



“You cannot collect data using your own resources and put it on open access”: Perspectives from Africa about public health data-sharing

Evelyn Anane-Sarpong  | Tenzin Wangmo | Claire Leonie Ward  | Osman Sankoh | Marcel Tanner | Bernice Simone Elger

Correspondence

Evelyn Anane-Sarpong, MPH/MSc, Institute for Biomedical Ethics, University of Basel, 4056 Basel, Switzerland.
Email: evelyn.anane-sarpong@unibas.ch

Abstract

Data-sharing is a desired default in the field of public health and a source of much ethical deliberation. Sharing data potentially contributes the largest, most efficient source of scientific data, but is fraught with contextual challenges which make stakeholders, particularly those in under-resourced contexts hesitant or slow to share. Relatively little empirical research has engaged stakeholders in discussing the issue. This study sought to explore relevant experiences, contextual, and subjective explanations around the topic to provide a rich and detailed presentation of what it means to different stakeholders and contexts to share data and how that can guide practice and ethical guidance. A qualitative design involving interviews was undertaken with professionals working in public health institutions endowed with data (HDSS), ethics committees, and advisory agencies which help shape health research in Africa. A descriptive form of thematic analysis was used to summarize results into six key themes: (1) The role of HDSSs in research using public health data and data-sharing; (2) Ownership and funding are critical factors influencing data-sharing; (3) Other factors discourage data-sharing; (4) Promoting and sustaining data-sharing; (5) Ethical guidance structures; and (6) Establishing effective guidance. The themes reveal factors regarding the willingness or not to share and an intricate ethical system that current discourse could reflect. Many of the concerns resonate with the literature, but a whole other gamut of people and process issues; commitments, investments, careers, and the right ethical guidance are needed to realize a sustainable goal of reaching ‘share’ as a default.

KEYWORDS

data-sharing, public health, health and demographic surveillance systems, research involving public health data, research ethics, Africa

1 | INTRODUCTION

Datasets, databanks, and data repositories are rapidly multiplying and expanding opportunities for data-sharing in order to advance global health.¹ Even in the Global South or the South, that is developing countries located primarily in the southern hemisphere,² many data repositories are being established. Two of the most notable public health database programs that feed into repositories in the South are the USAID's Demographic and Health Survey program³ and the International Network for the Demographic Evaluation of Populations and their Health's (INDEPTH) health and demographic surveillance system (HDSS). In 2015 for instance, HDSS data on cause specific mortality in low-to-middle-income countries was the largest to have been ever published.⁴ Africa constitutes 88% of HDSSs globally, with the rest in Asia, Oceania, and Central America.⁵ In this article, we use the HDSS as a profile example of public health systems that produce critical volumes of data for secondary research and for which data-sharing is a critical resource. We also refer to research based on the pre-collected routine public health data held by institutions like the HDSS as research using public-health data (RUPD).

Data-sharing is a non-negotiable source of HDSS activities and RUPD advances. It increases data volumes, velocity, and variety to solve complex research problems.⁶ It helps tackle the problems of irreproducibility in science, opens up methodological alternatives to otherwise costly research involving primary data,⁷ and enables scientists to fulfill their moral obligations to improve global health. However, collecting data, storing data, owning data, collaborating on data, sharing data or not, transferring data, and publishing on data involves a complex mix of concerns. Data is not a simple issue anymore: it is no longer based for instance on physical and specific storage on recognizable drives for controlled sharing. Rapid duplication, storage in multiple places at any one time, and concurrent use for multiple research are easy and cheap. This is perhaps one of the reasons why

public health data-sharing has been slow globally.⁸ As more data repositories develop, data requests increase,⁹ advocacy for data-sharing gets propelled,¹⁰ and the pressure to share data mounts from scientists, regulatory authorities, sponsors, and scientific journals,¹¹ considering what all these mean to both the scientifically productive and less productive sections of the scientific community is critical. Moreover, regions like Africa which have high burdens and risks of diseases may produce rich data, but it may not necessarily advantage them in scientific productivity. Reasons for such failure include resource constraints which in turn motivate the ethical considerations of contemporary data sharing.¹²

1.1 | Public health data-sharing and ethical guidance in Africa

The HDSS model involves the collection, storage, and management of longitudinal population level data to help inform public health activities and facilitate RUPD. The data undergoes annual, biannual, or quarterly updates that ensure their permanent connection to respective populations. Data from ongoing research projects are also added to grow the database. Although the HDSS is ideally planned like all public health institutions to operate under domestic law,¹³ legal and ethical provisions are generally insufficient in many African contexts.¹⁴ The authority and responsibility to share data may be mandated at institutional or national levels and governed legally, ethically or both depending on available governing structures. A code of conduct on public health data-sharing may be initiated locally, built on international provisions¹⁵ or simply assumed. There is yet to be an ethical guideline, endorsed reporting, or evaluative framework specific to public health data-sharing even in comparatively advanced systems like South Africa.¹⁶ Legislative landscapes in the North serve as useful guides, but they are sometimes poorly understood even in the North.¹⁷ Moreover, research contexts in the North differ from those of the South. Reliance on the research ethics committee (REC) and guidelines from international ethical organizations including the Council for

¹Pisani E, Aaby P, Breugelmans JG, D. Carr, et al. Beyond open data: realising the health benefits of sharing data. *BMJ* 2016; 355: 1-5; Wellcome Trust. 2016. *Sharing research data to improve public health: full joint statement by funders of health research*. Available at: <https://wellcome.ac.uk/what-we-do/our-work/sharing-research-data-improve-public-health-full-joint-statement-funders-health> [Accessed 1 Nov 2016]; Pisani E, Whitworth J, Zaba B, Abou-Zahr C. Time for fair trade in research data. *The Lancet* 2010; 375: 703-705; U.S. NIH. *NIH Data Sharing Policy and Implementation Guidance*. Available from: https://grants.nih.gov/grants/policy/data_sharing/data_sharing_guidance.htm [Accessed 13 June 2017].

²United Nations Development Programme, *South-South Cooperation*. UNDP, 2016; Demographic and Health Surveys Program(DHS). 2016. *The Demographic and Health Surveys Program*. Available at: <http://dhsprogram.com/> [Accessed 29 May 2016]; Brack M, Castillo T. *Data Sharing for Public Health: Key Lessons from Other Sectors*. Chatham House. Editor. 2015: London. Available at: https://www.chathamhouse.org/sites/files/chathamhouse/field/field_document/20150417DataSharingPublicHealthLessonsBrackCastillo.pdf [Accessed 15 Nov 2016].

³DHS, op. cit. note 3, p.1; INDEPTH Network. 2016. *About us*. Available at: <http://www.indepth-network.org/about-us>. [Accessed 20 Sep 2016]

⁴Herbst K, Juvekar S, Bhattacharjee T, et al. The INDEPTH Data Repository: An International Resource for Longitudinal Population and Health Data From Health and Demographic Surveillance Systems. *J Empir Res Hum Res Ethics* 2015; 10(3): 324-333.

