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Linking Participatory Action Research on Health Systems to Justice in Global Health: A Case Study of the Maternal and Neonatal Implementation for Equitable Health Systems Project in Rural Uganda

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Abstract

An ethical framework called "research for health justice" provides initial guidance on how to link health systems research in low- and middle-income countries to health equity. To further develop the largely conceptual framework, we tested its guidance against the experience of the Maternal and Neonatal Implementation for Equitable Health Systems (Manifest) project, which was performed in rural Uganda by researchers from Makerere University. We conducted 21 in-depth interviews with investigators and research implementers, directly observed study sites, and reviewed study-related documents. Our analysis identifies where alignment exists between the framework's guidance and the Manifest project, providing initial lessons on how that was achieved. It also identifies where nonalignment occurred and gaps in the framework's guidance. Suggestions are then made for revising and expanding "research for health justice."

Keywords

health systems research, research ethics, justice, equity, global health, participatory action research, low- and middle-income countries

Introduction

Health systems research[1] (HSR) is increasingly being funded and performed in low- and middle-income countries (LMICs), with investments coming from bilateral aid agencies, national and regional research funding bodies, and philanthropies (Bennett et al., 2008). Previous work in bioethics has argued that HSR in LMICs should help reduce global health disparities (Pratt & Hyder, 2015), which is consistent with recommendations made by the World Health Organization (WHO) and at global ministerial summits (World Health Organization Task Force on Health Systems Research, 2005; Ministerial Summit on Health Research, 2004). However, simply conducting HSR may not necessarily generate the knowledge needed to improve health systems for disadvantaged populations in LMICs. To explore what form of HSR in LMICs is needed to promote global health justice, an ethical framework called "research for health justice" was expanded to the HSR context. It provides initial guidance on what research questions and populations ought to be selected, what research capacity strengthening ought to be performed, and what poststudy benefits ought to be provided (Pratt & Hyder, 2015). This guidance is summarized in Box 1 and is intended to inform studies from their earliest stages, though it can be used as part of their evaluation as well. It contributes to a broader bioethics research agenda that explores how international research can promote justice in global health and that considers the ethics of HSR (Benatar & Singer, 2010; Hyder, Rattani, Krubiner, Bachani, & Tran, 2014; London, 2005).

Although funders and health systems researchers' obligations of global health justice are starting to be defined, their derivation has so far been a largely conceptual exercise, drawing on theory from political philosophy. The "research for health justice" framework, thus, constitutes a work-in-progress rather than a definitive set of

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Box 1. "Research for Health Justice" Guidance for HSR Projects.

Selecting a research population

"Research for health justice" calls for host countries of HSR to exhibit a substantial gap in health status from the optimal level achieved worldwide (in terms of morbidity and mortality indictors); Group(s) or region(s) selected as focus of projects should also exhibit a large gap in health status relative to other groups or regions within their host countries (Pratt & Hyder, 2015).

Selecting a research question

"Research for health justice" proposes that HSR questions be selected through an inclusive process that is led by LMIC researchers and involves LMIC policymakers and disadvantaged groups. It further calls for research questions (relating to interventions) to develop and evaluate interventions to address health system failings in terms of equal access and equitable financing (Pratt & Hyder, 2015). Previous work on inclusion in health research priority-setting suggests that it may consist of three key dimensions—breadth, equal voice, and non-elite participation (Pratt, Merritt, & Hyder, 2016). Breadth entails ensuring that the research question selection process involves researchers, research users, and research beneficiaries. Participants from all three categories should span a wide spectrum of roles and demographics to maximize the social knowledge used to set research priorities. Equal voice (or qualitative equality) means that the research question selection process should be structured to promote participants having an equal chance to express their views and influence the process. Depth of non-elite participation can be understood as a function of the stage at which disadvantaged groups enter the priority-setting process and the mode of their participation (decision making vs. consultation; Pratt et al., 2016).

Capacity development

At the project level, "research for health justice" calls for LMIC institutions and researchers' independent capacity to perform HSR, including research translation, to be strengthened. This capacity development should be tailored to meet their needs.

Poststudy intervention sustainability

"Research for health justice" recognizes that sustainable implementation of efficacious interventions often requires the *subsequent* conduct of implementation feasibility studies and effectiveness research (Pratt & Hyder, 2015). Where HSR demonstrates interventions' effectiveness in real-world settings, "research for health justice" proposes that a duty to promote sustained implementation of those interventions is owed poststudy. To uphold this duty, health systems researchers may have the following responsibilities:

- conduct formative work to understand the nature of the policy process and who the relevant policymakers, providers, and stakeholders are in the context of their host population;
- engage or partner with national and/or subnational policymakers, providers, and/or other stakeholders throughout the research process; and
- develop and execute other strategies to promote interventions becoming part of participating health facilities and/or governments' policy and practice poststudy (Pratt & Hyder, 2015).

Carrying out these strategies should facilitate the smooth hand over of intervention implementation to local and/or external actors involved in health programming or health systems strengthening. The "research for health justice" framework does not consider the same actor to be obligated to conduct the research and to implement interventions proven successful poststudy (Pratt & Hyder, 2015).

Note. HSR = health systems research; LMIC = low- and middle-income country.

prescriptions. It is open to revisions and negotiations in light of current practice, future conceptual work, and the views of researchers, policymakers, citizens, and others. To further develop "research for health justice" using a reflective equilibrium approach,[2] this article tests the framework against the experience of a HSR project with equity objectives. Case study research was undertaken on the Maternal and Neonatal Implementation for Equitable Health Systems (Manifest) project, which was conducted in rural Uganda by researchers at Makerere University as part of the Future Health Systems (FHS) consortium. Whether and how this participatory action research project on health systems achieved consistency with "research for health justice" is examined, bearing in mind that doing so constitutes a retrospective application of a new ethical framework. (The framework was not developed until the Manifest project had already been running for 3 years.) By comparing the two, the article identifies where alignment exists between them. It describes how the Manifest project was able to achieve the framework's guidance, providing useful lessons for health systems researchers seeking to connect their projects in LMICs to the promotion of health equity. The article also identifies where nonalignment occurred and gaps in the framework's guidance. Suggestions are then made for revising and expanding "research for health justice."

