government/Ministry of Health (1)
Academic institution (2)
Multilateral institution (e.g. United Nations, World Bank) (3)
Domestic non-governmental organisation (NGO) (4)
International non-governmental organisation (NGO) (5)
Independent consultancy (6)
Private industry (7)
Other, please specify (8)

5. In your current position, which of the following activities are you involved in?

Research (12)
Teaching (13)
Policy (14)
Clinical Practice (15)
Other, please specify (16)

6. Please select the most relevant research area(s) for your current work:

	Laboratory-based/ basic sciences (1)
	Clinical (2)
	Population/public health (3)
	Social sciences (4)
	Humanities (5)
	Other, please specify (6)
7. Please select	the country you are currently employed in.

▼ Afghanistan (1) ... Zimbabwe (1357)

8. In order to tailor the survey to your previous experience, please select which of the following you have worked on:

schistosomiasis (1)
 soil-transmitted helminths (2)
 schistosomiasis and soil-transmitted helminths (3)

9. Please select the country or countries where the majority of your work on [Schistosomiasis/STH/both] has focused.

10. Please select the statement which best characterises your research on [Schistosomiasis/STH/both]:

Currently, all or most of my research is focused on [Schistosomiasis/STH/both]. (1)

Currently, some of my research is focused on [Schistosomiasis/STH/both], but the majority of my research focuses on a different health or disease topic. (2)

Previously, all or most of my research was focused on [Schistosomiasis/STH/both], but my research is now focused on other health or disease topics. (3)

O My research has never focused specifically on [Schistosomiasis/STH/both], but I have worked on projects related to [Schistosomiasis/STH/both] on an ad hoc basis. (4)

O Other, please explain: (5) \_\_\_\_\_\_

11. Please specify which other health or disease area your work focuses on:

12. Please select the statement which best describes your peer-reviewed publication(s) related to [Schistosomiasis/STH/both]:

○ I have published more than 5 articles related to [Schistosomiasis/STH/both] in peerreviewed journals. (1)

○ I have published 2 to 5 articles related to [Schistosomiasis/STH/both] in peerreviewed journals. (2)

○ I have published 1 article related to [Schistosomiasis/STH/both] in a peer-reviewed journal. (3)

13. In relation to your research on [Schistosomiasis/STH/both], have you participated in any of the policy activities listed below?

Policy agenda setting (1)
Policy formulation (2)
Policy implementation (3)
Policy evaluation (4)
Policy brief(s) (7)
Other, please specify: (5)
$^{\otimes}$ I have not participated in any policy activities at any level (6)

# 14. Are you or have you been involved in the above policy activities related to [Schistosomiasis/STH/both] at the following levels?

	Currently involved (1)	Previously involved (2)	Never involved (3)
Local level (1)	0	0	0
National level (2)	0	$\bigcirc$	$\bigcirc$
International/global level (3)	0	$\bigcirc$	$\bigcirc$

15. Please provide any additional comments, for instance if you have been involved in informal activities that may be directly or indirectly related to local, national, or global policy?

16. From your perspective, is your research on [Schistosomiasis/STH/both] relevant to policies at the international/global policy level?

Yes (1)
 Maybe (2)
 No (3)

17. Have you discussed your research with **international** policy-makers? Please select all that apply.

 $\bigcirc$  Yes, please specify with an example (2)

O No (1)

18. From the following list of policy documents, please tick any in which your research has been quoted or referenced at the **international/global level**, to the best of your knowledge:

	Review (1)
	Report (2)
	Discussion paper (3)
	Draft or final policy (4)
	Formal directive (5)
	Program plan (6)
	Strategic plan (7)
	Ministerial brief (8)
	Budget bid (9)
	Service agreement (10)
service	Implementation plan, guideline or protocol with a focus on health /programme design or delivery (11)

Implementation plan, guideline or protocol with a focus on health service/programme evaluation or resourcing (12)

My research has influenced or contributed to international/global policy through other means not listed above (17)

$^{\otimes}$ None of the a
$\bigotimes$

bove (14)

<sup>⊗</sup>I don't know (15)

19. While, to the best of your knowledge, you may not have been quoted or referenced in any of the policy documents listed above, do any of the statements below apply to your experience with global policy? Please check all that apply.

My research has shaped global-level policy debates through informal discussions. (2)

My research has shaped global-level policy debates in formal settings, such as an advisory board or committee. (1)

I have not been presented with the opportunity to shape global-level policy with my research. (3)

Other, please explain: (4)

20. From your perspective, is your research on [Schistosomiasis/STH/both] relevant to policies at a national level?

Yes (1)

O Maybe (2)

O No (3)

21. Have you discussed your research with national policy-makers?

_	J	

No (1)

Yes, please specify with an example (2)

22. From the following list of policy documents, please check any in which your research has been quoted or referenced at the national level:

	Review (1)
	Report (2)
	Discussion paper (3)
	Draft or final policy (4)
	Formal directive (5)
	Program plan (6)
	Strategic plan (7)
	Ministerial brief (8)
	Budget bid (9)
	Service agreement (10)
service/pro	Implementation plan, guideline or protocol with a focus on health ogramme design or delivery (11)
service/pro	Implementation plan, guideline or protocol with a focus on health ogramme evaluation or resourcing (12)
means not	My research has influenced or contributed to national policy through other is listed above (17)
	$^{\otimes}$ None of the above (14)
	$^{\otimes}$ I don't know (15)

23. While, to the best of your knowledge, you have not been quoted or referenced in any of the policy documents listed above, do any of the statements below apply to your experience with global policy? Please check all that apply.