⁵INDEPTH Network. op. cit. note 4, p.2.

⁶Brack, Castillo, op. cit. note 3, p.1.

⁷Wellcome Trust, op. cit. note 1, p.1; Pisani et al. (B), op. cit. note 1, p. 1; Pisani E, AbouZahr C. Sharing health data: good intentions are not enough. *Bull World Health Organ* 2010; 88(6): 462-466.

⁸van Panhuis WG, et al., A systematic review of barriers to data sharing in public health. *BMC Public Health*, 2014; 14.

⁹Pisani et al., op. cit. note 1, p.1.

¹⁰Ibid; Bull S, Phaik YCPY, Denny S, et al. Best practices for ethical sharing of individual-level health research data from low- and middle-income settings. *Journal of Empirical Research on Human Research Ethics* 2015; 10 (3): 302-313.

¹¹Pisani et al., ibid ; Wellcome Trust, op. cit. note 1, p.1; Taichman DB, Backus J, Baethge C, et al. Sharing Clinical Trial Data: A Proposal from the International Committee of Medical Journal Editors. *PLOS medicine* 2016. <https://doi.org/10.1371/journal.pmed.1001950>.

¹²Brack, Castillo, op. cit. note 3, p.1; Bull et al., op. cit. note 11, p.3.

¹³Bayer R, Fairchild A. Ethical issues to be considered in second generation surveillance. WHO/UNAIDS Surveillance Working Group. Geneva, CH: WHO. Available at: http://www.who.int/hiv/pub/epidemiology/en/sgs_ethical.pdf?ua=1. [Accessed 13 June 2017].

¹⁴Bull et al., op. cit. note 11, p.3 ; Anane-Sarpong E, et al., *Application of Ethical Principles to Research using Public Health Data in The Global South: Perspectives from Africa*. Dev World Bioeth, 2016.

¹⁵Wellcome Trust, op. cit. note 1, p.1; Anane-Sarpong et al., ibid.

¹⁶van Panhuis, op. cit. note 9, p.3.; Denny SG, et al., *Developing Ethical Practices for Public Health Research Data Sharing in South Africa*. *J Empir Res Hum Res Ethics*, 2015. 10(3): p. 290-301.

¹⁷Brack, Castillo, ibid.

International Organizations of Medical Sciences (CIOMS);¹⁸ the US Department of Health and Human Services;¹⁹ Wellcome Trust;²⁰ and the H3Africa Working Group²¹ is common and helpful. They are however unmatched with the novelty, quick technological advances, and implications for data producers and production processes in ways which had not been present before or as complex as they have become.

1.2 | Concerns about data-sharing

Reported obstacles to data-sharing in Africa include the following: loss of control once data is shared; sub-optimal gains to those who create and manage data; undue advantages to more technologically resourced contexts because of technological imbalances and skill-sets in their favor; and technical issues including data quality, interoperability, and risks of misinterpretation due to unfamiliarity with data-originating contexts.²² Many of the technical obstacles are understood to be largely resolved.²³ What remains less reported are issues pertaining to fears, risks, and uncertainties on the part of data-producers in under-resourced contexts like Africa, who may be unable to maximize the benefits of data-sharing to match their burdens of data production. That these contexts are also generally characterized by weak ethical developments²⁴ adds to the challenge. Evidence-based views from Africa are limited, but it is by stepping into their context, experiences, and concerns that ongoing data-sharing discussions can be brought in touch with practical standpoints that could inform data-sharing calls more comprehensively.

We undertook this study to explore relevant experiences, contextual, and subjective meanings, as well as values that public health stakeholders in Africa attach to the scientific, socio-professional, and ethical dynamics of data-sharing. The project is directed towards understanding the forms of skepticism that characterize data-producing scientists' interests and willingness to share public health data. We sought to explore and provide a rich and detailed collection of the informed perspectives of the selected stakeholders. The importance we attach to the views expressed by the participants is based on their practical engagement and direct experiences with data production and sharing. The reported themes in this article are therefore descriptively derived from the data gathered, rather than advanced from the study team.

¹⁸CIOMS, *International Ethical Guidelines for Health-Related Research Involving Humans*. 2016, CIOMS/WHO: Geneva.

¹⁹US Department of Health and Human Services. 2009. *Code of Federal Regulations: Title 45 Part 46. Human Research Protections*. Available at: <http://www.hhs.gov/ohrp/humansubjects/commonrule/> [Accessed 29 Jan 2015].

²⁰Wellcome Trust. 2010. *Policy on data management and sharing*. Available at: <http://www.wellcome.ac.uk/About-us/Policy/Policy-and-position-statements/WTX035043.htm> [Accessed 3 Nov 2016].

²¹H3Africa. 2016. *Data sharing policy*. Available at: <http://h3africa.org/> [Accessed 1 Nov 2016].

²²Pisani et al., *op. cit.* note 1, p.1; Pisani et al., *op. cit.* note 2, p.1; Brack, Castillo, *op. cit.* note 3, p.1; Taichman et al., *op. cit.* note 12, p.3.

²³Brack, Castillo, *op. cit.* note 3, p.1.

²⁴Bull et al., *op. cit.* note 11, p.3.

2 | METHODS

We employed a qualitative design in our exploration of the perspectives of stakeholders experienced or knowledgeable about the HDSS, public health, and RUPD. Our choice of participants was based on their involvement in the relevant administration, conduct, and or scientific and ethical oversight of issues related to data-sharing. We also sought the views of independent experts who play advisory roles to international agencies involved in helping shape health research in Africa. Our elaboration of the study results are based on the subjective, interpretative, and context based accounts of the participants.

2.1 | Collaborators and study area

This international study was undertaken as part of a PhD project in Switzerland in collaboration with INDEPTH-member HDSSs in Ghana and Tanzania.²⁵ INDEPTH is the unifier-organization of HDSSs across Africa, Asia, Oceania, and Central America and has been particularly involved in promoting the sharing of HDSS data.²⁶ Four institutional and two national RECs which oversee HDSS activities were included in the study. Practitioners from the ministries of health, international agencies, and the country offices of the WHO also participated in the study. With seven HDSSs between them, both Ghana in the West and Tanzania in Eastern Africa have seen repository (HDSS) operations for over 20 years.

2.2 | Participants

We purposively sampled 50 respondents via recommendations by HDSS leaders and REC administrators. Further snowballing was done based on referrals. The characteristics collectively shared by our sample in relation to the science, ethics, and regulation of RUPD provided diverse, rich, and relevant answers concerning the willingness, capacity, and enthusiasm to share data. The directors, REC administrators, and several other participants had earlier met and interacted with the interviewer during scoping visits. With three experts unavailable at different appointed times and one participant's withdrawal of his recording because he thought his responses may not have been good enough, our analysis eventually included 46 interviews.

