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

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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

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 (1). 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 (2). Much scholarship addresses applied methods for: "bridging the gap" between research and policy (3), models of research uptake by decision-makers (4), and, more recently, on knowledge translation or brokerage (5). 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 (1,6), 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 (7). 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 (1). 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 (8–10)).

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 (11) – 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 (12). 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) (13–18). LMIC researchers face barriers to research involvement, dissemination, and influence, often imposed and perpetuated by institutional structures and how research is funded in HICs (11,16,18–20).

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 (21–25), 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 (26) to “rescue the bottom billion (27)”. This assertion, however, lacks broad consensus (28): 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 (28). 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.

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 (21,25).

Sampling frame

An intention behind assignment and order of authorship of peer-reviewed publications is to indicate contribution, responsibility, and credit for published research (30–33). Norms and standards of authorship assignment, however, vary substantially across disciplines (for examples, see (32,34,35)), and remain subject to controversy and debate (30,36,37). 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 (38), and up to half within five years of publication (39).

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 (21). 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.

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 (40,41), health policy documents (42), evidence uses and preferences of health policy-makers and practitioners (43), 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 (44). 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.

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.

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 (45). 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 (29)) 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.)

Results

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 (29)), 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.

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 (46)), the highest numbers of publications within each region came from those with corresponding authors with institutional affiliations in the given region (Figure 1A.) By grouping the countries of corresponding author affiliation and research focus using World Bank income categories (47), 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).

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 (21,25). 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.

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.

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.

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.

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 (48). Recognition of structural

disparities (13–18) 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 (11,12). 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 (11,16,18–20).

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 (1). 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 (49). 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 (27). 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 (50).

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 (51). 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.

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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Table 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

Table 2. Schistosomiasis and STH prevalence estimates and relative ranks amongst the ten most frequent countries of research focus from systematic review

Country	Region	Number of published articles	Relative rank by number of published articles	Schistosomiasis prevalence (per 100,000)	Relative rank by schistosomiasis prevalence	Soil transmitted helminth prevalence (per 100,000)	Relative rank by STH prevalence
Kenya	AFR	64	1	13,667	17	11,110	73
Ethiopia	AFR	52	2	19,830	11	27,945	22
Tanzania	AFR	42	3	21,867	8	32,763	14
Uganda	AFR	36	4	26,512	6	27,160	23
Nigeria	AFR	26	5	16,406	14	26,284	27
Côte d'Ivoire	AFR	24	6	26,054	7	13,840	61
Ghana	AFR	19	7	4,611	37	16,363	51
Philippines	WPR	18	8	1,166	49	33,709	11
India	SEAR	16	9	0	N/A	17,009	48
Peru	AMR	14	10	0	N/A	6,297	105

Note: N/A, prevalence estimates were equal to zero therefore not included in the ranking; prevalence estimates for year 2014 from (45).