Method

The Case Under Study

The Manifest project was selected as the case under study because it was conducted as part of the FHS (2016) consortium,[3] which performs HSR to improve the equity of service delivery in LMICs. The project was undertaken by researchers from Makerere University in partnership with district health teams[4] (DHTs) in three districts in

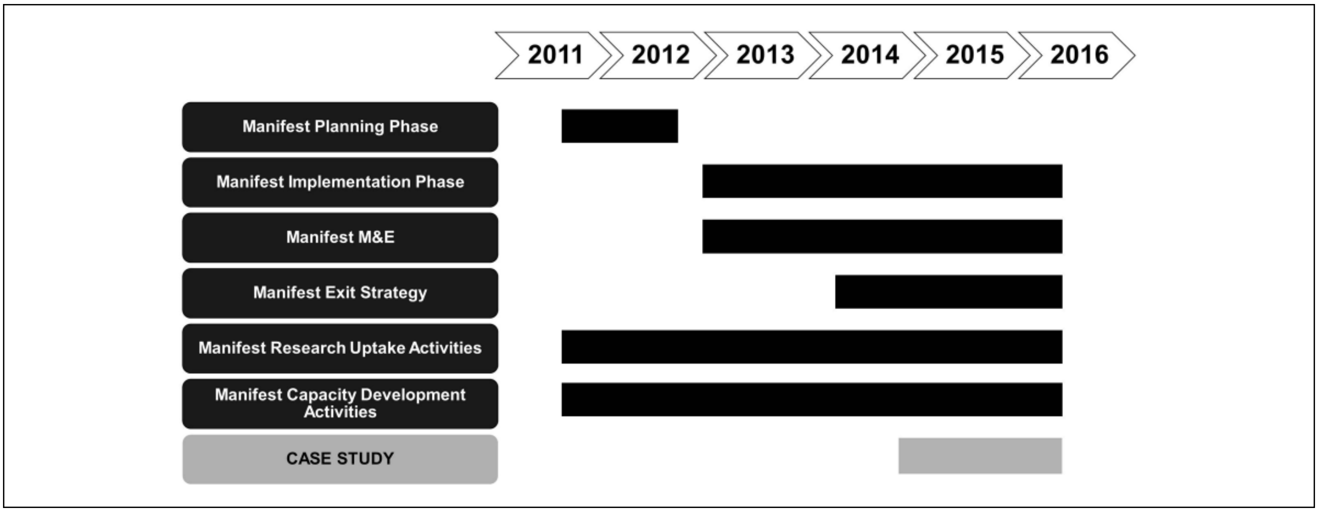

Figure 1. Manifest project and case study timelines.

Uganda—Kibuku, Kamuli, and Pallisa—during *Phase-2* of FHS (2011-2016).[5] It aimed to develop sustainable mechanisms for improving access to, and quality of, maternal and child health services in rural Uganda. The project developed and tested an intervention consisting of two main components: (a) community empowerment for birth preparedness and improved health care seeking behavior and (b) health provider and management capacity building. Community empowerment consisted of three main activities: home visits by community health workers, community dialogue meetings and radio spots, and linking households with savings groups for transport (to delivery) and other aspects of birth preparedness. Village health teams (VHTs) and community development officers (CDOs) in Kibuku, Pallisa, and Kamuli conducted most of the community empowerment activities.[6]

The Manifest project began in September 2011 with a yearlong planning phase, which included selecting the research questions and designing the intervention. The subsequent implementation phase ran from January 2013 to April 2016 (Figure 1). Monitoring and evaluation was performed throughout the implementation phase using multiple methods: key informant interviews, focus groups, health facility assessments, and district and subcounty[7] implementation committee meetings.

Although FHS is funded by the U.K. Department of International Development (DFID), not all projects performed as part of the consortium's research program are primarily supported by DFID. The Manifest project was largely funded by Comic Relief.

Case Study Methods

Data were collected using a triangulation approach that consisted of in-depth interviews, document analysis, and direct observation during the Manifest project's implementation phase. A total of 21 semi-structured in-depth interviews were conducted with Makerere researchers (six interviews); a funder representative (one interview); DHT members from Kamuli, Kibuku, and Pallisa (seven interviews); CDOs from Kibuku and Pallisa (two interviews); and VHT members from Kibuku (five interviews). In all, 10 women and 11 men were interviewed. Recruitment of more interviewees from Kibuku and Pallisa reflected direct observation being undertaken in those districts in accordance with project activities at the time of data collection. Specific CDOs, VHT members, and DHT members were suggested for interview by Makerere researchers. Those who agreed to participate were interviewed. Separate interview guides were used for the various types of stakeholder but each focused on the same four topics: selection and health status of host districts, selection of the research question, capacity development, and poststudy intervention sustainability. Interviews were performed in English, except for two interviews with VHTs where a translator was used. He translated the interviewer's questions into Ateso or Lugwere for interviewees and then reported their responses back in English.

Interview data were supplemented by direct observation over a 2-week period in October 2014. Day-to-day project activities were observed by Bridget Pratt (BP), including meetings of DHTs and CDOs, VHT training meetings, and subcounty implementation meetings. The stance of the observer as participant was adopted (Adler & Adler, 1994) because the authors were not members of the Manifest research team. In effect, BP's activities were known to the group being studied and the emphasis for her was on collecting data rather than participating in the observed activities (Kawulich, 2005). During each observed meeting, shorthand notes were taken regarding who spoke, who led the meeting, who made decisions, the ratio of Makerere researchers and DHT members to local residents, and the content of discussion. These notes were expanded upon after each observed meeting. Project-related documents were collected, including the research proposal, funding application, yearly and quarterly work-plans, capacity development strategy, and research uptake strategy.

Interviews were transcribed verbatim and thematic analysis of interview data, project-related documents, and direct observation notes was undertaken in the following five phases: initial coding framework creation, coding, intercoder reliability and agreement assessment, coding framework modification, and final coding of entire dataset (Campbell, Quincy, Osserman, & Pedersen, 2013; Hruschka et al., 2004). Two coders independently examined six transcripts and identified categories and subcategories. They then developed an initial coding framework together. Next, they began an iterative process of coding a transcript, assessing intercoder reliability and agreement, and modifying the coding framework (Hruschka et al., 2004). Here, a "negotiated agreement approach" was adopted. Campbell et al. (2013) recommend using such an approach where one coder has much greater familiarity with the topic: in our case, the ethical framework and case study. Given the high levels of intercoder *agreement* achieved after coding two transcripts (100% at both the primary and secondary levels,[8] with 68% of coding differences going the way of the coder better versed in the topic), a single coder then deployed the revised coding framework to code the remaining 19 transcripts. According to Campbell et al. (2013), once high intercoder agreement is reached, a single person can perform the remaining coding, provided it is the person whose coding generally carried the day during the negotiation process.