The mean age of participants was 44 years (range: 29-59). Participants had spent six years (range: 1-15) on average at their current roles with all except two having participated in research ethics training. Additional participant characteristics are shown in Table 1.

²⁵INDEPTH Network, *op. cit.* note 4, p.2.

²⁶Wellcome Trust, *op. cit.* note 1, p.1; Sankoh O, Usselmuiden C. Sharing research data to improve public health: a perspective from the global south. *The Lancet* 2011; 378 (9789): 401-402.

TABLE 1 Characteristics of interviewed participants (N=46)

Variable	Category	Ghana (n=21)	Tanzania (n=25)
Sex	Male	13	18
	Female	8	7
HDSS Role (n=26)	Director or ex director	3	2
	Chief scientist	1	3
	Head of unit or field supervisor	3	8
	Site manager	0	2
	Scientist	2	2
REC Role (n=14)	Chairperson	1	0
	Committee member	3	4
	Committee administrator	3	3
Independent (n=6)	Policy agency or Ministry of health	2	0
	Law	1	1
	International research organization	2	0
Primary training	Social Sciences	4	9
	Medicine	8	4
	Health and allied sciences	4	3
	Epidemiology	4	2
	Physical sciences	1	4
Years of experience	Other	0	3
	1-3	1	6
	4-6	3	4
	7-9	2	3
	10-12	6	3
	13-15	4	1
	16-18	0	1
	>18	2	6
	Unspecified	3	1

2.3 | Study procedure

Ethical approval for the project was first sought from the Ethics Commission of North Western and Central Switzerland which oversees research at the University of Basel. In Ghana, the Ghana Health Service, Dodowa Health Research Center, and Navrongo Health Research Center RECs granted review and approval. In Tanzania, approvals were obtained from the National Institute for Medical Research and Ifakara Health Institute RECs as well as the regulatory Commission for Science and Technology. Participant information leaflets and consent documents (Appendix S2) were sent to all prospective interviewees. The documents were returned signed to the researcher during or before interview dates. We undertook all procedures in accordance with the ethical standards of the respective RECs.

A semi-structured interview guide comprising open-ended questions was developed by the research team (Appendix S1). The questions were broadly related to the HDSS-RUPD context, experiences around data-sharing, descriptions of ethical structures, data-sharing initiatives, perceived risks and benefits, and expectations about data-sharing. The guide made space for soliciting additional specific views relating to data-sharing. It was pilot-tested with colleagues at the Institute for Biomedical Ethics (IBMB), University of Basel, three HDSS student-practitioners studying in Basel, and two REC members in Ghana. Authors 1 and 3, PhD students and research assistants at the IBMB organized and undertook the scoping and data collection visits. They however, focused on interviews for different research questions. All interviews for this article were conducted by Author 1 in English, lasted 19 to 69 minutes (mean of 38), and took place at a venue of the interviewee's choice. Twelve participants asked to see and were availed the interview guide prior to the interview dates. Of the 46 interviews, 21 were conducted in Ghana between November 2014 and January 2015 and 25 in Tanzania from January to February 2015. The point of saturation was reached by the 15th interview in both countries,²⁷ but to confirm saturation, delve into grey areas and clarify issues, already scheduled interviews were continued to completion. Except for two pairs of field-supervisors who asked for joint interviews, all interviews were individually conducted face-to-face, on site, and tape recorded with no one else present at the venue. Notes were taken with participants' permission if they had additional contributions before or after the interview.

2.4 | Data Analysis

Author 1 transcribed the recorded data into a WORD document and subsequently checked a sample of the transcripts with the tapes to confirm accuracy. The processes from transcription to coding assignments were as follows: (1) The transcriptions and initial checks allowed Author 1 some degree of immersion into the data; (2) Authors 1 and 2 carefully read ten randomly selected transcripts to identify various concepts, ideas, and explanations given. During this process, relevant texts including concepts, information, and reasons for them were assigned codes that captured their descriptive elements. We grouped the codes into ideas that complemented participants' arguments and reasoning to result in themes and sub-themes. Doing the initial coding together improved the accuracy of characterizing responses and served to control for reviewer biases.²⁸ It resulted in an agreed basic coding framework; and (3) The rest of the coding was independently done by Author 1 using MAXQDA 12.

The initial interpretation of the findings were compiled and sent to two authors who presented their critique of the results, organization, and interpretation of the themes. This iterative process continued until three authors agreed on the themes, sub-themes, and their meanings. The thematic analysis was guided using Guest et al (2012) and Braun & Clarke.²⁹

²⁷Guest G, MacQueen KM, Namey EE. 2012. *Applied thematic analysis*. Los Angeles, CA: SAGE Publications Inc.

²⁸Dawson B, Trapp RG. 2004. *Basic and clinical biostatistics*. New York, NY: 337-338.

²⁹Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Research in Psychology* 2006; 3(2): 77-101.

Because we used a qualitative thematic approach for data analysis, participants' opinions were taken at face value and interpreted as depicting their true views, regardless of whether they were in line with the literature. These opinions guided us in developing themes in line with our research questions and the relevant literature. Six key themes were identified: (1) The role of the HDSS in RUPD and data-sharing; (2) Ownership and funding are critical factors influencing data-sharing; (3) Other factors discourage data-sharing; (4) Promoting and sustaining data-sharing; (5) Ethical guidance structures; and (6) Establishing effective guidance.

In our presentation of the findings we avoid exact frequency counts, but use the following terms when a sizeable number of interviewees dwell on a theme or meaning: "most", when more than twenty-three participants report a meaning; "frequently", "many" or "often" for ten or more participants; and "some" or "other" for less than ten. We corrected non-significant grammatical mistakes in the quotes to aid readability and comprehension. For anonymity, we classified interviewees using participants' sex (M or F), interview number, institution of affiliation, role, and background training. Where descriptors were inadequate to protect anonymity, we dropped background training. For instance, Interviewee Number 15, a female REC administrator with training in Sociology is denoted as F15_REC/Administrator/Sociology or only F15_REC/Administrator if identification is possible. Independent experts are denoted by "IE". Combined descriptors denote dual affiliation. Once a participant is introduced in full, their subsequent quotes are identified by sex and number only.

3 | RESULTS

3.1 | The role of the HDSS in RUPD and data-sharing

For most participants, the HDSS-RUPD and data-sharing relationship revolved around the growing resourcefulness of accumulated HDSS data. The data serves as a sampling frame for RUPD. For instance, M1_HDSS-IE/Medicine-Epidemiology pointed out the following:

The HDSS is community based. There is a certain need for the population to serve as a platform for looking into the future as far as health problems are concerned. The data provides a sampling frame. To that extent, there is a relation between the data and what is needed for research.