My research has shaped national-level policy debates through informal discussions. (2)

My research has shaped national-level policy debates in formal settings, such as an advisory board or committee. (1)

I have not been presented with the opportunity to shape national-level policy with my research. (3)



Other, please explain: (4)

24. Is your research on [Schistosomiasis/STH/both] relevant to the implementation and/or delivery of health interventions or services?

○ Yes (1)

○ No (3)

O Maybe, please clarify: (2)\_\_\_\_\_

25. In terms of the implementation/delivery of health interventions or services, where is your research on [Schistosomiasis/STH/both] relevant ? Please check all that apply:

	In the study site(s) where it was conducted. (1)
	Elsewhere in the country where it was conducted. (2)
	In other countries in the same region where it was conducted. (3)
	Anywhere that is endemic for [Schistosomiasis/STH/both]. (4)
[Schistosc	For health interventions or services beyond issues related to pmiasis/STH/both]. (6)
	Additional comments or clarifications: (7)

26. Please read the following statement with the options below and indicate the extent to which

you agree on the sliding scale (from 0 for disagree to 10 for strongly agree.)

When I read a paper based on primary research, I will judge it on the basis of: Disagree Somewhat agree Strongly agree



27. Do you think that similar judgements are made by policymakers when reviewing research?

○ Yes (2)

○ No (3)

O Maybe (4)

Please explain:

28. Would you accept the findings of an ethnographic or qualitative study if there are no supporting statistical findings?

O Yes (1)

🔾 No (2)

Maybe, please explain: (3)

29. Would you accept the findings from an ethnographic or qualitative study that contradict existing statistical evidence?

Yes (1)
 No (2)
 Maybe, please explain: (3)

30. Would you accept the findings from an ethnographic or qualitative study that contradict existing policies related to [Schistosomiasis/STH/both]?

Yes (1)
No (2)
Maybe, please explain: (3)

31. Do you perceive that your research outputs related to [Schistosomiasis/STH/both] are being sufficiently utilised by individuals in the following categories?

	My research is not relevant to this group (1)	My research is relevant but <u>not</u> used sufficiently by this group (2)	My research is relevant and used sufficiently by this group (3)
Research community (1)	0	$\bigcirc$	0
Practitioners or local authority at the study-site (2)	0	$\bigcirc$	$\bigcirc$
National level policy- makers (3)	0	$\bigcirc$	$\bigcirc$
Global level policy-makers (4)	0	$\bigcirc$	$\bigcirc$
Health practitioners (5)	0	$\bigcirc$	$\bigcirc$

32. In your view, do the priorities and goals of each of the following entities always, sometimes, or never <u>determine research agendas</u>:

	Always (1)	Sometimes (2)	Never (3)
United Nations (e.g. Sustainable Development Goals) (1)	0	0	0
National government/Ministry of Health (2)	0	$\bigcirc$	$\bigcirc$
Funders of the research (3)	$\bigcirc$	$\bigcirc$	$\bigcirc$
Donor organisations involved in the health or disease topic (4)	$\bigcirc$	$\bigcirc$	$\bigcirc$
NGOs working in the area (5)	$\bigcirc$	$\bigcirc$	$\bigcirc$
The academic institution where I work (6)	$\bigcirc$	$\bigcirc$	$\bigcirc$
Local (e.g. district/county) priorities and needs (7)	$\bigcirc$	$\bigcirc$	$\bigcirc$

At the national and global levels, do the priorities of each of the following entities always, sometimes, or never <u>determine which research is incorporated into policy</u>:

### 33. National-level policy

	Always (6)	Sometimes (7)	Never (8)
United Nations (e.g. Sustainable Development Goals) (1)	0	0	0
National government/Ministry of Health (2)	$\bigcirc$	$\bigcirc$	$\bigcirc$
Funders of the research (3)	$\bigcirc$	$\bigcirc$	$\bigcirc$
Donor organisations involved in the health or disease topic (4)	0	$\bigcirc$	$\bigcirc$
NGOs working in the area (5)	$\bigcirc$	$\bigcirc$	$\bigcirc$
The academic institution where I work (6)	$\bigcirc$	$\bigcirc$	$\bigcirc$
Local (e.g. district/county) priorities and needs (7)	$\bigcirc$	$\bigcirc$	$\bigcirc$

### 34. Global-level policy

	Always (6)	Sometimes (7)	Never (8)
United Nations (e.g. Sustainable Development Goals) (1)	0	0	0
National government/Ministry of Health (2)	0	$\bigcirc$	$\bigcirc$
Funders of the research (3)	$\bigcirc$	$\bigcirc$	$\bigcirc$
Donor organisations involved in the health or disease topic (4)	$\bigcirc$	$\bigcirc$	$\bigcirc$
NGOs working in the area (5)	$\bigcirc$	$\bigcirc$	$\bigcirc$
The academic institution where I work (6)	$\bigcirc$	$\bigcirc$	$\bigcirc$
Local (e.g. district/county) priorities and needs (7)	$\bigcirc$	$\bigcirc$	$\bigcirc$

35. In your view, what are the three main challenges in transforming research outputs into tangible policy or practice?

Challenge 1 (1)	 
Challenge 2 (2)	
• endirenge 2 (2)	 
Challenge 3 (3)	 

36. Are there any other comments that you have regarding the use of your research for policy or practice? Please enter below:

5.7.3 Flow diagram of systematic review search results



### 6 Conclusion

This thesis began by discussing how the global-level health goals have not been met, and contends that one of the reasons for this is the use of reductionist or linear approaches to underpin analyses across global health. Further, much of the evidence base for decision-making for some aspects of global health is derived from studies which are not designed to engage with the complexities of the system. To address these issues, this thesis furthered the current knowledge related to the global health system by engaging with the dynamic, non-linear relationships between actors and processes across the governance, financial, and delivery arrangements within the system. To conclude this thesis, I first present a summary of key findings and contributions, including paper-specific implications on policy and practice. This is followed by a critical discussion of the thesis findings and methodologies. Finally, I provide cross-cutting insights gained through this thesis and future directions for the research.