The coding framework's 23 categories and their collated data extracts were examined and then grouped into four main themes: selection of the research question, selection of host districts, capacity development, and creating lasting change (see the appendix). Some categories fell into multiple themes. Three of the four themes corresponded directly to framework domains. Creating lasting change, however, encompassed but was not limited to promoting poststudy intervention sustainability. For each theme, the information in its categories' collated data extracts was examined for consistency with the matching/relevant framework domain's guidance. This process was iterative, as it involved repeatedly going back and forth between the data and the framework to ensure the analysis was credible and trustworthy. Data analysis was performed by both authors.

Ethical approval for the study was obtained from the Johns Hopkins Bloomberg School of Public Health Institutional Review Board and the Makerere University School of Public Health's Higher Degrees Research and Ethics Committee.

The Authors' Positionality

The authors were members of FHS at the time of the case study, performing ethics research relevant to the consortium, and FHS funding partially supported the case study. The potential for the authors' role in FHS to affect their analysis of the Manifest project's alignment with "research for health justice" is acknowledged. Given this, reflexivity in the thematic analysis process included constant questioning of whether consideration of the Manifest project's research priorities, capacity development, and poststudy benefits were affected by the authors being part of FHS. To further promote validity and reliability of data analysis, thematic analysis was undertaken by two coders, one of whom was not part of FHS.

Results

Selecting the Research Question

The Manifest project demonstrated that the selection of research questions may be divided into three phases for HSR projects testing interventions: selection of the research topic, selection of the research objectives and methods, and intervention design.[9] This division was described by interviewees and in project-related documents. Each phase and its alignment with "research for health justice" will be discussed below.

Research topic. The Manifest project focused on improving access to, and quality of, maternal and child health services in rural Uganda. According to project documents and interviewees, it built on research undertaken during FHS Phase-1 (2005-2010), so its focus was largely determined in 2005 by Makerere researchers. A researcher affirmed that

> [t]his work dates back to a few years back when we noted . . . those in urban areas generally having better access to services than those in rural areas . . . So we decided that was an area we wanted to explore. And within that of course there are different types of services, and we decided to focus on maternal health because, as a country, we have a very high maternal mortality rate, and access to effective maternal health services is one of the things that could help to be able to decrease this kind of high mortality.

Interviewees further stated that the selection of maternal and child health as the research topic was informed by a systematic review on access to health services in Uganda and a *consultative* meeting at the start of FHS Phase-1, where attendees included international- and national-level stakeholders.

Yet, Makerere researchers' ability to choose a research topic reflecting problems identified by district- and community-level stakeholders was hampered to some extent by their funder. According to an interviewee, prior negotiation of the broad topic area with the funder meant that the topic fit within the funder's agenda but limited researchers' flexibility to conduct fully community-led research.

Having a research topic selected by *local researchers* demonstrates that the Manifest project was LMIC-led, which is consistent with "research for health justice." Also in accordance with the framework, Makerere researchers identified an equity-related shortcoming of the Ugandan national health system as their research topic. Although national-level stakeholders were involved in selecting the topic, the data do not speak to how inclusive national-level consultations were in terms of breadth, equal voice, and non-elite participation. It suggests that funding constraints restricted *subnational* stakeholders' capacity to be heard in the selection process.

Research objectives and methods. The Manifest project aimed to identify community empowerment strategies that could reallocate or increase local resources for quality maternal and child health services in rural Uganda. This objective was chosen to promote the sustainability of demand and supply-side initiatives proven highly effective in two previous research projects. Makerere researchers stated that *decision making* on the research objective was largely performed by three senior researchers.

Their decision to develop and test a community mobilization intervention strongly reflected input from the project's eventual funder, Comic Relief. An interviewee affirmed, "part of that [decision] was the funder telling us that they want something more sustainable . . . something which requires the communities to be able to be empowered." A national workshop also served as a key *consultative* mechanism and source of input for the Manifest project research objectives. The issue of the previous initiatives' sustainability strongly emerged at that workshop. According to Makerere researchers, workshop participants

> were like "now, this is good. How do we maintain this? How do we support the communities to do this without donor support?" So that's when we came in with the idea of Manifest to really focus on more community involvement and community ownership.

Makerere researchers specified that national workshop participants represented the global, national, and district levels; they included international organizations, external donors, Ugandan Ministry of Health (MOH) officials, national health-related nongovernmental organizations (NGOs), national organizations representing vulnerable groups, and DHTs and administrative leaders from the FHS Phase-1 project's host districts.

This choice of research objective had significant implications for the research model used in the Manifest project. Participatory action research methods were selected and DHTs in specific districts—Kamuli, Kibuku, and Pallisa—were approached to partner with Makerere researchers. (The choice of these districts is discussed later in the article.) To some extent, decision making on Manifest's research topic and objectives was shared with the three DHTs because their agreement was necessary for the project to move forward. Although "Makerere University came up with this project," when asked who decided that it would focus on improving access to maternal and child health services, DHT members from Kamuli and Pallisa districts reported that they "decided as a team" with Makerere researchers. The DHTs came on board as partners because improving maternal and child health was a priority for them. In Pallisa, for example,

> [i]t was the district that made that decision from the analysis of our situation. We realized that was one of our major problems and we wanted whoever a partner who would come in at that time who wanted to focus on that. As much as we had other problems, but that was almost priority number one according to the situation that we had at that time.

They were also in agreement with the chosen research objectives. As noted by a Pallisa DHT member, "we said the best solution, this is to involve the community so that we empower them and they are responsible for their health."

Having research objectives selected by local researchers again demonstrates that the Manifest project was LMIC-led. Consulting and sharing decision making with national and district policymakers and organizations representing disadvantaged groups is also consistent with "research for health justice." The data, however, do not speak to whether strategies were used to promote different stakeholders having an equal opportunity to share their ideas during the national workshop or whether the voices of consulted disadvantaged groups were reflected in the research objectives. Deeper nonelite participation would have been achieved if vulnerable groups (or organizations representing them) had participated as decision makers.