Although we tried to explicitly delineate RUPD from core HDSS public health activities, responses frequently echoed a conflation of the two. There were differing opinions on whether RUPD constituted research and whether it and data-sharing required ethical considerations. M8_HDSS/Medicine-Epidemiology for instance argued that "[They are] all for the general good and require no ethical interference". In contrast, most participants acknowledged a need for ethical considerations e.g., "Research is becoming more complex. Data is becoming the currency with which you can do a lot. It is important that we take [ethics] seriously" (F16_REC-HDSS/Scientist).

Many participants mentioned the growth and inevitability of data-sharing and urged adequate preparedness e.g., "Science is evolving; technology is evolving. With my cellphone, I can transfer data anywhere" (M32_REC, IE/Medicine-Public health). Another added,

The world has become like a single village: information can move across very quickly. People have to be prepared or else they will collect lots of information only to find it out there in a span of one or two months. (M33_HDSS/Medicine-Epidemiology)

3.2 | Ownership and funding are critical factors influencing data-sharing

One critical issue influencing the willingness to share data was the question of "who owns data?" There were differing views ranging from institutional assumption of complete ownership to their role as custodians holding data in which other stakeholders have important stakes. Many respondents cited investments in data production as reasons for claims to ownership and hesitation to share:

We (institution) own the data and it costs us so much not only in terms of finance, but also in terms of our time, managing it, and participants who we visit over and over. It's not really value for investment to just give out the data to a third party. F36_HDSS/Epidemiology

Others believed that HDSS data was a public good that should naturally be shared:

There is a public good here. There is some ceding of individual and community liberties towards this good [when communities supply data]. The liberty given to researchers is in the name of the public good. If [HDSS] lacks integrity with the public good, it has no business being in existence.

M1

Some participants saw HDSSs as custodians who could not be the sole arbiters in decisions to share data:

[HDSS] doesn't own data. They can advise that "ok we don't have the right permission from the community..." That is why they (HDSS) also need to have guidelines in terms of releasing data to others. F16

Funding was another critical factor in data-sharing e.g., "once the data is funded by us [HDSS], nobody influences how it should be used. But sponsors and funders have a say" (M14_HDSS/Epidemiology). A clarification was made:

The HDSS is not like the DHS which is funded by government to gather information and make them publicly

available. We have multiple people funding it and you cannot just say yes to anybody who needs the data. **F17**_HDSS, REC/Epidemiology

3.3 | Other factors discourage data-sharing

Support for data-sharing was deemed good at national and institutional levels, but difficult to implement at individual levels e.g., "the willingness [to share] is there at least at the management level, but it's hard to get individuals to actually do it" (**F23**_HDSS/Unit-Leader/Epidemiology).

Reasons underlying low motivations to share data were mostly underpinned by distributive justice concerns (fairness), reciprocity, and inclusiveness. **F17** for instance argued that they "look at what that person can also contribute to the system, because over the years somebody else has built the system". Another stated that "we have issues with sharing data. These days the thing that has come up all over the world is 'open access'. You cannot collect data using your own resources and put it on open access (**M8**)! The need for the principle of reciprocity was emphasized in the following two quotes:

I collected your data, what position are you going to give me in authorship? Are you just going to acknowledge me or make me second author? Do I sell the data? Without me collecting data, there won't be secondary analysis. **F42**_REC/Scientist/Bioethics

You are not a primary source of the information: you earn a PhD or become an expert and those who are the source of the information have nothing? **M4**_IE/Medicine-Law

Others bemoaned concerns with transparency e.g., "Data is used out of the country without the original collectors only to later hear of a new publication. It's not fair (**M43**_REC/Theology)! Another stated that "it's all been taken for granted... If somebody at the country level does not raise eye brows, [data] just goes" (**F17**).

Some participants were discouraged by the inadequacies of local resources and oversight:

The complexity comes from investments in technology. We in Africa and poorly resourced countries do not have the capacity to make sure that we safeguard or monitor anything. This is a very big challenge. No matter how many laws or regulations there are, they cannot do anything. We have the DTA [Data Transfer Agreement], but with these developments DTA cannot help. **M32**

Trust was a major concern. Participants noted risks to the HDSS-community relationship as noted in the following two quotes:

When we go to collect data, they give it to us as an institution; people that they know and have worked with for

decades. They have a relationship with us, but might not have a relationship with [secondary user]. **F16**

People ask for analysis to be done left, right, and center without consideration for ethical standards. Scientists might overlook these things, but we forget that they can have a huge impact on our relationship with communities.

M33

Some participants pointed to gaps in international guidelines e.g., "some journals are even requiring [data-sharing], but the guidelines around it are very loose" (**F12**_REC/Medicine-Public health).

Issues of professional ethics were also raised e.g., "I foresee stealing of other people's data and issues of authorship" (**F42**).

3.4 | Promoting and sustaining data-sharing

Measures to promote and sustain data-sharing were suggested. Within descriptions especially by participants at management levels, it was observed that institutional policies were being developed to encourage data-sharing while guarding data use and transfers. **F23** explained that her institution "allows two years of use by [data producers], another two years of open access to staff and after these four years, openly avail the data to the world". Other managers described different institutional arrangements:

We have elements of data that you can freely download [institutional website], some that require institutional permissions and REC review, and others that you cannot download. The latter have restrictions: obtain REC approval and we will analyze the data for you. **M24**

We study our own data, state purposes of collection per data-set, and consider how the data could be used or not. **M33**

Financial contributions were deemed important for sustenance in data-sharing e.g., "because data is maintained at a cost, there should be a fee for use. You have to contribute to make sure we keep it going" (**M41**).

For some participants, the principles of inclusiveness, collaboration, and capacity building were needed to promote and sustain data-sharing e.g., "We want to see the involvement of local scientists. We have limited capacity. Hence, a PI who wants to share data must help add capacity" (**M41**). Another requested that they should "be notified about data requests to enable them to plan collaborations and agreements" (**F21**/REC/Bioethics). To **M11** (IE/Law) local scientists simply "want to finish their publications first. When they are satisfied with what they can, they shall make data available". Equity and benefit sharing could not be over-emphasized e.g., "a researcher who is tapping into the data of another should give credit where credit is due" (**F13**_IE/Medicine-Public health). "Transactions should be mutual for everybody to be happy. That's the bottom line" (**F42**). Another concluded that "issues of intellectual property, patenting, and ownership" (**M4**) were also critical.

3.5 | Ethical guidance structures

This part of the results relates to the role that ethical structures were expected to play. Although national and international guidelines, institutional policies, and REC oversight were predominantly mentioned, most participants expressed uncertainty about their existence or how their provisions informed data-sharing.

Regarding international guidelines, **F17** stated this: "I'm yet to see any guideline that talks about [data-sharing]". **M24** insisted that "It's clear! As far as I know [guidelines] do not exist. If somebody comes up and pulls one, it will be very useful". In contrast, REC members exhibited awareness about international guidelines on data-sharing. Some preferences were stated e.g., "the WHO guidelines seem ok, but CIOMS is quite appealing" (**F16**). Another observed that "CIOMS gives you flexibility. It's too broad, but it makes it possible to adjust and to think of what suits particular issues" (**F15_REC-HDSS/Administrator-Scientist**). No specific provision on data-sharing was mentioned.