Table 3. Characteristics of survey respondents

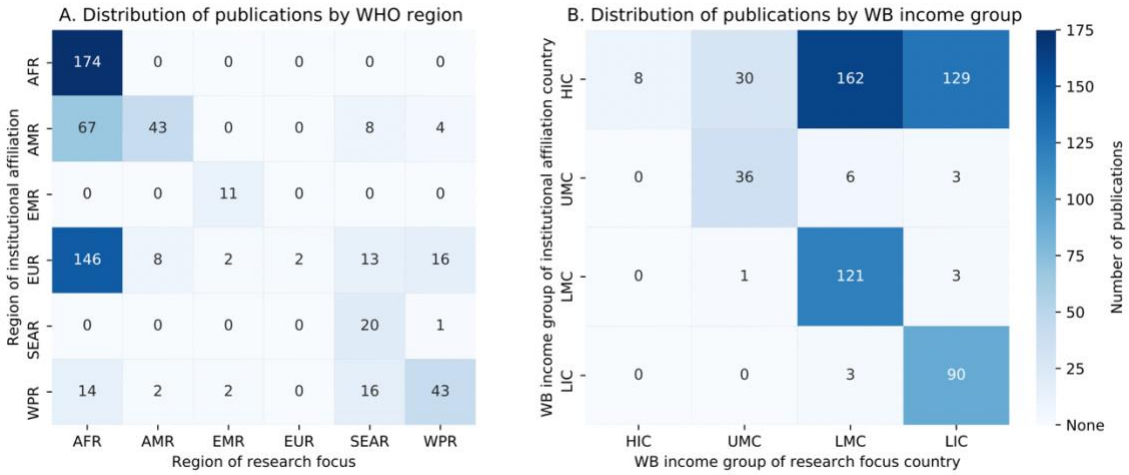
Characteristic	Percent (n)
Years of professional experience (n=125)	
<5	5.6 (7)
5 to 10	33.6 (42)
11 to 20	32.0 (40)
> 20	28.8 (36)
Peer-reviewed journal publication history (n=120)	
> 5 articles on SCH/STH	59.2 (71)
2 to 5 articles on SCH/STH	32.5 (39)
1 article on SCH/STH	8.3 (10)
Current employer (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)

Table 4. 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 regions		AFR		AMR		EMR		EUR		SEAR		WPR	
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
	Never involved	21%	21	0%	0	57%	17		nr	18%	4	0%	0	0%	0
National	Ever involved	61%	61	69%	22	50%	15	100%	2	50%	11	100%	2	75%	9
	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