Intervention design. As described by interviewees and in project-related documents, the Manifest intervention design was undertaken through a "bottom-up" two-phase process of *consultation* across three levels (national, district, and subcounty), lasting nearly 1 year, and *shared decision-making* by Makerere researchers and DHTs. According to interviewees and annual workplans, in the first phase, input was gathered on what problems were faced in accessing maternal and child health at a national-level meeting, three district-level meetings, and then 12 subcounty meetings. In the second phase, input was sought through these meetings on possible solutions to the problems identified in the first phase, whether proposed solutions could be implemented at the district and community levels, and how that could be achieved.

DHT members reported that they were responsible for inviting participants to district- and subcounty-level meetings. They and project documents specified that, at the national level, representatives came from the MOH, NGOs, and advocacy groups. International organizations working in Uganda were also present such as the WHO, PLAN, Save the Children, the Red Cross, and UNICEF. At the district level, meeting participants included district political leaders, district technical leaders (including the heads of government departments of health education, health, and community development), hospital leaders, and religious leaders from all three host districts. At the subcounty level, meeting participants included local political leaders, VHT leaders, opinion leaders, religious leaders, transport providers, and men and women from within the subcounty, including adolescents and older women.

Interviewees (DHT and VHT members) and attendees at the observed meetings identified the following groups as having a harder time accessing maternal and child health services: pregnant teenagers, disabled women, poor women, HIV+ women, women in physically abusive relationships, widows, unmarried mothers, and women living in remote or very rural areas. Interviewees noted the participation of poor women, disabled women, and widows (e.g., as represented by the Kadama Widow's Association) at subcounty meetings.

Makerere researchers and DHT members from each host district described employing multiple strategies to promote district and subcounty stakeholders having an equal opportunity for to participate in the intervention design process. These strategies included (a) dividing into small groups at meetings to discuss certain issues, (b) dividing vulnerable populations (e.g., teenage mothers and disabled women) into their own groups to discuss certain issues, (c) having DHT members lead meetings rather than Makerere researchers, (d) running meetings primarily in local languages rather than English, and (e) holding meetings at locations within the subcounty, rather than in hotels or boardrooms, which might have been intimidating.

In the second phase of intervention design, national, district, and subcounty meetings' focus was narrowed by the research team to concentrate on a subset of barriers to access. According to a Makerere researcher, they did so

> [b]ecause at the end of the day, much as you may find many problems, you may find you might not be able to address all of them. So we found a general picture of what the problem was but also zeroed a little bit on some of those areas related to service delivery, related to access to transport, but also related to finances because it needed to be in line with the potential source of funding that we were seeing.

Clear alignment between these barriers to access in Kamuli, Kibuku, and Pallisa and the Manifest intervention components was described by DHT members, CDOs, and VHT members and in project documents. Makerere researchers and DHT members affirmed that the solutions informing the intervention design came directly from communities in Kibuku, Kamuli, and Pallisa:

> So the solutions that we're coming up with were really solutions that they suggested. Because at the end of the day we ask them "okay, suggest different things" and then we're asking them to draw . . . I forget now what the diagrams are called, but to look at the feasibility of doing some of those things and find out the things they can do very easily without any help or minimal help, and the other things where they require some help, and things that are out of their control. So we tended to focus most on things that are really within their control with minimal external help. (Makerere researchers)

> What we are implementing under Manifest is out of the ideas of the community. So Manifest was now addressing the voice which the community had echoed to us. (DHT member)

Multiple interviewees noted that the intervention did not strongly focus on reaching women who were vulnerable or disadvantaged *within* host districts. However, the chosen intervention components were those the research team thought would promote service delivery to everyone, including the vulnerable. For example, Makerere researchers and DHT members (eight in total) reported that the use of VHTs for home visits made it possible to reach all women in the districts irrespective of their status.[10]

As per "research for health justice," LMIC citizens spanning multiple roles and levels (national, district, local) were consulted and strategies were enacted to promote their equal voice in intervention design. The barriers and solutions they identified influenced the intervention design. The consultation of vulnerable groups and enacting strategies to promote their opportunity to participate is consistent with "research for health justice." The data did not speak to whether the barriers and solutions vulnerable groups identified were reflected in the intervention's design (i.e., in its components). Deeper non-elite participation would have been achieved if vulnerable groups had participated as decision makers.

Also in accordance with "research for health justice," the Manifest intervention was designed to improve unequal access to maternal and child health services between urban and rural districts, and thereby addressed *within-country* inequalities. It was not designed with a primary aim of combating *within-district* inequalities in access. Although this was not required by the ethical framework, it may be an important consideration to incorporate into its guidance.

Selecting Kamuli, Kibuku, and Pallisa Districts

The Manifest project research topic and objectives necessitated selecting *rural* host districts. According to Makerere researchers, study design and feasibility considerations such as avoiding duplication and security limited them to working in Uganda's Eastern region.[11] Consideration of sustainability also played a part in the decision. Makerere researchers were concerned that their exit would reverse some of the health gains achieved in the Eastern districts under FHS Phase-1, as they "could actually see the indicators were beginning, again, to go down" after the project ended.

Makerere researchers reported that, within the Eastern region, the three host districts were chosen primarily for trial design–related reasons. As all Eastern districts are rural, Makerere researchers were of the opinion that there was not much variation between them. The Ugandan Demographic Health Survey showed that rural districts generally perform worse than urban districts. All Eastern districts were, therefore, thought to be equally worst-off.

Makerere researchers and DHT members affirmed Kamuli, Kibuku, and Pallisa performed poorly in terms of their population health outcomes and access to maternal and child health services. However, DHT interviewees gave mixed responses to the question: How did Kamuli, Kibuku, and Pallisa compare with other districts in Uganda in terms of access to services and outcomes in maternal and child health before Manifest? Some indicated that the districts were "among the bottom level" compared with other districts, others said their district's performance was equal or better than the national average, and another subset affirmed that districts in the northern region performed much worse relative to the Manifest host districts. MOH Annual Health Sector Performance Reports from 2010/2011 and 2011/2012 place all three districts below the national average in terms of women attending antenatal care visits but just above or above the national average in terms of facility deliveries (MOH Uganda, 2011, 2012).