### 6.1 Summary of key findings and contributions

The overarching research question of this thesis was:

How can methodological and conceptual approaches to complexity in quantitative analysis improve evidence and decision-making, specifically for schistosomiasis control in Uganda and more broadly within global health?

To address this, the following sub-questions were posed by the four papers in this thesis:

- 1. Using dynamic network analyses, how did the distribution of global health actors and the power dynamics evolve through the MDG-era?
- 2. How does linking participatory and computational modelling improve the quality of evidence with regards to schistosomiasis interventions in Uganda?
- 3. Drawing on the specifics of programmes in Uganda, how do the outputs of participatory and computational modelling impact the results of economic evaluations of mass drug administration for schistosomiasis?
- 4. Using network sampling and remote surveys, what do we learn from the perspectives of primary data gatherers and researchers working on mass drug administration in reference to their roles in policy and practice?

Broadly speaking, this thesis has shown that while reductionist, linear perspectives in global health may be part of the reason for the continuation of ineffectual policies and practices, the confluence of politics, power relations, and economies in the context of a complex system of actors and processes plays a significant role with regards to policy and practice decision-making in global health. Paper 1 addressed Research Question 1, Paper 2 addressed Research Question 2, Paper 3 addressed Research Question 3, and Paper 4 addressed Research Question 4.

Using the definition of global health described in the introduction, the papers in this thesis examined aspects of decision-making across the governance (Paper 1 and Paper 4 [Chapter 2 and Chapter 5]), delivery (Paper 2 and Paper 4 [Chapter 3 and Chapter 5]), and financial (Paper 1 and Paper 3 [Chapter 2 and Chapter 4]) arrangements which comprise the global health system. While this generally describes the focus of each paper, they all integrate aspects of evidence, decision-making, and the financial, governance, and delivery arrangements within global health, and demonstrate how these facets of the system are interlinked. As a starting point, Paper 1 [Chapter 2] took a macro perspective of the global health system and examined one aspect of governance, namely the power as derived from financial arrangements in development aid. This paper engaged with the complexity of financial arrangements using a dynamic network analysis. Next, Paper 2 [Chapter 3] and Paper 3 [Chapter 4] focused in on the

delivery and financial arrangements of one specific disease problem, schistosomiasis control and elimination in Uganda. Paper 2 [Chapter 3] used networks in the form of participatory systems mapping to elicit the perspectives of key decision-makers, and linked these to evidence development using graph theory and individual-based modelling. Paper 3 [Chapter 4] utilises these outputs to build an economic analysis and what is ultimately a critique of cost-effectiveness analyses commonly used to support the continuation of MDA. These methods explicitly engage with the complexities of decision-making and schistosomiasis transmission to produce evidence that is responsive to the needs of decision-makers. Paper 4 [Chapter 5] examined the perspectives of researchers who produce evidence to support MDA for schistosomiasis and other NTDs. In this study, networks again formed the basis for data collection, whereby a systematic literature review and subsequent bibliographic analysis produced the sampling frame employed to conduct an online survey to elicit researcher perspectives. The contexts and cases used in this thesis were representative of aspects of the global health system and incorporated aspects of complexity to provide insights on globally-focused disease problems, the implementation of global health interventions used to address them, and the dynamic relationships of actors within the system. The remainder of this section describes the key findings and contributions of each paper.

Paper 1 [Chapter 2] examined governance in terms of power across the changing landscape of actors in global health. While acknowledging that funding allocations are an important, though not an isolated or absolute, source of power, the aims of this paper were to examine the changes in the landscape and shifts in power using data on disbursements of development assistance for health (DAH). Using a typology of actors developed from previous literature and refined through an empirical analysis of DAH, the characteristics of the global health landscape were described over the twenty-five year period leading up to and encompassing the MDG era (years 1990 through 2015.) To examine aspects of power, the emergent network structures of DAH flows between global health actors and positionality of actors within the network were analysed over this same time period. With the establishment of the MDGs, including three of the eight goals explicitly targeting health, DAH became an important political tool and symbol. These goals were meant to serve as apolitical objectives around which everyone working in development could coalesce (McCoy et al., 2009). Similar to the rhetoric surrounding the broad goal of poverty reduction, the narrative around DAH has been apolitical in nature, where even questioning aid disbursements has been "obstructed by the moral oratory of 'saving lives' and 'fighting disease"' (McCoy & Singh, 2014). It quickly becomes apparent how understanding power dynamics in global health is necessary to tackle health inequities (Marmot et al., 2008) and enhances "our ability to promote transparency, accountability and fairness" (Sriram et al., 2018). To this end, this study contributed an updated, comprehensive typology of global health actors involved in development assistance for health, and analyses of the emergent network structure of development assistance for health from 1990 through 2015. The analysis of power using network metrics provided multidimensional insights as to the importance of actors in the system and changes in their positions leading up to, and through, the MDG era.