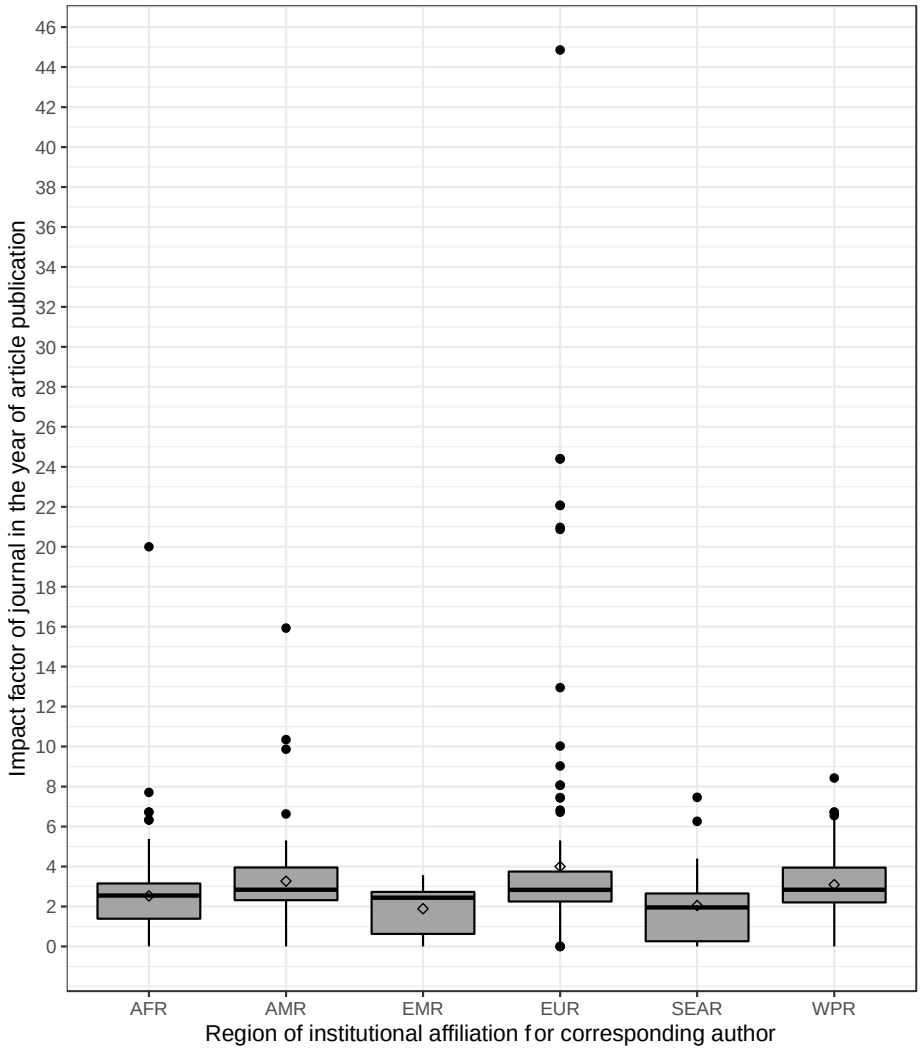
Note: nr, no responses to this question

Figure 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 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.

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

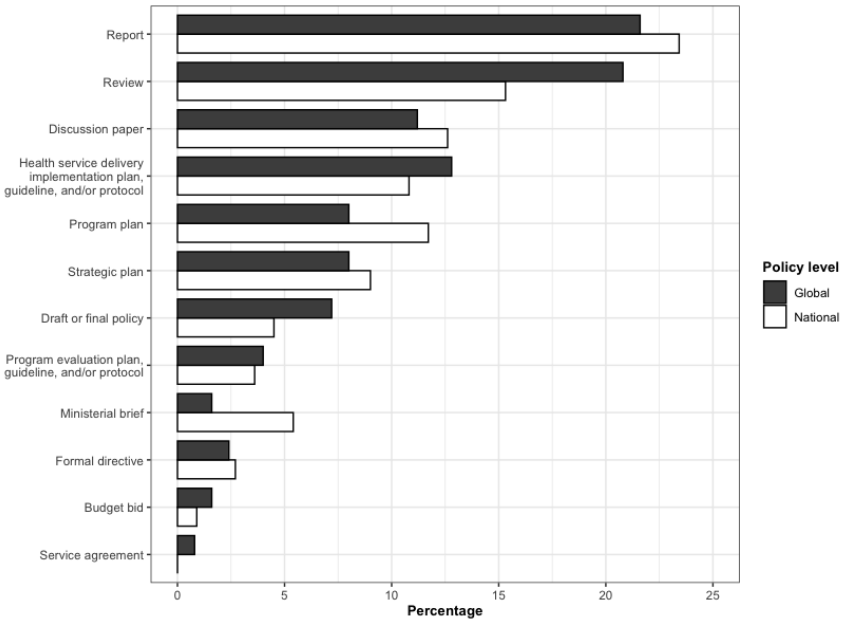
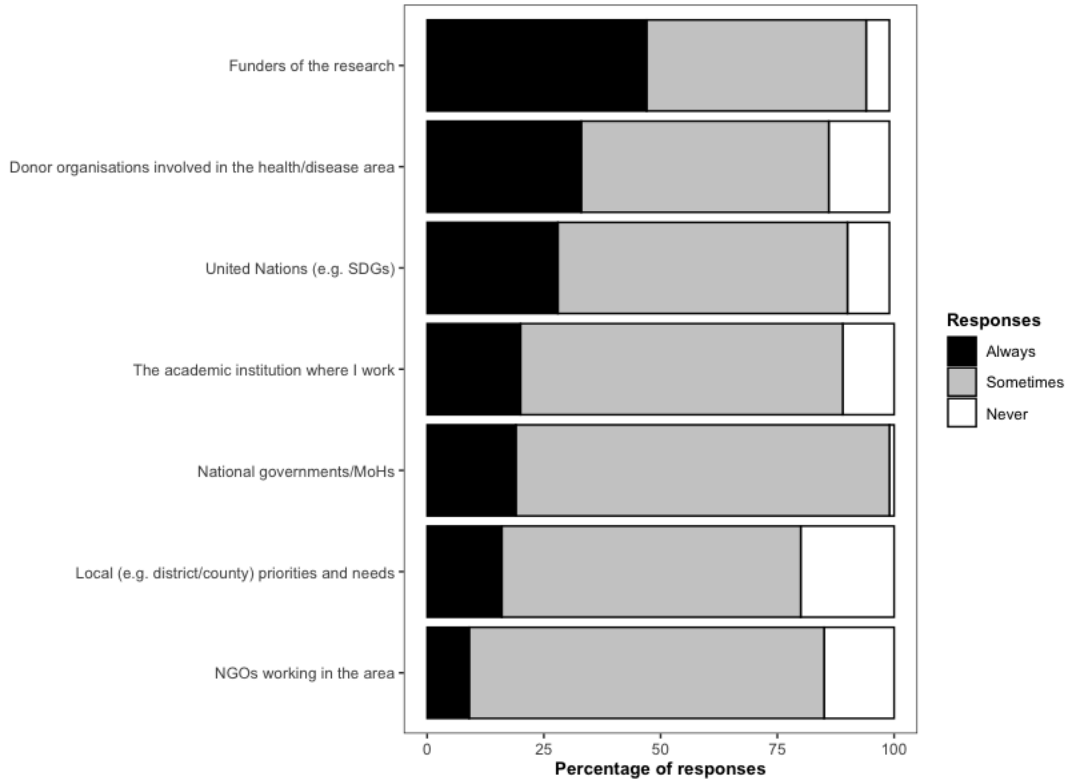