Given this data, it is somewhat unclear whether Kamuli, Kibuku, and Pallisa were worst-off in terms of health in Uganda. Achieving above national averages suggests that they may not have fallen into the bottom third of districts in the country. Being restricted to working in the Eastern region thus constrained Makerere researchers' ability to choose rural districts that were worst-off nationally, and the selection of Kibuku, Kamuli, and Pallisa may not have aligned with "research for health justice."

Capacity Development

Interviewees and workplans indicated that capacity development activities was performed throughout the Manifest project. The capacity of Makerere researchers and research implementers were built through a combination of training workshops and learning-by-doing.[12] Makerere researchers reported developing the capacity to independently conduct participatory action research and qualitative data analysis during the Manifest project. They are collectively now able to "synthesise ideas from the ground up to make a concrete intervention to implement." Interviewees affirmed having learnt how to identify and approach local partners, collaborate with local partners while building their capacity to implement an intervention, build rapport with communities, and continually monitor and modify an intervention throughout its implementation. A Makerere researcher is also completing his PhD as part of the Manifest project.

DHT members reported receiving training in management and monitoring and evaluation from Makerere University. They also reported developing skills in planning, budgeting, and coordinating people and activities as part of the Manifest project. Makerere researchers have witnessed increased DHT capacity to implement the Manifest intervention. By being made responsible for leading its implementation, they have become well-versed in the cycle of implementing, reviewing, and changing aspects of the intervention to make it better. CDOs expressed having built capacity in financial management as a result of their role in initiating and helping sustain savings groups. They have also gained health education and leadership skills.

Strengthening researchers' and research implementers' capacity is consistent with "research for health justice." The framework, however, also calls for developing institutional HSR capacity, which was not described by interviewees or project documents. Consistent with previous studies (Pratt et al., 2014), this may demonstrate that building such capacity through single projects is difficult to achieve. It may further reflect the fact that Makerere University already had relatively strong research capacity.

Creating Lasting Change

Research uptake entails purposefully promoting the use of research results to foment changes in policy and practice. The Manifest project's research uptake objectives and strategies are discussed below, followed by an in-depth look at its efforts to promote one of those objectives: poststudy intervention sustainability.

Research uptake. As part of FHS, Makerere researchers were required (by DFID) to develop a research uptake plan for their projects. The plan was developed by two Makerere researchers, a Makerere research uptake officer, and a communications officer at the Makerere College of Health Sciences. Guidance throughout this process was provided by the FHS research uptake manager (from the U.K. Institute of Development Studies). The plan's content was informed by the Makerere team's research uptake plan from FHS Phase-1, the Manifest research protocol, and information gathered from stakeholder analysis, the FHS Phase-1 project's national dissemination workshop, and community members during the Manifest planning phase.

Table 1. Manifest Project Research Uptake Objectives, Their Audience Targets, and the Channels Relied Upon to Achieve Them.

Objective	Audience	Channels
To change practices in preparing for birth at the community and household levels	Households (women and men), local council leaders, opinion leaders (elders, religious), mothers-in-law, DHTs	Information provision via community dialogues and home visits by VHTs
To change practices at the health facility level to improve quality of service delivery	DHTs, health workers at health centers in host districts	Training in skills and management for health workers; sharing of best practices between facilities
To contribute to the evidence base used to make maternal and child health policy at the district and national levels	DHTs, ministry of health, media, members of parliament, national NGOs working on maternal and child health	Meetings to share learnings from the Manifest project; media cafes to train journalists on how to report maternal and child health issues
To ensure that host districts and communities own the intervention, and that it continues to be implemented once the research project ends	DHTs, CDOs, VHTs, district and subcounty political leaders, the ministry of health and members of parliament, international donors, district government's community development department, NGOs working on maternal and child health	See Table 3

Note. DHT = district health team; CDO = community development officer; VHT = village health team; NGO = nongovernmental organization.

The resultant research uptake plan consisted of four main objectives that targeted changing either policy or practice at a particular level(s): community and household, health facility, district, and/or national (Table 1). An interviewee noted that the strategy was "to start more from the community and district . . . and then share with the national-level." However, another interviewee argued that focusing on both the district and national levels were key to effecting local change, stating,

> there is a thinking in the team that what we are doing is primarily to benefit the district people, so our focus should be on the district, which makes sense, somehow. But sometimes what happens in the district is influenced at national-level, so we need to strike a balance.

Poststudy intervention sustainability. Intervention sustainability at the district level was one of the Manifest project's research uptake objectives. Seven channels or strategies for promoting its achievement were identified by Makerere researchers and DHTs: DHT leadership, use of existing district structures, capacity development for existing structures, multisectoral engagement, advocacy, building links with other stakeholders working in similar areas, and integration of Manifest activities into district routines (Table 2). Makerere researchers reported the former four strategies were employed from the planning phase onward, and the latter three strategies were employed in the implementation phase.

Interviewees reported that, beginning in Year 2 of the implementation phase, research uptake activities included discussions with host districts and subcounties about how successful aspects of the Manifest intervention could be sustained without dependance on Makerere researchers or external donors. This is consistent with observations at subcounty meetings and the project timeline, which indicated that exit strategy planning would begin in Year 2.

The channels listed in Table 2 were intended to promote sustained implementation of a *modified* version of the Manifest intervention that preserves those components proven successful. The nature of these successful components may vary from the original intervention, depending on what is feasible to maintain at the end of 2016. For example, the use of VHTs as community mobilizers for maternal and child health will continue but may either be on a voluntary basis (unless Uganda's national government starts paying them as part of its health system strategy) or be integrated into other local organizations' health education programs.

The research team's conduct of stakeholder analysis, partnership with DHTs, and use of the seven sustainability strategies is consistent with "research for health justice." As per the duty to promote poststudy intervention sustainability, the strategies were intended to ensure financing and implementation was smoothly handed over to LMIC stakeholders. It is also important to note that the Manifest project is consistent with fulfilling Makerere researchers' obligation to conduct follow-up research after prior research demonstrated intervention effectiveness. Yet the framework's guidance focuses on intervention sustainability rather than the broader area of research uptake. What its guidance calls for is then narrower than what was undertaken in equity-oriented research practice.