National guidelines and institutional policies were seen as intertwined in their guidance relationship, relevance, and authority over data-sharing. A quote by **M11** succinctly captured several views by other participants:

Regulatory institutions' policies are useful because nations appreciate that they cannot make laws to regulate some situations (like data-sharing). Policies must fall within the law and become part of administrative processes. If [HDSS] has a policy, you must follow it. You cannot substitute it with an international policy: you'll fall into conflict. Precisely because we (Africans) have not found relevant national laws in some countries, let's ask for acceptable terms and allow HDSSs to negotiate them within the country's law.

Reliance on institutional policies was however deemed to have a major flaw: "institutional policies, as regulatory procedures, are binding on individuals who subscribe to it. If an HDSS has a policy, it is their policy in-house" (**M32**). By this assertion, scientists external to an HDSS were not necessarily bound by their institutional data-sharing policies.

The role of RECs in data-sharing was largely recognized as necessary and protective, but developmental e.g., "until recently we [REC] were not reviewing HDSS activities and data issues" (**F16**). A few participants opposed the involvement of RECs in HDSS data-sharing issues e.g., "I don't think National Births and Deaths or Statistical Service undergoes [REC review]. They don't obtain any REC approval" (**M8**). Nonetheless, some participants insisted that anyone wishing to share or use HDSS data secondarily should either "obtain REC review or go back to the community [for permission]" (**M19_ HDSS/Epidemiology**).

3.6 | Establishing effective guidance

Given the perceived inadequacies of guidance structures explained above, participants justified a need for new provisions suited to their

circumstances. **M5** (REC-HDSS/Medicine-Public health) for instance argued for a new framework because he thought that "[data-sharing] is an evolving area. I'm sure the crafters of the original [guidelines] hadn't envisaged that this is the way things will grow". Others had had practical challenges with what exists: "[Named REC] once reviewed a protocol. All members had different opinions. If we have a framework, it will be good" (**M27_REC/Biostatistics**).

Given the foregoing, some participants argued that "we need a new framework" (**M26_REC/Theology**) while others thought that "further expansions to the available guidelines would help" (**M5**). Other ideas were suggested: "Perhaps we should get one document that picks the strengths of the individual guidelines and put them together into one [guideline]" (**F12**). To be effective, this process would "require an engagement with stakeholders to examine local norms, values, and assumptions" (**M4**) for inclusion in the framework.

4 | DISCUSSION

We have analyzed views expressed in an empirical qualitative study involving public health professionals from Ghana and Tanzania involved in the planning and ethical oversight of HDSSs. Other participants were independent experts who play advisory roles for HDSS institutions. Our goal was to explore and understand perceptions, experiences, practices, and attitudes influencing data-sharing decisions. We focused the study on contexts where the translation from data production to scientific productivity may be generally slow. These contexts hold great prospects for producing quality useable data for useful data-sharing because of the high burdens of public health issues,³⁰ the perpetual growth of the data, the routine updates the data undergoes, and the under-utilized data they often hold, even at the stage of the publication of an analysis. Data-sharing is highly justified for such settings. We sought to explore and understand challenges and reasons that constrain their data-sharing potential, in spite of the prospects. The study uncovers distinctive characteristics of under-resourced scientists and institutions relative to their resources including skillsets that may restrict their full realization of data-sharing benefits and hence deter sharing.

To the best of our knowledge, the extent of the risks and implications of data-sharing remains unknown.³¹ They are also beyond the scope of a qualitative study. What this study contributes are therefore simple but practical considerations and recommendations that could increase data-sharing from contexts which may otherwise have reasons not to share. What is unique about the findings lies in the nuanced explanations regarding perceived and real risks behind the current low levels of public health data-sharing.³² Despite Africa and HDSSs' great potential to share quality useable data, their voices have been largely unheard in the ongoing data-sharing discourse. There is

³⁰United Nations. *Transforming our world: the 2030 Agenda for Sustainable Development* 2015 19 Jan 2016; Available at: http://www.un.org/ga/search/view_doc.asp?symbol=A/RES/70/1&Lang=E; [Accessed 13 June 2017].

³¹Brack, Castillo, *op. cit.* note 3, p1.

³²van Panhuis, *op. cit.* note 9, p3; Denny, et al. *op. cit.* note 17, p4.

no empirical data on their perspectives. Some articles from the South share general perspectives on public health data sharing,³³ but they are dominated by issues pertaining to research data or individual level data. The data in this article is not only informative for Africa, but for other contexts in the South which operate HDSSs and have comparable characteristics.

The findings are suggestive of views that both align and conflict with the global interests and expectations in data-sharing. The community-related issues uncovered in the study were deemed largely dealt with in the literature.³⁴ Hence we limited this discussion to issues concerning the scientist and the data-repository.

The view that accelerated data growth makes data-sharing a scientific and ethical imperative³⁵ to increase new knowledge production, promote health, and save lives³⁶ is largely supported by the study. The results however, speak to questions of fairness, reciprocity, equity, transparency, inclusiveness, protection, trust, and capacity building in reaching the data-sharing imperative. The results unearth duties and responsibilities which could exemplify a system of best practices and guidance for data-producing and user scientists. Data-sharing is expected to go hand in hand with minimizing risks and losses and assuring equity in benefit-sharing between the sharer and user. The general concerns of the participants—scientists, managers, administrators, consultants, REC chairpersons, and administrators—are not entirely new.³⁷ The specific intuitions, meanings, and experiences expressed in them are rather clearer for aiding a better understanding of how data-sharing is perceived, feared, and managed. They also help conceptualize practices and expectations that could be motivated by these characteristics.

First, the results indicate that data-sharing is critically thought of in relation to ownership and funding, contrary to global interests and expectations.³⁸ Some of the reasons underlying this persistence are underpinned by Africa's systemic resource constraints³⁹ and an urge to maximize the value of data at the local level. They reinforce the

overarching call for equitable rather than free data-sharing⁴⁰ to at least promote positive burden-benefit ratios in data-sharing decisions. While we agree with the general critique of data-ownership entitlements as detrimental to data-sharing for the public good, we also acknowledge that investments in data production fuel feelings about rights to ownership that cannot be ignored. Persons who believe in ownership rights generally lay claim to their investments in producing the data. Disrupting ownership rights to open up benefits would require sharing in the burden of investments. Thus, where feelings of entitlements are difficult to curb, cost sharing would help by first normalizing situations in which all contributors to the burden of data production become positioned as co-owners. This will continue until such a time that ownership and perceptions of decisional-authority are too widespread to claim at individual or institutional levels. We therefore argue for collaborative partnerships⁴¹ that share investment burdens as better arguments against "data ownership" than simple critique. Ongoing developments like the Research Fairness Initiative (RFI)⁴² could also be drawn on to complement quality data-sharing partnerships, remove "ownership" hurdles, and introduce the needed balance to enhance accountability and responsibility in data-sharing.⁴³

There is some indication that data-sharing is ongoing at local and regional levels as evidenced by the increasing numbers of inter-HDSS publications⁴⁴ as well as specified provisions in institutional policies that are fashioned to enable local scientists maximize data utility before international data-sharing. This is suggestive of challenges to sharing that may be peculiar to international data-sharing.