In terms of specific findings, the dynamic network analysis provided several empirical insights to address Research Question 1. From the early 1990s through the end of 2015, the system of actors engaged in development for health became denser, as the numbers of actors and relationships between actors increased substantially. The dynamic network analysis captured the increased dispersion of funding. Of particular importance to the discussion of power was the decreased concentration in flows of aid from large bilateral and multilateral organisations. In the context of this analysis on power, the United States government, through its bilateral aid agencies, was found to have maintained the most central position across all network metrics reported here across all years. This trend was not observed across the rest of the public actors studied. Through a combination of the massive influx of new funding sources and a decrease in

public spending, the majority control of financial resources in the DAH network receded from public entities and gave way to civil society organisations (CSOs) and public-private partnerships (PPPs). The most prominent of these were the BMGF and GFATM, which were found to have risen to the third and fourth most central, important positions within the DAH network by 2015. While discussions on the implications of the emergent power of CSOs, PPPs, and other nonpublic entities in global health are not new, this type of system-level empirical assessment is not common. The dynamic network analysis accommodated the complex nature of development assistance for health data and provided fruitful insights as to the emergent system-wide trends over the twenty-five year time period.

Paper 2 [Chapter 3] aimed to develop evidence for decision-making in response to the needs of policymakers and practitioners, with a focus on schistosomiasis transmission and control activities in Uganda. This was accomplished by (1) capturing the perspectives of decision-makers on schistosomiasis transmission using participatory modelling, and (2) using the participatory modelling outputs to inform mathematical model simulations in response to the evidence needs. The digitised versions of the systems maps, the outputs of participatory modelling, served as depersonalised expressions of consensus by small groups that facilitated conversations in the large group about difficult topics, such as the distribution of resources, data gathering, and the lack of sustained reductions in schistosomiasis prevalence. These discussions may not have otherwise taken place openly given the social dynamics between district-level and national-level participants. The participants indicated that they hoped to use the systems maps to advocate for resources they deemed necessary from both domestic and international source. In this capacity, the maps were viewed as leverage in a system of perceived top-down decisionmaking around schistosomiasis control activities. Participatory systems mapping provided a tool with which potential solutions could be developed based on lived experiences. From the systems maps, it was clear that participants at the national, district, and village levels were most focused on factors that increase or decrease infested water contact, a key intervention point in the schistosomiasis transmission cycle. This perspective was used to guide the model simulation activities. An individual-based model was employed to simulate the impacts of age-specific reductions in water contact under various scenarios. The results showed that employing MDA alone, at either the current or target levels of SAC coverage, did not result in achieving the most recent NTD Road Map to 2030 targets of morbidity control or elimination in high prevalence settings within the specified timeframe. However, when combined with water contact reduction activities, morbidity control was reached in S. mansoni settings and morbidity control and elimination were achieved in S. haematobium settings within the same ten-year time period.

To answer Research Question 2, the results of this study demonstrated that the combination of participatory systems mapping and individual-based modelling was a rich strategy which explicitly integrated the perspectives of national and subnational policymakers and practitioners into the development of evidence for decision-making related to schistosomiasis control. There were several important insights from this study relevant to the broader context of the NTD Road Map to 2030 and the global strategies for achieving schistosomiasis morbidity control and elimination. The participatory systems mapping supported critiques about mass deworming strategies as vertical, top-down interventions (Mazigo, 2019; Tchuem Tchuenté et al., 2017). The simulations provided further evidence that MDA alone will not achieve the prevalence reduction targets (Li et al., 2019; Toor et al., 2020). Individuals from village health teams (VHTs) were the only group to specifically discuss the implementation of MDA in relation to schistosomiasis transmission, most likely because they were directly responsible for carrying out these activities. The lack of access to treatment for routine care within the communities, leading to the inability to provide adequate case management, were important gaps highlighted in the context discussions about MDA.

Paper 3 [Chapter 4] showed that the degree to which mass drug administration for schistosomiasis in its current form can be considered cost-effective is debatable. The results

indicated that the most cost effective scenario is a system of implementation reliant on the unpaid labour of individuals within communities, either teachers or health workers, and free drugs, donated by pharmaceutical companies. When these costs are included, especially those related to 'volunteer' time, the cost-effectiveness of MDA drops precipitously in high transmission settings. Further, over the thirty-year modelling period, MDA was less cost effective when compared to interventions aimed at reducing water contact. This is largely due to the annual long-term impact of avoiding diarrhoea. The results presented here indicate that MDA in its current form will not achieve the targets regarding the schistosomiasis burden established by the global community.

To answer Research Question 3, these analyses contest the assertions regarding the health and cost implications of continued school-based MDA campaigns, especially those related to impact evaluations and long-run economic benefits. Further, they present potential opportunities which are more aligned with the aims of country-led sustainable development, as described by the UN's Sustainable Development Goals and the WHO's Roadmap for Neglected Tropical Diseases. Previous economic evaluations on the effects of deworming were part of the justification for Professor Michael Kremer's 2019 Nobel Prize<sup>38</sup>. The notoriety of this work makes it difficult to challenge aspects of the analysis for those in less authoritative positions. That said, this paper provided insights on some of the key components that contribute to the cost effectiveness analyses and other economic evaluations. The most notable of these are the reliance on donated medications and volunteers for implementation. Economic evaluations are the cornerstone of many decision-making processes in global health, especially related to the distribution of financial resources. Therefore, it is important that the analytical components and inputs are thoroughly understood and examined. Paper 3 provided one analytical framework to implement this type of investigation, while taking the complexity of schistosomiasis intervention implementation and prevalence into account.