Facilitating Factors

Interviewees identified a multitude of factors that facilitated the Manifest project's alignment with "research for health justice." The decentralized governance approach adopted

Table 2. Channels for Promoting Poststudy Intervention Sustainability in the Manifest Project.

Channel	Description	Rationale	Number of interviewees that identified the strategy
District leadership and ownership of the project	The Manifest project entailed having DHTs in host districts take the lead in coordinating most activities at district and community levels during the implementation phase.	District leadership and ownership promotes both the capacity development and normative shift necessary for district stakeholders to continue implementing the Manifest intervention poststudy: "I think when the project was being designed this issue of letting the districts take the lead was very, very, very important. Because we are not in the district most of the time and we will not be there forever. So by making sure that the district teams take the lead in implementing some of the activities, we are helping inculcate into them that belief that this is part of their work and they should continue doing."	3 (Makerere)
Use of existing structures	VHTs carry out the community mobilization component of the Manifest intervention, and CDOs develop and support its savings group component. DHTs oversee and supervise the intervention's implementation.	These structures will remain after the project ends and can continue to implement the intervention: "The district health team supervises the sub-county cadre, where we have health assistants and community development officers, who also supervise the village health teams, check on the saving groups and the transporters. So we [Makerere] don't have any role anywhere among those levels of supervision. So we are sure that if everything works out these people are able to continue with their roles and everything will continue moving on smoothly."	4 (3 Makerere, 1 DHT)
Capacity development for existing structures	The Manifest intervention was designed to include a capacity development component for health workers, DHTs, VHTs, and CDOs. Capacity development strategies included training and learning-by-doing.	Capacity development will help existing structures to perform better, which will facilitate their implementation of the intervention on their own poststudy: "Although we use the health workers to supervise the VHTs, I think even in the plan for the study we knew it's not sustainable. So we are doing it first to build the competencies of the VHTs and then later we have that cadre called the super VHTs, they are fellow VHTs at parish level, then we need to empower those ones to continuously support their colleagues rather than having health workers to go and supervise the VHTs."	3 (Makerere)
Multisectoral engagement	Stakeholders outside the health sector were engaged in implementing the Manifest intervention.	Engagement of these stakeholders promotes their continued role and support poststudy: "Those different stakeholders have appreciated the work, especially what the health workers are doing, the VHTs, and they are ready to support these people, use any means that they can. Like, for example, some sub-counties have agreed to put some money aside to continue facilitating the VHTs with some transport."	2 (Makerere)
Integration of Manifest activities into district routines and activities	Rather than having separate district meetings on maternal and child health, the topic is being added into quarterly review meetings for the district. Rather than having community dialogues for maternal and child health alone, the topic is being added into other social functions in the different villages to generate dialogue.	Adding maternal and child health activities into things that already happen routinely means that additional resources are not needed to perform them, which increases the likelihood that they will continue once the research project ends.	5 (3 Makerere, 2 DHT)
Advocacy	Makerere researchers and DHTs advocate for resources to support the intervention poststudy. Targets include host districts' political leaders, the ministry of health and members of parliament, and international donors.	Advocacy is meant to ensure needed resources are available for intervention implementation once the research project ends.	4 (3 DHT, 1 Makerere)

(continued)

Table 2. (continued)

Channel	Description	Rationale	Number of interviewees that identified the strategy
Building links and partnerships with other stakeholders	Relationships and partnerships are established with other stakeholders that have shared goals, are doing similar work, and have a longer life span than the Manifest project.	Where these organizations conduct similar activities to the Manifest project such as community mobilization by VHTs, they can incorporate a maternal and child health component into their activities, thereby enabling Manifest intervention components' implementation to continue poststudy.	3 (1 DHT, 2 Makerere)

Note. DHT = district health team; VHT = village health team; CDO = community development officer; NGO = nongovernmental organization.

by FHS meant that Makerere researchers took the lead in choosing their research topic and objectives. The funder's grantmaking principles promoted partnering with DHTs and consulting Ugandan citizens. To support Makerere researchers doing so, the funder awarded them a planning grant to develop those partnerships and undertake consultations at national, district, and subcounty levels. As previously stated, even with these grantmaking principles, subnational-level stakeholders' input into the research topic was limited due to prior negotiation of the topic with the funder.

Makerere researchers' consideration of equity and sustainability from the start of the Manifest project meant they were reflected in its research objectives and intervention design. For example, equity considerations led to the selection of research objectives focused on reducing inequalities in access to health services between urban and rural populations within Uganda. Sustainability considerations led the research team to test a community mobilization intervention using participatory action methods.

Starting discussions around how to sustain the Manifest intervention with 2 years running on the project was identified as critical by a DHT member. Effective sustainability strategies—specifically, developing capacity for DHTs, savings groups, and health workers; promoting DHT leadership and ownership of the project; using existing structures; and having a multisectoral engagement approach (Table 2)—were also identified as facilitators of intervention implementation poststudy. Local ownership was built over the course of the project, with DHT members reporting Manifest was "district-led" and "actually empowered us, it is our own project . . . we own it." This sense of ownership and empowerment suggests DHTs will endeavor to sustain the intervention after the research ends, stating "we feel it is a venture we do not want to say 'just leave it.' We have put in a lot of our time, our thinking, and it is not something someone else brought." DHT members strongly confirmed that the multisectoral approach of involving district political and administrative leaders from the start of the Manifest project made those leaders appreciate what the project has achieved and more aware of the problems it addressed. This, in turn, has meant the leaders were more receptive and willing to do things to support continued intervention implementation *and* resulted in their increasing resource allocation to the health sector in host districts.

Discussion

The "research for health justice" framework constitutes a work-in-progress rather than a definitive set of prescriptions. The case study's findings suggest two areas where "research for health justice" might be usefully revised. The main area where the Manifest project was constrained in its ability to fully align with the framework's guidance was in selecting a worst-off research population. Additional considerations affected the choice of the research population—study design and feasibility. The framework's requirement of working with worst-off populations within host countries may require a qualification: freedom from completing obligations that preclude upholding it. Relevant competing obligations might include avoiding compromising study design and/or researchers' safety. Where such competing obligations exist, researchers should, nonetheless, work with worst-off populations in the regions of a country in which they are able to perform research.