The most extreme and feared form of international data-sharing is deemed to be 'open access' requirements.⁴⁵ Such data are generally stripped of both identity (participant/communities) and source (scientist/repository/community). While this process reduces risks to participants and communities, it paradoxically reduces opportunities of benefit to the producing scientists and institutions. This is because data is delinked from them as the original sources. The situation evokes concerns about reciprocal justice and is partly responsible for the reported sub-optimal gains in data-sharing.⁴⁶ Many are therefore unwilling to accept open access data-sharing in particular, approach it hesitantly, or insist on conditional sharing.⁴⁷ Likely conditions might include making only basic data available and leaving out data essential for fuller engagement and analysis. The initiatives reported in this

³³van Panhuis, *ibid*; Hate K, et al., *Sweat, Skepticism, and Uncharted Territory: A Qualitative Study of Opinions on Data Sharing Among Public Health Researchers and Research Participants in Mumbai, India*. *Journal of Empirical Research on Human Research Ethics*, 2015. 10 (3): p. 239-250; Bull et al., *op. cit.* note 10

³⁴Brack, Castillo, *op. cit.* note 3, p.1; Bull et al., *op. cit.* note 11, p.3; Jao I, Kombe F, Mwalukore S, et al. Research stakeholders' views on benefits and challenges for public health research data sharing in Kenya: The importance of trust and social relations. *PLoS One* 2015; 10(9).

³⁵CIOMS, *op. cit.* note 19; Aellah G, Chantler T, Geissler PW, *Global Health Research in an Unequal World: Ethics case studies from Africa*, ed. Hemming D. 2016, Croydon: CAB International

Herbst et al., *op. cit.* note 5, p.2; Pisani et al., *op. cit.* note 1, p.1; Bull et al., *op. cit.* note 11, p.3; Pisani et al. (B), *op. cit.* note 1, p.1; Taichman et al., *op. cit.* note 12, p.3; U.S. NIH, *op. cit.* note 1, p.1; INDEPTH Network. 2016. *iShare2*. Available at: <http://www.indepth-network.org/projects/ishare2> [Accessed 20 Nov 2016].

³⁶Pisani et al., *op. cit.* note 1, p.1; Wellcome Trust, *op. cit.* note 1, p.1; Sankoh, Ijsselmuiden, *op. cit.* note 27, p.7.

³⁷Pisani et al., *op. cit.* note 1, p.1; Brack, Castillo, *op. cit.* note 3, p.1.

³⁸Pisani et al., *op. cit.* note 1, p.1; Wellcome Trust, *op. cit.* note 1, p.1; Pisani et al. (B), *op. cit.* note 1, p.1; Pisani & Abouzahr, *op. cit.* note 8, p.2; Asia Pacific Association of Medical Journal Editors. 2015. *Manila declaration on the availability and use of health research information in and for low-and middle-income countries in the Asia Pacific region*. Manila. Available at: http://www.hifa.org/sites/default/files/publications_pdf/Manila_Declaration_2015_FINAL_August_242.pdf [Accessed 10 Nov 2016].

³⁹Aellah et al., *op. cit.* note 34, p.23.

⁴⁰Sankoh, Ijsselmuiden, *op. cit.* note 27, p.7.

⁴¹Emanuel EJ, Wendler D, Killen J, Grady C. What makes clinical research in developing countries ethical? The benchmarks of ethical research. *J Infect Dis* 2004; 189(5): 930-937

⁴²Council on Health Research for Development (COHRED). Research Fairness Initiative. Geneva. Available at: http://rfi.cohred.org/wp-content/uploads/2017/01/RFI_ReportingGuide_20170112_V2.pdf [Accessed 18 March 2017].

⁴³European Commission. 2013. *Guidelines on open access to scientific publications and research data in Horizon 2020*. Available at: http://ec.europa.eu/research/participants/data/ref/h2020/grants_manual/hi/oa_pilot/h2020-hi-oa-pilot-guide_en.pdf [Accessed 22 Aug 2015].

⁴⁴INDEPTH Network. 2015. INDEPTH Scientific Conference. Available at: http://indepthnetwork.org/images/stories/isc_program_final.pdf [Accessed 31 Mar 2016].

⁴⁵Ault A, *Experts call for broad sharing of clinical trial data: From the New England Journal of Medicine* Frontline Medical News, 2013.

⁴⁶Pisani et al. (B), *op. cit.* note 1, p.1; Brack, Castillo, *op. cit.* note 3, p.1.

⁴⁷Herbst et al., *op. cit.* note 5, p.2.

article to grant exclusive periods to data-producers to help maximize utility before sharing are good steps to safeguard producing scientists' interests.⁴⁸ They may slow down international data-sharing, but help increase local scientific productivity in research that is aligned to local needs without crippling global needs.

Dimensions revealed in our data about authorship and capacity development issues highlight a discourse on secondary-user duties: a duty to credit those who make data possible, invest⁴⁹ in sustaining data production, and share tangible rewards like authorship opportunities. Although data is acknowledged as a public good for the public good, the practice and recommendations of merely acknowledging data-producers⁵⁰ in publications is generally deemed inadequate. Since collaboration may also not be desired by secondary-users at all times, good-faith negotiations that contain equitably tangible incentives for both data producing scientists and users should be promoted.⁵¹ This would necessarily require proactive efforts by secondary data users to involve producing scientists in their secondary analysis and production of new knowledge. The onus lies on the secondary user to take the necessary steps to invite and include intellectual input from data producing scientists to enable them access the ultimate benefits of their data production for science. That ultimate is publications and its associated recognition in the scientific community. Maximizing co-authorship opportunities in secondary research for the data producer would require their prior notification and invitation to contribute to manuscripts. Therefore, conducting secondary analysis and scientific writing independent of data-producing scientists must be progressively directed to become exceptions rather than the norm in ethical data-sharing. Persons who have produced data that is good enough for secondary analysis that result in publications have certainly made prior intellectual input in decision-making on what data to collect. Adding more to lead their data to its most effective ends of publications deserve optimal opportunity. We therefore argue that authorship involving data producers should be a matter of order ranking in authorship lists than a question of inclusion to promote inclusiveness in science.