Paper 4 [Chapter 5] examined the contributors to a specific form of evidence base used to support global health policy and practice, peer-reviewed literature. Generally, for policymakers and practitioners responsible for the implementation of population-based health interventions, decision-making requires that they weigh the evidence of effectiveness alongside the myriad of other political, economic, and social factors (Oliver & de Vocht, 2015). Previous studies have shown that the evidence used to make decisions regarding implementation of intervention come from a variety of sources (Oliver et al., 2014; Oliver & de Vocht, 2015). Despite being the basis for international standards and recommendations, and considered an integral part of evidence-informed decision-making, studies have shown that peer-reviewed published literature is often not considered amongst the most useful or relevant to individuals directly involved in implementation decisions (Campbell et al., 2009; Holmes et al., 2012; Sibley et al., 2017).

The aim of this paper was to assemble and describe the network of actors and perspectives of those who contribute to this important evidence base. To do so, a systematic review was conducted to construct a network of contributors as sampling frame. This was followed by a bibliographic analysis and electronic survey to elucidate the perspectives of authors of published articles on MDA. The findings contribute to debates in global health on researchpolicy engagement in public health. To answer Research Question 4, the results of this study illustrated ongoing structural disparities in research leadership, as evidenced by the location of researcher affiliations and their associated position within the published author list. Most first and last authors were located in the US, UK, and Europe, and while this is an imperfect measure of leadership, it does demonstrate that the disparity exists at some point in the process from research inception to publication. Survey participants expressed broad concern about opportunities and disconnects that limit engagement between themselves and decision-makers,

<sup>&</sup>lt;sup>38</sup> <u>https://www.who.int/news/item/06-10-2021-2019-nobel-laureate-michael-kremer-emphasizes-wash-and-deworming-benefits</u> (accessed 29 June 2022.)

despite knowledge that their work is used to support policy and practice. Some of these concerns included misinterpretation or the potential for over-generalisation of the results they had published. Previous work on the research to policy process has been largely focused on the perspectives and activities of policymakers and practitioners. While it is important to understand the utilisation of research by these actors, to ultimately improve this process, it is also imperative to explore the perspectives and activities of those producing the research. The use of network sampling was an effective strategy to construct a sampling frame and obtain contact details for a wide array of individuals dispersed across the globe. Importantly, as a result of the choice of sampling, the diverse sample included authors from across fields, working on a variety of aspects related to MDA were included in the sample. Likewise, remote surveys accommodated the geographic limitations that would not have easily permitted collection of these data using inperson survey methods.

To summarise, there were several key contributions made by the work presented in this thesis, some of which I will highlight next. Firstly, I developed a current and comprehensive typology of global health actors, which can be applied in future research on global health and easily integrated into analytical frameworks. In my own work, I used this typology to evaluate power shifts in the global health landscape by capturing the emergent network structure of development aid for health, marking a contribution to the work on power in global governance, both in theory and methodology. I developed and implemented a protocol which linked participatory and computational modelling to integrate new perspectives into the development of evidence and contested the status quo of top-down health intervention implementation decisions, contributing to the theoretical and methodological underpinnings of intervention development. I demonstrated the utility of remote research during a pandemic using electronic surveys, and showed that stepping back to investigate the abundance of information in published work can be fruitful through the application of bibliographic analyses. Finally, I believe that the work presented in this thesis tried to integrate and amplify voices which are not often heard in global health settings, to the extent that this was possible given my own positionality and the pandemic context of the past two years.

### 6.2 Critical discussion of findings

### 6.2.1 Conceptual considerations

How we define "global health" depends on the context and aims. It is a contested term — in the most basic sense for its lack of distinction from international health (Peters, 2017) or public health (Fried et al., 2010). This thesis engaged with the definition from Hoffman and Cole (2018), which was built on the previous work of Szlezák *et al.* (2010), Hoffman *et al.* (2012), and Frenk and Moon (2013), and defined global health as a complex system of "transnational actors that have a primary intent to improve health and the polylateral arrangements for governance, finance, and delivery within which these actors operate." For the sake of distinction, the positionality of these polylateral arrangements in the complex system of globally-driven health services and practices is what distinguishes global health from international health, public health, and other overlapping iterations and similar conceptual designations in the context of this thesis. In this definition, the finance, governance, and delivery arrangements are the observable and measurable outcomes of individual and institutional decisions, power dynamics and relationships between actors, and interactions with other sectors. These dynamics ultimately impact the health of world's population through resource allocation, normative guidance, health service delivery, and other outputs.

Power asymmetries exist across all facets of society and directly impact health outcomes. The unequal distribution of power at the global level was reported as one of the main contributors to "the poor health of poor people, the social gradient in health within countries, and the substantial health inequities between countries" by the World Health Organization's (WHO) Commission of Social Determinants of Health (Marmot 2008). These power asymmetries are often discussed from the individual, household, community, and population perspectives as well as the manifest outcomes in terms of inequitable access to quality care and services. To provide new insights, this thesis engaged with the perspectives of non-beneficiary global health actors (i.e. those who are not health service targets or recipients.) The studies presented spoke to aspects of differential power arrangements across the governance, financial, and delivery arrangements within the global health system using different methods of inquiry and units of analysis.

More specifically, Paper 1 [Chapter 2] analysed the shifting landscape of actors involved in the network of development assistance for health from the early 1990s through the end of the MDG era in 2015. While this presented important descriptive analyses and new empirical insights using network analysis, asymmetries of power and influence in global health are not straightforward concepts derived solely from economic resources, but rather, as described by Shiffman (2014), emerge from a myriad of sources. Therefore the use of this most explicit source of power to discuss the relational power of global health actors over time is problematic because it excludes those actors who derive power solely from non-financial sources.

