



We Asked the Experts: 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. Access to surgical care is highly inequitable particularly for marginalised groups. This article describes community participation in global surgery research from a pro-equity approach and outlines 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. The diversity and complexity of surgery means research within the field can benefit from a health system strengthening approach which moves beyond the individual

to investigate societal health goals and how to achieve them.

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” [1]. Underlying community participation is power, and how participation redistributes power to communities involved in the research process [2]. 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.

Community participation in health research is operationalised in a variety of ways. Through it there is potential for community empowerment to increase the capability of communities to influence, control and hold accountable institutions that affect the wellbeing of the community [3]. For example, through community participation, researchers can work with diverse communities to identify locally relevant issues, investigate these, and co-produce new knowledge and solutions that are responsive to local contexts. 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 [2, 4].

However, community participation risks being exploitative rather than empowering. 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

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reproduce conditions of marginalisation and exclusion [4]. It is the responsibility of researchers to enable equitable partnerships in culturally relevant and sensitive ways, and to consider why communities would want to participate in research processes and how they would actively benefit from this.

Practical considerations of community participation in global surgery research

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 [5]. Jumbam et al. [6] define surgical communities as a complex ecosystem of surgical providers and patients. The *provider community* includes specialist and non-specialist surgical and anaesthetic clinicians, 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 [6].

Identification and inclusion of relevant communities should occur as research topics are first developed. Given the breadth that global surgery research encompasses, the way in which communities can participate in the research process may vary. Persons and groups outside those traditionally included in the research process are important to consider, e.g. community leaders and advocacy groups who may be impacted by the research and hold gatekeeping positions within communities. 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 are important. If researchers are uncertain, they can seek input from local knowledge holders who often know best who to include.

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 of 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 surgeons to baseline discussions of a study to investigate barriers to access to timely surgical care. In these discussions, these surgeons may reveal that undocumented migrants have particularly complex social reasons to delay seeking care which fall outside the surgeons' knowledge. Researchers then might include undocumented migrants in the agenda setting process to further refine the research question.

Allowing provider and patient 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. 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.

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 alone, and are often defined differently by various communities that view these issues through different social lenses [7]. Often, those closest to a problem are best informed to understand the best ways to investigate it. Local surgical communities can also advise on data and resources that may already exist which might influence 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 [8]. 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 [9]. 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.

Research dissemination and impact

Research communities can provide nuanced interpretations of results during data analysis, given their unique perspectives and expert local knowledge. This 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 [10]. 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

Community participation in global surgery research should strive to increase collective control of decisions or actions that contribute to social transformation and political change [11]. Different surgical communities have different degrees of power, and support should be given to those with little power to make their voices acknowledged and amplified. 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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