Figure 4. Corresponding author perspectives on whose goals and priorities determine research agendas



Supplementary materials

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Section 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

2. (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

Section 2. Survey questionnaire

1. Please select the best description of your current employment status:

- ☐ Currently employed (1)
- ☐ Currently pursuing a degree (2)
- ☐ Currently retired (3)
- ☐ Other, please provide additional details: (4)

2. How many years professional experience do you have?

- ○ Less than five years (1)
- ○ 5 to 10 years (2)
- ○ 11 to 20 years (3)
- ○ 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)
- ○ 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)
- ○ 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 peer-reviewed journals. (1)
- ○ I have published 2 to 5 articles related to [Schistosomiasis/STH/both] in peer-reviewed 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) _____
- [ ] ⊗ 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)	○	○	○
National level (2)	○	○	○
International/global level (3)	○	○	○

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.

○ Yes, please specify with an example (2)
_____

○ 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)

☐ Implementation plan, guideline or protocol with a focus on health service/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)

☐ ⊗ None of the above (14)

☐ ⊗ 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)

○ Maybe (2)

○ No (3)

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

☐ 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)
- ☐ Implementation plan, guideline or protocol with a focus on health service/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 national policy through other means not listed above (17)
- ☐ ⊗ None of the above (14)
- ☐ ⊗ 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)

○ 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)

☐ For health interventions or services beyond issues related to [Schistosomiasis/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

	0 1 2 3 4 5 6 7 8 9 10
the extent to which the results are meaningful and relevant to settings/contexts beyond where it was conducted ()	
the extent to which the results can be reproduced in the same setting/context at a different point in time ()	
the extent to which the results capture the phenomena being studied ()	
the degree to which the results can be verified with those produced from other methods ()	
confirmation of the results by other published findings ()	
how closely it confirms or coincides with the existing scientific consensus ()	

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

- ○ Yes (2)
- ○ No (3)
- ○ Maybe (4)

Please explain:

_____

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

- ○ 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 not used sufficiently by this group (2)	My research is relevant and used sufficiently by this group (3)
Research community (1)	○	○	○
Practitioners or local authority at the study-site (2)	○	○	○
National level policy-makers (3)	○	○	○
Global level policy-makers (4)	○	○	○
Health practitioners (5)	○	○	○

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

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

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

33. National-level policy

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

34. **Global-level policy**

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

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) _____

○ 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:

_____

Section 3. Flow diagram of systematic review search results