To this point, epistemic and normative assertions are two particularly potent sources of power. Their power asymmetries are justified by the perceived legitimacies from the knowledge and motives of some actors when compared to others (Brown, 2015; Shiffman, 2014). Analyses of these dynamics have largely focused on large global health entities, such as the World Health Organization (Brugha, 2010; Buse et al., 2012), Global Fund to Fight AIDs Tuberculosis and Malaria (Clinton & Sridhar, 2017), the GAVI Alliance (McNeill & Sandberg, 2014), and the Institute of Health Metrics and Evaluation (IHME) (Hanefeld & Walt, 2015) -- incidentally, these are also amongst the most powerful actors identified through the analysis of development aid for health in Paper 1 [Chapter 2]. In the example described by Hanefield and Walt (2015), the annual Global Burden of Disease (GBD) estimates are largely perceived as 'neutral' and 'scientific' pieces of evidence, widely distributed and used to as evidence to inform decisionmaking related to the funding and delivery of global health interventions. As the producers of this knowledge, IHME derive a substantial amount of power and legitimacy from their perceived authority on the matter. Their primary funders, the Bill and Melinda Gates Foundation, also gain substantial power by directing the financial support to support their research interests - in this example, to support the production of specific disease metrics that rival those produced by the country-driven processes at the WHO (Mathers, 2020).

Papers 2 and 3 [Chapters 3 and 4] engaged with these concepts of power derived from epistemic and normative assertions in the context of the governance and delivery of health interventions in the case of schistosomiasis control and elimination in Uganda. The Vector Control Division (VCD) has accumulated legitimacy and authority in terms of surveillance and implementation capacity since its reinvigoration in the 1990s. Since this time there have been highly regarded and often cited studies on schistosomiasis-related activities authored by the VCD. and the capacity of the agency has been acknowledged through the considerable financial and delivery-related resources for schistosomiasis control and elimination from actors in the private sector and civil society organisations (Dunne et al., 2006; Fenwick et al., 2021; Molyneux et al., 2021). Yet the normative guidance and evidence used to inform decision-making regarding the delivery of schistosomiasis control activities and design of MDA are still largely produced outside of the areas of implementation. It is in this space, with the "global health interventions", that we need to formally and explicitly engage with individuals who live and work in the areas of implementation. Paper 2 [Chapter 3] in particular provided a framework to shift these dynamics and explicitly incorporate the perspectives of national and subnational practitioners and policymakers into the development of evidence to support the design of schistosomiasis interventions. However, as discussed above, sources of power are both integrated and dynamic and therefore

the degree to which the results are applicable or feasible on a larger scale, or within other contexts within Uganda and in other countries, require further elucidation.

These analyses of power also underscore the difficulties with addressing asymmetries of influence between global-level actors and those operating at the level of implementation and programme-level decision-making, who in some cases what may be referred to as local actors. While there is clear distinction about who holds authority and influence in some contexts, such as the WHO's role as the global authority on normative guidance in the production of schistosomiasis guidelines, e.g. (WHO, 2022), most of the contexts related to national and subnational governance and delivery arrangements are less clear. While actors may have global headquarters or exist as polylateral organisations, regional, country-level, and subnational representatives hold heterogeneous positions of power that do not sum to represent the whole at the organisation level. These complexities of dynamic relationships between actors and resources underscore the limitations faced in papers presented in this thesis.

These challenges also capture the discussion of "local" versus "global" in the context of this work. Papers 2, 3, and 4 [Chapters 3, 4, and 5] emerged from a research programme called the Localised Evidence and Decision-making (LEAD) Project. Initially, in the context of the LEAD Project, the idea of "local" referred to an administrative unit which was assumed to include enough variation to have a significant effect on the implementation aspects of a health intervention (MDA) or an outcome of interest (schistosomiasis), and evidence that was produced should be responsive to the specific needs of the target group of decision-makers at this level. Over the years of this project, and as it came to be reflected in this thesis, the idea of "local" evolved to take on a more nuanced and context-specific meaning. That is, "local" came to refer to context-specific units of analysis or interest, which may be defined as concrete or abstract categories with similar characteristics known or hypothesized to have significant explicit or implicit impacts on the question under discussion. Thus, in the LEAD Project, "local" came to be considered the defined contexts relative to the question at hand, such as district-level practitioners in Uganda, village health teams in Jinja, and MDA policy-makers or researchers.

#### 6.2.2 Methodological innovations and limitations

The aims and research questions of this thesis point to an engagement with the complexity of actors and processes in global health. As such, the choice of research methods required an accommodation of dynamic and non-linear relationships across the financial, governance, and delivery arrangements in the global health system. The methodological approaches used allowed for the observation of collective behaviours or patterns which emerge from the actions and relationships of smaller components in a system. In addition, they were able to manage the multi-level, non-linear, dynamic processes. This included various uses of network theory in data collection and analytical frameworks and individual-based modeling. As a whole, these are very data and computationally intensive activities, and also require substantial training and knowledge to employ. In the first instance, these characteristics impede their widespread adoption and use in decision-making processes related to health policy and practice. The methods and results are in this sense limited in their immediate impact on widespread policy and practice. However, with the continued advances in computational power and accessibility of such technologies, the methodological approaches presented here can be viewed as stepping stones to engaging with complexities across global health in rigorous and accessible ways.