Data commodification via fee-for-use arrangements is considered a possible solution to funding shortfalls in under-resourced contexts. It is however, unsustainable for our increasingly complex data world and the multiple parties involved in public health data production. Questions about who to bear data-production costs for continuity in data-sharing are legitimate, but they still find answers in the many organizations which are willing to fund public health and research for health. The changing dynamics of governmental interests in research funding can also avert some of the funding concerns.⁵²

Regarding guidance structures, our findings highlight inadequate awareness, skepticism, and the absence of one go-to ethical framework for data-sharing as limiting to data-sharing prospects. There is

yet to be a unified international guideline that focusses on the totality of the data-sharing issues raised. There is no reporting or evaluative framework either.⁵³ The virtuous researcher has to find relevant bits and pieces of different guidelines to consider in using secondary data produced by other scientists. This practice is overly onerous for busy scientists and risks encouraging "cherry picking" of ethical considerations: provisions which are favorable and obvious to detect may be implemented while more demanding requirements like seeking and inviting intellectual input from those from whom data emanated may be ignored. In line with the findings about challenges surrounding the authority of local guidelines and institutional policies in international data-sharing, limitations in their application to scientists who are external to an issuing region or institution, and possible inter-institutional conflicts,⁵⁴ we support the study participants' advocacy for developing a new framework. One selected international document, preferably the CIOMS guidelines, given its reported advantages for developing settings⁵⁵ as well as its 'flexibility' could be adapted to accommodate regional policies like the INDEPTH's.⁵⁶ With effective consultation, such a document would be more universal in implementation and adherence. Situating the foregoing indications with the calls for a new data-sharing framework strongly supports the case for a new data-sharing framework. Its development should also benefit from relevant excerpts from other guidelines, note the identified gaps pertaining to the interests of producing-scientists as well stakeholder views about what might additionally count as ethical in data-sharing. Figure 1 below conceptualizes the basic principles that could form part of this framework-development endeavor.

Because national ethical and legal frameworks are generally at developmental stages in Africa,⁵⁷ developing strong institutional policies will remain necessary. Institutional policies have the advantage of context, administrative, professional, and practice suitability when tailored to specific endeavors like data-sharing. Another key advantage they have is their preclusion of countries with weak national ethical systems from being completely orphaned in ethical safeguards.

Regarding RECs, their acceptance seemed challenged and sometimes misunderstood. Their involvement in data-sharing considerations is not always supported. Even for pro-REC participants, the normal conflation of the HDSS, public health, and RUPD, backed by assumptions that public health activities do not require ethical considerations fuel apathy towards ethical review. The inability of RECs to monitor secondary data use because of financial and infrastructural constraints also reduces researcher confidence in their oversight roles. In spite of these challenges, we believe that they remain the best suited ethical authority to help control data-sharing risks and institute requirements that could help data-producers to maximize benefits. It may be

⁴⁸Pisani et al., *op. cit.* note 2, p.1; Brack, Castillo, *op. cit.* note 4, p.1; Pisani, AbouZahr, *op. cit.* note 8, p.2; H3Africa, *op. cit.* note 22, p.5.

⁴⁹Pisani et al., *op. cit.* note 1, p.1.

⁵⁰Wellcome Trust, *op. cit.* note 1, p.1; Pisani et al. (B), *op. cit.* note 1, p.1.

⁵¹Pisani, AbouZahr, *op. cit.* note 8, p.2.

⁵²Brack, Castillo, *op. cit.* note 3, p.1.

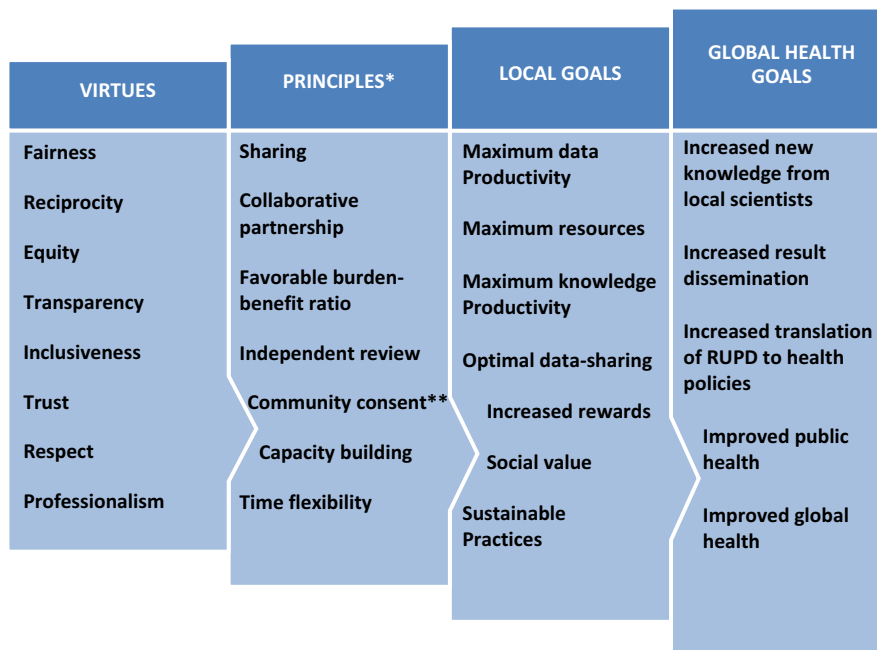
⁵³Brack, Castillo, *op. cit.* note 3, p.1.

⁵⁴Brack, Castillo, *op. cit.* note 3, p.1.

⁵⁵Largent EA. Recently proposed changes to legal and ethical guidelines governing human subjects research. *J Law Biosci* 2016. <https://doi.org/10.1093/jlb/lsw001>.

⁵⁶INDEPTH data sharing and access protocols. Available at: <http://www.indepth-network.org/data-stats/data-sharing-and-access-policies-and-protocols>. [Accessed 1 Jun 2017]

⁵⁷Bull et al., *op. cit.* note 11, p.3.



* The proposed principles align with the Emanuel Framework (E.J. Emanuel, D. Wendler, J. Killen & C. Grady. What makes clinical research in developing countries ethical? The benchmarks of ethical research. *J Infect Dis* 2004; 189(5): 930-937)

**The study findings about community consent are not reported in this paper since, like other findings concerning community issues, they are largely dealt with and supported in the scholarly literature.

FIGURE 1 Relevant virtues and principles for designing an ethical framework for reaching data-sharing goals [Colour figure can be viewed at wileyonlinelibrary.com]

efficient for countries to invest their limited available resources in RECs to help them undertake effective monitoring of data-sharing risks since they are fewer than research institutions and can concurrently serve many institutions and scientists. Modern technological infrastructure like digital data finger-printing⁵⁸ which enable tracing, monitoring, and informing of stakeholders about data-shared could enhance REC oversight. The literature has also theorized expedited reviews and training as helpful solutions to delays and other poor researcher-REC experiences that reduce researcher confidence.⁵⁹ Finally, RECs could collaborate with local data repositories to define and document context appropriate ethical direction in data-sharing for the future.

The foregoing discussion provides an empirical frame of ethical dimensions that could be situated into key ethical principles and virtues for accelerating global data-sharing goals with under resourced contexts.

