Title: Community participation in global surgery research

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Introduction

The academic field of global surgery aims to develop and advance research agendas to improve access to quality, timely, and affordable surgical care for all.[1] Access to surgical care is, however, highly inequitable particularly for marginalised groups.[2] Veerappan & Jindal have previously highlighted the importance of community participation in global surgery.[3] In this commentary, we define community in research as local stakeholders directly affected by clinical and public health research initiatives, including as potential research participants.[4] We aim to further describe community participation in global surgery research as a pro-equity approach, particularly in low- and middle-income countries (LMICs), and outline practical considerations of the challenges and benefits of community participation throughout the research process.

Surgical care is an integral component of a functional and responsive health system.[1] Surgery is cross-cutting by nature, addressing multiple conditions including communicable and non-communicable diseases, injury, and maternal and neonatal health. Research in global surgery is therefore broad, ranging from investigation into clinical outcomes to the social determinants of health. The diversity and complexity of surgery means it can benefit from a health system strengthening approach which moves beyond the individual to investigate societal health goals and how to achieve them.[5]

Community participation in health refers to "people's individual and collective power and involvement in the conditions, decisions and actions that affect their health and health services."[6] It encompasses a number of different terms including community engagement and social participation. Underlying community participation is power, and how participation redistributes power to communities involved in the research process.[7] The relationship, and power sharing and dynamics between researchers and communities is critical in realising the

potential of participation in global surgery research to address inequalities in access to care. Broader power structures also influence the research process, but are sometimes outside the direct control of researchers.

Community participation in health research is operationalised in a variety of ways. Through it there is potential for community empowerment, defined as "the expansion of capability to participate in; negotiate with; influence, control, and hold accountable institutions that affect the wellbeing of the community".[8] For example, through community participation, researchers can work with local communities to identify locally relevant issues, investigate these, and co-produce new knowledge and solutions that are responsive to local contexts. Through the redistribution of power, research can provide a platform to shift knowledge generation and decision-making in health into the hands of communities. Thus, there is greater ability for communities to control their decisions and actions around health, and ultimately address inequities in access to health care.[4,7]

However, community participation risks being exploitative rather than empowering for communities. If researchers only involve communities to "consult" or "inform" about research agendas, study designs, and results, without enabling active participation in the research process then community participation can become tokenistic. This can further exacerbate differences in wealth, power and culture between researchers and communities, and inadvertently reproduce conditions of marginalisation and exclusion.[4] It is the responsibility of researchers throughout the research process to enable equitable partnerships in culturally relevant and sensitive ways, and to consider why communities would want to participate and how they would actively benefit from it.

Practical considerations for community participation in global surgery research

To date, there has been limited consideration of community participation in global surgery research. Given the breadth that global surgery research encompasses, the way in which communities can participate in the process may vary. Below, we outline some practical steps for community participation in the global surgery research process.

1. Identification of communities in global surgery

Community refers to people living and interacting in particular areas or with common or shared interests, recognising the social diversity that exists within communities.[9] Jumbam et al define surgical communities as a complex ecosystem of providers and patients.[10] The *provider community* includes specialist and non-specialist surgical and anaesthetic providers, nurses, mid-level providers, community health workers and other cadres without which surgical care would not be possible. It also includes professional associations which often represent the collective voices of surgical providers. The *patient community*, often neglected in global surgery research, includes patients and their family/caregivers, patient advocacy groups, and community leaders.[10]

Identification and inclusion of relevant communities should occur as research topics are first identified and developed. Persons and groups outside those traditionally included in the research process are important to consider e.g., beyond surgical patients to community leaders and advocacy groups who may be impacted by the research and hold gatekeeping positions within communities. Researchers should pay particular attention to identifying both those who have less power, such as marginalized communities, as well as those who hold political and social power relevant to the research topic. If researchers are uncertain, they can seek input from local collaborators and knowledge holders who often know best who to include.

2. Agenda setting

Community participation is essential to setting any local research agenda which should be co-produced through broad engagement and based on local needs. Agenda setting is an iterative process that should happen concurrently with the identification relevant communities. Communities engaged at the outset of the agenda setting process might aid in the identification of further relevant communities, and are often the experts in this regard. For example, researchers might initially invite local surgical providers to baseline discussions of a study to investigate barriers to access to timely surgical care. In these discussions, local providers may reveal that undocumented migrants have particularly complex social reasons to delay seeking care which fall outside providers' knowledge. Researchers then might include undocumented migrants in the agenda setting process to further refine the research question.

Allowing patient and provider communities to identify their own priority issues leads to research that is responsive and accountable to local contexts. The assumption is often made that local communities, particularly marginalised groups, do not have the means, capacity or expertise to contribute to the research agenda, and so are excluded. The more these communities are bypassed, the less their needs are heard and met. This perpetuates a cycle of further marginalisation. Engaging and empowering local communities to identify and implement their own solutions to accessing care based on their own systems of belief must start during research agenda setting.

3. Research methods

Co-designing research methods with communities can improve the investigation of and solutions to complex local issues. In any local context, multiple interacting factors contribute

to the lack of equitable access to surgical care. These are beyond the scope of any single individual or organisation to understand and respond to, and are often defined differently by various communities that view these issues through different social lenses.[11] Often, those closest to a problem are best informed to understand the best ways to investigate it. Local surgical communities can also advise on existing data and resources influencing the research process.

An example of the need for community participation in global surgery study designs comes from the African Surgical Outcomes Study 2 which implemented an intervention bundle to reduce post-operative mortality in multiple countries.[12] The study reported poor implementation of some interventions and ultimately no difference in the primary outcome, in-hospital mortality. The authors acknowledged that active involvement of relevant communities during research design would have helped to identify which interventions would have been feasible at each study site, and might have improved implementation.[13] Communities should actively participate in the design of their own systems of change in research processes to meaningfully address systematic differences in access and quality.

4. Research dissemination and impact

Research communities can provide nuanced interpretations of results during data analysis, given their unique perspectives and expert local knowledge, which can help to ground study findings in local realities. Surgical communities can become change agents and advocates for equitable access to surgical care in their own health districts, and enhance their own health outcomes. This requires providing them with the necessary resources to do so, and actively empowering communities to make the changes they desire. Platforms that support local ownership of study findings should be created throughout the research process. This includes consideration of who has access to and ownership of study data, as well as the ability of

communities to interpret results and implement recommendations, although this might be outside the reasonable scope of practice particularly for marginalised groups.

For example, a study in Malawi, Tanzania and Zambia sought to test a model of district-level surgical capacity building through supervision by specialists.[14] The study utilised participatory action research methods to design bespoke interventions in each country to address specific local needs through consultation with district-level hospital staff and their supervisors throughout the research process. Iterative learning cycles took place to embed the research within each local setting, with the formation of sustainable relationships between researchers and surgical communities.

Conclusion

In conclusion, community participation in global surgery research should strive to increase collective control of decisions or actions that contribute to social transformation and political change.[15] Embedding a sustainable system of local knowledge production and exchange in the research process can aid in reaching marginalised groups to improve access to the care and resources they require, and reduce inequalities in access to health. Different surgical communities have different degrees of power, and support should be given to those with little power in order to make their voices heard and responded to. Steps should be taken at each phase of the research process to ensure that participation of communities enables fair benefit, and to avoid exploitation as passive participants. Through collective action on the root causes of entrenched inequalities in global surgery, community participation can improve access to surgical care for all.

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