In terms of networks, Paper 1 [Chapter 2] demonstrated the utility of network analysis to observe power in global health. However, aside from the limitations related to the analysis of development assistance as a source of power discussed above, the method itself is limited by data availability and quality. The period described was 1990 through 2015, which encompassed the MDG era. The intention was not to describe power across the global health landscape as it exists today, or in the SDG era, but rather to see what might be learned about the shifts in the system

leading up to, and through, the MDGs. The data used for this particular study came from IHME's financial tracking programme (Dieleman et al., 2016), which relies on algorithms to extract the data from programme reports to supplement a composite database derived from publicly-available development assistance data reporting mechanisms from the OECD, USAID, the World Bank, and others. Each of these facets of the dataset development contain biases and decisions made by researchers that are not captured or reported in a meaningful way. Data-intensive processes required for the sort of network analysis used in Paper 1 [Chapter 2] sacrifice levels of transparency, which may non-systematically exclude important features of the system, due to the nature of data assembly.

This thesis also demonstrated the utility of using networks for data collection purposes: as tools for capturing perspectives of health practitioners and policy-makers in Paper 2 [Chapter 3] (which then formed the basis for analysis in Paper 3) and as a sampling frame derived from bibliographic analysis in Paper 4 [Chapter 5]. In relation to capturing the perspectives of health practitioners and policy-makers, participatory modelling was used to develop systems maps, or networks of factors, related to schistosomiasis transmission. Participatory modelling is very resource intensive, both in time and money. Prior to the implementation of the activities, I spent a substantial amount of time building relationships to foster credibility and buy-in from participants. In terms of outputs, fundamentally, the systems maps are abstractions of reality. These are negotiated representations of individual perspectives which do not 'objectively' nor entirely capture the system which results in schistosomiasis transmission. In this way, actually, the outputs of participatory modelling are akin to the outputs of mathematical modelling: both are inherently biased by the composition of individuals whose inputs drive and shape these processes. In fact, one of the starting points of this research was to explore how I might explicitly use these biases to allow for locally fostered approaches to evidence for decisionmaking.

The systems maps were integrated into individual-based modelling simulations by providing the scope of the simulations and informing the parameters. This study used the open source SCHISTOX model, developed by (Graham et al (2021). This is a type of closed system model, where an environment or setting is explicitly defined and then actions within which actions and interactions of autonomous agents, governed by sets of rules, are simulated over a series of time steps. The aim of this type of modelling activity is to observe and gain insights on the emergence of complex phenomena or collective behaviour, which in this case was the prevalence of schistosomiasis in community members. There are several limitations to individual-based simulations. For one, the simulation depends on the initial conditions that are set. Therefore if the intention is to use them beyond theoretical exploration, it is imperative that the initial settings include as much data about the setting of interest as possible. At a fundamental level, this type of model is flawed in that we can never perfectly quantify or describe our environments because we have an imperfect and incomplete understanding of our environments. We can include as many modules of behaviours and agents as we like, but there will always be under-explored dimensions of the systems under investigation that may significantly impact our results. Of particular importance to the SCHISTOX model, and the estimates of schistosomiasis prevalence, the roles of zoonotic transmission dynamics are not integrated in a meaningful and explicit way. As described in the introduction to this thesis, it is not possible to engage only with human reservoirs when considering control and elimination activities. In the end, the combination of participatory systems mapping and individual-based modelling was a rich strategy for its purpose, which was to explore modes of integrating the perspectives of national and subnational policymakers and practitioners into the development of evidence.

### 6.3 Implications for policy and practice

The policy and practice implications are detailed in the conclusions of each paper and the crosscutting themes are summarised here. To start with, power asymmetries impede our ability to fully realise health and wellness for all. They underscore the most important discussions happening today in global health related to economic and other inequities, climate, decolonisation, racism and diversity – especially in light of the ongoing COVID-19 pandemic. It is therefore important for more widespread scholarship regarding power in global health, especially beyond case studies, to be undertaken and integrated more regularly into discussions of the financial, delivery, and governance arrangements within the system. Further, and more explicitly, it is important to decide to what extent it is appropriate for global health actors to enrich themselves from their involvement in the governance, financial, and delivery arrangements in global health – to ask what then are the implications when these same actors hold high positions of power within global health? Ultimately, this research can feed into improvements in accountability and transparency of global health actors.

Normative guidance and evidence for decision-making is sometimes considered a 'one way street', directed from Northern centres of authority to Southern sites of implementation. This is often where the power asymmetries persist. In one sense, the real value of global-level deliberative bodies and centres of authority lies in the suitability and adaptability of information as it travels to the levels of implementation or service delivery. In terms of guidance, the directed flow of information is exemplified in the relationships between WHO Headquarters in Geneva, regional offices, country-level representatives, and through the levels of Ministries of Health, as well as the private, civil society, and other public actors present at each of these levels. The contentious relationships between the WHO and other global health actors, and the more recent contested status of WHO as the global authority on normative guidance, have been well documented<sup>39</sup>. While the power of WHO derived from its perceived authority on setting norms and standards may have receded in other disease areas, its position remains relatively intact with regard to neglected tropical disease targets and delivery strategies into country-led policy documents.