The overall findings do beg for concerned authorities to consider the following:

- Lead in defining and standardizing data-sharing plans that stipulate adequate periods for local data optimization before wider sharing;⁶⁰
- Create an enabling environment for the growth and sustenance of the needed virtues and principles for promoting data-sharing;

- Institute guidelines and agreement templates that could guide equitable data-sharing negotiations;
- Need-based data-sharing should be considered as an alternative to open access sharing which is deemed most risky,⁶¹ at least in the initial steps towards creating a new culture of sharing;
- Collaborations can leverage technology and capacity building to increase Africa's scientific productivity⁶² and align RUPD to local needs to spur improvements in public and global health. They will also enhance skillsets, resources, and idea-sharing. Data-sharing should be made an avenue for collaboration;
- Secondary-users should be mandated to attest in their publications that their use of data is in accordance with prior agreements.⁶³ This will encourage ethical adherence and inclusiveness;
- RECs need to be resourced to monitor reports and publications involving data shared. Increased confidence in their ability to reduce data-sharing risks will help encourage the practice;
- Incentivization of quality data-production and sharing is long overdue.⁶⁴ Efforts must be made to include quality data production in the global recognition framework. Assessment of scientists' suitability for research career progressions must for instance recognize quality, useable data production as a step to sustain data-production for increased data-sharing.

⁵⁸Paskin N. Digital Object Identifier (DOI) System. In: Pisani E, AbouZahr C. Sharing health data: good intentions are not enough. *Bull World Health Organ* 2010; 88(6): 462-466.

⁵⁹World Health Organization (WHO). 2011. *Standards and operational guidance for ethics review of health-related research with human participants*. Geneva, CH: WHO. Available at: <http://www.who.int/tdr/publications/documents/ethics.pdf?ua=1> [Accessed 20 Jan 2015].

⁶⁰Pisani et al. (B), *op. cit.* note 1, p.1.

⁶¹Ault, *op. cit.* note 46, p26.

⁶²Wellcome Trust, *op. cit.* note 1, p1; Taichman et al., *op. cit.* note 12, p.3.

⁶³Taichman et al., *ibid*; Herbst et al., *op. cit.* note 5, p.2.

⁶⁴Pisani, AbouZahr, *op. cit.* note 8, p2.

Africa remains the bearer of the highest burden of diseases globally and is behind in reaching the SDGs.⁶⁵ Local scientists have moral obligations to increase scientific productivity for the populations' and global health. The region also remains largely challenged by resource constraints. RUPD via data-sharing is an efficient option for resource constrained scientists, but their confidence in fair data-sharing will go a long way to validate their obligations to increase new knowledge for health. Much attention to the new data-sharing culture is focused on data. It should however, shift to consider issues underlying people and processes that make data possible. We risk sacrificing diversity of ideas for speed in data-utility in creating new knowledge (publications) if the under producing sections of the scientific community are not helped to catch up on productivity rather than competing too early for data they produce and share. There are inconveniences in being ethical in every endeavor, but they are not comparable to the ultimate benefits. As this study has shown, there is room for making data-sharing more ethical with a little ingenuity.

4.1 | Limitations

The varied contributions across levels of staff, fields of experience, and institutions allowed us to explore diverse perspectives. Regardless, lead professionals and those who were recommended to be invited for participation could likely have had perspectives different from those who were not. Generally, qualitative studies cannot claim representativeness.⁶⁶ Although the findings are suggestive of hesitations about data-sharing, we should be wary of assuming that Africa may necessarily be vulnerable in data-sharing.

5 | CONCLUSIONS

We have explored and unpacked the perspectives of public health professionals who operate in under-resourced regions and discussed their implications for international data-sharing. We considered their expertise and roles to enable us bring together practical and diverse views underlying general hesitations to share data in spite of the indisputable global gains attached to it. There are institutional, administrative, financial, ethico-legal, scientific, and relational views about why this is so. The following issues are highlighted as the major impediments to international data-sharing prospects:

- risks faced by under-resourced scientists and institutions which are slower in translating data produced into new knowledge;
- the absence of a harmonized guideline and structures to help address the risks and institute fairness in data-sharing rewards;

- inadequate confidence in available protective safeguards including guidelines and RECs.

Scientists and institutions which produce great volumes of rich data (problem-wise) may not be able to direct their data cycles into knowledge production at the speeds ideal for reaching global health goals. The differences in data production and knowledge production strengths across different sections of the global resource divide must motivate collaboration to maximize both data and scientific productivity. It is important to note that although scientists are generally not a population which requires ethical safeguards, this study's findings indicate need for a new dynamic of ethics which could protect the interests of under-resourced scientists in the new data-sharing era. Meanwhile, data-sharing deliberations need to shift from the focus on access to data to considering the whole gamut of people and processes that make data possible. The ongoing data sharing discussions should therefore be placed within a broader context of safeguarding science, data production, and human systems. We finally recommend that because the true extent of data-sharing risks is yet to be measured and beyond the scope of qualitative research, a comparative quantitative study that involves under-resourced settings which are advantaged by the proposals advanced in this article and in the literature versus settings without would help quantify the level of threat to data-sharing. Such a study would help validate our recommendations and attract the needed global responses to them.

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CONFLICT OF INTEREST

No conflict declared.

⁶⁵United Nations, *op. cit.* note 34, p23.

⁶⁶Mays N, Pope C. Rigour and Qualitative Research. *BMJ* 1995 311(6997):109–12.

EVELYN ANANE-SARPONG, MPH/MSc, is a final year PhD student of public health ethics at the Institute for Biomedical Ethics (IBMB), working in collaboration with the Swiss Tropical and Public Health Institute, University of Basel, Switzerland. She holds Master degrees in Bioethics and Health Services Planning and Management. Her interests are in health research ethics.

TENZIN WANGMO, PhD, is a senior researcher at the IBMB and the immediate supervisor of the project. Her other research interests are empirical methods in bioethics, health of older prisoners, elder abuse, and the ethical care of older adults in medical institutions.

CLAIRE LEONIE WARD, LL.M., is a final year PhD student of public health ethics at IBMB, collaborating on the overall public health ethics project and focusing on different but related topics in ethics. She is a Barrister at Law and holds a degree in Pharmacology. Her interests are in public health ethics.

OSMAN SANKOH, PhD, is the Executive Director of the INDEPTH Network, Accra, Ghana. His works in population and health have been published extensively in international journals.

MARCEL TANNER, PhD, is Professor (Chair) of Epidemiology and Medical Parasitology and the immediate past director of the Swiss Tropical & Public Health Institute, University of Basel. His research, teaching, and health planning are based on long term work in Africa and Asia.

BERNICE SIMONE ELGER, PhD, is Professor and Head of the IBMB. She has taught and written widely in bioethics and health law. She is also an Associate Professor at the Center for Legal Medicine, University of Geneva.

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