The Manifest project further indicates that "research for health justice" should consider poststudy commitments in HSR more expansively than promoting intervention sustainability. The framework should call for creating lasting change, which encompasses an obligation to promote research uptake. To uphold the obligation, researchers would be expected to set research translation objectives, identify channels/strategies for achieving the objectives, and execute them during research projects. These objectives and strategies should reflect that local change can be encouraged through activities targeting the subnational and national levels. Where HSR tests interventions, projects should have research uptake objectives and strategies for promoting sustainable intervention implementation poststudy. In addition, the case study highlights that research uptake responsibilities are jointly shared by researchers, research uptake managers, and nonresearch LMIC partners (e.g., DHTs). These parties' roles should be explicitly defined in HSR projects. Beyond research uptake, creating lasting change could also be understood to entail an obligation to promote empowerment, particularly where HSR uses participatory action research methods. What that obligation might entail requires further exploration.

There were a number of limitations inherent to this case study research. First, the main tool for data collection focused on the four domains of "research for health justice," which meant that the case study did not test whether those domains are the (only) ones considered essential for linking HSR to global health justice. Although no interviewees disputed any of the domains in interview, discussions with Makerere researchers at the 2016 FHS annual meeting identified data sharing and ownership as a potential additional domain that might be added to the framework. Second, interviewees consisted of researchers and research implementers (DHTs, CDOs, and VHTs) in the three host districts. The perspectives of those consulted during intervention design or living in the host districts did not inform the case study. Third, due to the timing of this study, direct observation was undertaken during the Manifest project's implementation phase and was not performed during the selection of its research objectives or intervention design. As a result, data on who was included, equal voice, and nonelite participation comes solely from interviews and project documents. Data on equal voice were especially limited. Fourth, many of the observed implementation activities were conducted in English *and* local languages. As BP is not fluent in those languages, she could not fully observe the activities' content. Where possible, a Makerere researcher translated comments made in local languages for BP. Fifth, the case study focused on a single project rather than the full body of research undertaken by Makerere researchers as part of the FHS consortium, which has run for 10 years. Although the relationship between previous studies from FHS Phase-1 and the Manifest project was captured, the full picture of research capacity development under FHS may not have been. Finally, the case study did not look at empowerment as a way in which the Manifest project created lasting change. Participatory action research is concerned with knowledge creation in ways that empower those engaged rather than maintaining the status quo (Hall, 1992). How this played out and was actualized by the Manifest project was not a focus of data collection, but future work looking at the links between participatory action research on health systems and global health justice should do so.

Ultimately, this case study has provided some initial lessons on how HSR projects can be designed to promote health equity and has informed the development of the "research for health justice" framework. We hope that this study and the questions it raises will stimulate more exploration of what ethical requirements are needed to link HSR in LMICs to justice in global health and how they can be translated into practice.

Best Practices

This section describes what might be termed "best practices" for achieving consistency with "research for health justice." Although the framework remains open to revision and further development, HSR often seeks to contribute to reducing health disparities between and within countries. Thus, how alignment with "research for health justice" was attained can still usefully inform health systems researchers' current practice.

The Manifest case study provides multiple initial lessons for other research teams. Alignment with the framework is facilitated where researchers

- consider equity when selecting their research topic and populations, for example, whether they experience poor health status, poor access to health services, or systematic disadvantage in their country;
- consider sustainability when selecting research objectives and designing interventions;
- partner with local stakeholders to conduct studies;
- conduct consultations across national, district, and local levels, including with relevant vulnerable groups, when selecting research objectives and designing interventions; and
- employ strategies to promote intervention sustainability from early in the research project to its end.

Funders' and consortium's policies also promote alignment with "research for health justice," where they require and support decentralized governance, engagement with local stakeholders from research priority-setting onward, and the development and implementation of research uptake plans.

Research Agenda

Multiple directions for expanding the "research for health justice" framework emerged from this case study. The Manifest project shows that considerations of equity and sustainability can be applied at multiple stages of the HSR process, which suggests that "research for health justice" should include guidance on intervention design and on monitoring and evaluation. For example, the case study raised questions regarding whether and to what extent consideration of inequalities *within* the research population should factor into intervention design. Is it sufficient for projects' interventions to reduce inequalities within host countries? Or should projects' interventions also be required to consider whether they are reducing inequalities within the research population? Requiring the latter would mean that an additional question to explore is how should inequalities within the research population affect intervention design in terms of its components and reach? For example, it might entail ensuring that intervention components address the barriers to health system access experienced by vulnerable groups and that the intervention is designed to reach those groups. There may also be important trade-offs to consider between breadth of intervention components and depth of access to them. The Manifest experience suggests having a large number of intervention components may make it harder to focus on ensuring the worst-off have access to all of them.

Furthermore, exploration of what policymakers and disadvantaged groups' "involvement" in priority-setting should entail is needed to ensure shallow and tokenistic participation is avoided. This would encompass a clearer description of the aims of citizen engagement under the framework, who should be engaged, at what levels, and when. The Manifest case raises questions about the nature of shared decision making between researchers and nonresearch LMIC partners: Is agreement on the research topic and objectives sufficient? Or should both parties have also developed them together? The framework currently does not answer these questions but having equal voice would favor the latter. In the Manifest project, Makerere researchers partnered with district policymakers and consulted with disadvantaged groups. Both were involved in priority-setting, as per "research for health justice," but policymakers shared decision making power with researchers and vulnerable groups did not. The framework is silent as to whether this distinction is ethically significant or not. In addition, national organizations representing vulnerable groups were consulted as part of setting Manifest research objectives, whereas vulnerable women at the subcounty level were consulted during intervention design. This highlights that vulnerable groups can be consulted at different levels and as either representatives of groups or as individuals (who may not consider themselves representatives). It raises questions such as who should be consulted (representatives, individuals, and/or both), at what level(s), and when? Is it acceptable not to consult vulnerable groups at the subnational level until intervention design? Finally, the case shows that articulating funders' ethical responsibilities will also be critical to reduce the likelihood that they limit researchers' flexibility to conduct fully community-led research.

Educational Implications

Research ethics training for health systems researchers should include topics relevant to linking HSR projects to global health equity: selecting worst-off research populations, selecting research questions that address health inequities, undertaking inclusive and deliberative LMIC-led priority-setting, undertaking research capacity development, and promoting research uptake that benefits the worst-off in host countries. As part of this training, health systems researchers should gain practice designing studies with the aforementioned features. The Manifest project described in this article can inform researchers as to how one might design an equity-oriented HSR project in practice.