In terms of the delivery of health interventions in the name of sustainable development, calls for country-led processes, supported by outside partners, need to be taken seriously. If this is meant beyond rhetoric, partner organisations need to engage with policymakers and practitioners in endemic countries, not only as the recipients of evidence for decision-making or facilitators of interventions produced outside the communities, but as individuals capable of driving these processes. The research linking participatory and computational modelling demonstrates one of many possible strategies to integrate a wider range of perspectives in the form of individuals directly involved in the policy, oversight, and implementation of disease control and elimination strategies within endemic countries. While this took place specifically in Uganda and engaged with schistosomiasis transmission, the methods can be used for other diseases in other places. The degree to which the results can be generalised to other contexts, the key point to come out of this research is that inclusivity and the flexibility to allow innovation to be driven by a more diverse set of voices and experiences will facilitate the sustainable reduction in the disease burden. In one sense, we can call this a "localisation" of decision-making. To this end, the focus on MDA as a representative global health intervention and schistosomiasis control interventions more broadly, have provided insights as to the disconnect between evidence and decision-making at levels near implementation.

<sup>&</sup>lt;sup>39</sup> See for example Cueto (2019), Brown et al (2006), Buse (2012), Walt (1994).

### 6.4 Final Thoughts and Future Directions

There are several research streams, both broad and specific, that emerged from this thesis. The decision to engage with complexity through methodological choices provided insights that would have been otherwise obscured had the choice methods been based in reductionist approaches and linear theories of change. I do think it can become exceedingly messy to actively accommodate heterogeneities, dynamic interactions, what may be considered biases, and other forms of complexity into our approaches to answering research questions. However, as discussed at the beginning of this thesis, not engaging with these aspects of the financial, governance, and delivery arrangements in global health will continue to contribute to the stagnation of progress seen toward development goals for health. In addition, these quantitative and mixed methods approaches used in this thesis can serve as confirmatory or supplementary techniques to the insights gained from qualitative methods, which are often used to study governance in global health.

In terms of my own research in complexity methods, I am interested in further developing what I consider to be true mixed-methods approaches, that is linking participatory and mathematical modelling. This space is very undeveloped, but I believe it has the potential to create more relevant processes of evidence development related to intervention design and implementation. For schistosomiasis control in particular, the overlapping complex biological, social, economic, and political systems of transmission require this type of innovative methodological approach to develop evidence to support decision-making at the sites of intervention design and delivery. Aside from the active harm caused by continuing to implement unethical health interventions, which some argue is the case for MDA, I recognise that there are is a continuum of truth about 'what works' and 'why' and 'where' in the context of global health. The methods used in this thesis are steps toward actively engaging with this continuum, and their further development will support the implementation of effective, acceptable, and relevant health interventions.

In terms of the shifting landscape of global control of neglected tropical diseases, and schistosomiasis in particular, it is clear that the path forward is one which needs to be more inclusive and adaptable. These sentiments are echoed in discussions related to the most recent WHO guidelines on schistosomiasis control and elimination (Lo et al., 2022; WHO, 2022). The involvement of global level actors is bound to continue, especially related to the development of normative guidance, though the degree to which they will drive the country-level control programmes will ultimately depend on the abilities of Ministries of Health to (re)gain power derived from financial and epistemic sources. Ultimately though, even this latter source of power is dependent on the abilities of countries to largely fund their own public health and research initiatives. This is the case across the spectrum of disease problems in places where private sector and civil society organisations provide substantial amounts of funding to support the delivery of health services and programmes, including Uganda's NTD programme for schistosomiasis. The challenges in obtaining domestic funding to support widespread schistosomiasis control interventions, including community distribution, have been discussed in a number of contexts<sup>40</sup>. Until this occurs, the country-led development of evidence to support decision-making is perhaps the most important asset to (re)gain widespread domestic control and full ownership of NTD programmes and implementation initiatives.

Regarding further research on power as captured by networks in global health, I am aiming to layer the network structures of additional forms of power related to cultural, symbolic, and social sources to the one of financial arrangements presented here. This would provide a more complete picture of the distribution of power across the global health system. In addition, further analyses linking the impact of power derived from financial sources on funding decisions

<sup>&</sup>lt;sup>40</sup> See for example Tchuenté & N'goran (2009)

and the achievement of health targets are ongoing, as is an examination of the dynamic roles of non-OECD-DAC countries in the DAH network. The extent to which these analyses can interrogate the meaning of 'effectiveness' in cost effectiveness analysis is similarly being explored. Once the data are available, an analysis including the SDG era (years 2016-2030) would permit additional comparisons over time and encompass additional shifts which impact the global health landscape, such as the COVID-19 pandemic. Power asymmetries underscore the most important discussions happening today in global health, and elsewhere, related to economic and other inequities, climate, decolonisation, racism and diversity -- especially in light of the ongoing COVID-19 pandemic as described by Abimbola et al. (2021), AlKhaldi et al. (2021), Hassan et al. (2021), and Kashyap et al (2021). It is therefore important for more widespread scholarship regarding power in global health, especially beyond case studies, to be undertaken and integrated more regularly into discussions of the financial, delivery, and governance arrangements within the system.

The final thought about the papers in this thesis is the degree to which they are about communication. Many of the critiques with which I engage, particularly those regarding the effectiveness of MDA, have been discussed at length in the social sciences. The lack of engagement with the social sciences by health practitioners and policy-makers has also been frequently identified as a key component to improving the development and delivery of health interventions. Nonetheless, a disconnect persists. Engagement with the language and methods of fields outside of our own is challenging and takes work and humility. This thesis uses language and methods common in health sciences to communicate critiques in a way that can be engaged with by health policy-makers, practitioners, and many public health researchers. Finally, this thesis has demonstrated the potential of network analysis and computational methods to advance our understanding of aspects of the global health system. Future research stemming from the papers presented here will use these insights as a starting point and to frame the objectives, methodological choices, and dissemination of the work.

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