Research ethics committees' consideration of HSR projects' social value (i.e., likelihood of reducing global health disparities) can also be informed by the analysis undertaken in this article. The analysis can be used as a model of what to assess proposed projects for and how to do so. For example, research ethics committees can consider the selection of project's research questions over three phases (research topic selection, research objectives' selection, and intervention design) and across multiple criteria (range, mass, equal voice, and non-elite participation). They can consider whether projects have research capacity development and research translation objectives and strategies.

Appendix

Categories (Derived From Interview Data) Grouped by Theme.

Selection of the research topic and question
Aim of Manifest project/intervention
Research topic and question selection process
District health needs/priorities
Health inequalities in Uganda
Alignment with Future Health Systems crosscutting themes
Intervention design and implementation process
Manifest intervention
Equity-oriented intervention
Role of local stakeholders in Manifest
Role of Makerere researchers in Manifest
Role of funder in Manifest
Disadvantage within Manifest host districts
Local health system structure
Selection of the host districts

Rationale for selection of research population
District structure
Health inequalities in Uganda
Role of local stakeholders in Manifest
Role of Makerere researchers in Manifest
Role of funder in Manifest
Disadvantage within Manifest host districts

Capacity development
Capacity development
Role of local stakeholders in Manifest
Role of Makerere researchers in Manifest
Role of funder in Manifest

Creating lasting change
Research uptake
Sustainability and scale-up
Agenda setting role of Manifest project
External support
Duplication
Role of local stakeholders in Manifest
Role of Makerere researchers in Manifest
Role of funder in Manifest
Role of village health teams outside Manifest

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Notes

1. Health systems research (HSR) seeks to understand and improve health systems in their real-world contexts and, consequently, is commonly embedded in health care practice. Such research is characterized by the questions it asks, which typically focus on assessing health system performance, exploring the causes of poor performance, or developing and evaluating interventions to address particular health system shortcomings (Gilson, 2012). Its methods and interventions are frequently iterative and dynamic, changing over the course of studies (Gilson, 2012). It relies on a wide range of quantitative and qualitative methods such as cluster randomized controlled trials, observational studies, participatory action research, and economic evaluations. Interventions can consist of novel health delivery mechanisms for existing services, methods of creating demand for existing services, or human resource management strategies for clinics and hospitals (Hyder, Rattani, Krubiner, Bachani, & Tran, 2014).
2. Reflective equilibrium involves working back and forth between theoretical considerations and the considered judgments and experiences of third persons who are well-positioned to make decisions about the topic under study, refining each until equilibrium is reached (Beauchamp & Childress, 2008; De Vries & van Leeuwen, 2010). The approach constitutes a strong methodological option for developing ethical guidance informed by both theory and practice. In this study, the theoretical considerations were the requirements of "research for health justice." The relevant third persons were parties who conducted an equity-oriented HSR project (i.e., the Manifest project).
3. Future Health Systems (FHS) consists of six partners: Johns Hopkins Bloomberg School of Public Health (United States); the Institute of Development Studies (United Kingdom); Makerere University School of Public Health (Uganda); the International Centre for Diarrhoeal Disease Research, Bangladesh; the Indian Institute of Health Management and Research; and the China National Health Development Research Center.
4. District health teams (DHTs) are district-level department of health staff; they are responsible for coordinating the delivery of health services to their district's population.
5. The FHS Phase-1 lasted from 2005 to 2010. The consortium is now operating in its second phase, which is slated to run from 2011 to the end of 2016.
6. Village health teams (VHTs) are groups of community volunteers who are responsible for community mobilization and linking individuals in their villages with the formal health facilities. Community development officers (CDOs) are district-level department of community development staff.
7. The subcounty constitutes the subdistrict level in Uganda. Districts in Uganda (such as Pallisa, Kibuku, and Kamuli) are comprised of numerous subcounties, with the number of subcounties varying by district.
8. Intercoder agreement at the primary level was assessed by dividing the number of categories agreed upon after negotiation by the total number of categories identified. Intercoder agreement at the secondary level was assessed by dividing the number of categories and subcategories agreed upon after negotiation by the total number of categories and subcategories identified. For example, where there were 116 categories and subcategories agreed upon and two that were not, intercoder agreement was 98% (116/118).
9. Although the Manifest project's research objectives and intervention design were largely set prior to intervention implementation, they were continually revised and fine-tuned during the implementation phase. This is common for participatory action research.
10. DHT members stated that VHTs were responsible for recording who was pregnant in their villages and this included keeping track of and "paying more attention" to certain categories of women such as "those who are vulnerable" or "risky mothers," most of whom are disadvantaged. VHT members confirmed that they reached widows, poor women, and/or disabled women, going door to door as part of their work for Manifest. Despite this feature of the intervention's design, there were limits to reaching everyone in the host districts during the implementation phase. For example, a DHT member stated, "during the designing of Manifest we did not take in account those hard to reach areas [three villages located on islands in Pallisa district] . . . Because they become one of the minority groups, which are being left out." This shortcoming was recognized by the wider research team. At the subcounty meetings observed in October 2014, a question put for discussion was who are the vulnerable groups, how can we identify their members, and how can we better reach them with the Manifest intervention? Suggestions were proposed for the first two questions but discussion was short due to time constraints. A pertinent point raised that also went unanswered was that, in the FHS Phase-1 project, they had decided against identifying members of vulnerable groups due to the risk of stigmatization. Subsequent subcounty meetings may have revisited these questions but, as they were not observed, the data collected for this case study cannot confirm it.

11. Over the last two decades, the Karamoja region in Uganda's Northern region been markedly affected by insecurity and violence (Ministry of Health, Uganda, 2005). As a result, Makerere researchers stated that, in consultation with ministry of health officials, they chose to focus on performing research in more secure regions of the country. As the United States Agency for International Development (USAID) was already carrying out maternal and child health projects in the Western region of Uganda, the Eastern region was selected to avoid duplication and contamination of the study area.
12. As health provider capacity building was a core component of the Manifest intervention, the project also strengthened the abilities of health workers in Kibuku, Kamuli, and Pallisa in health facility management, monitoring and evaluation, and obstetric care.

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