

# Community participation in global surgery

Vigneshwar R Veerappan,<sup>1</sup> Rahul M Jindal <sup>2</sup>

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## INTRODUCTION

Global surgery is a multidisciplinary academic field that aims to deliver equitable access to safe, timely, affordable surgical care in all countries.<sup>1</sup> Research in global surgery is generally focused in low-income and middle-income countries (LMICs) and has traditionally been led by researchers from high-income countries (HIC), with a sizeable proportion of literature having minimal input from researchers in LMIC at all.<sup>2</sup> While the field has grown exponentially and there is more awareness of equity, gender equality, human rights,<sup>3</sup> and the need for inclusivity of authors from LMIC, there is still a need for better accountability and ethical framework.<sup>4</sup>

Accountability is a crucial component in a global surgery project.<sup>4 5</sup> Several barriers to achieving accountability have been identified, such as poor infrastructure, lack of partnerships with local collaborators, lack of patient understanding and literacy among many others.<sup>6</sup> Another issue may also be limited supervisory systems in LMIC. Luan *et al*<sup>6</sup> emphasised the importance of identifying and engaging with all stakeholders to address these issues—patients and service users themselves. The recently published National Surgical Obstetrics and Anesthesia manual has strongly supported engaging with patients to improve surgical systems.<sup>7</sup> In this commentary, we make a case for mandatory community participation for research in different facets of global surgery.

## WHAT IS COMMUNITY PARTICIPATION?

In any global surgery project, collaboration, communication and coordination between local and global partners, ministries of health, academic institutions and funding partners is key. Community participation is a way in which research participants themselves can contribute to the study design, analysis and implementation of research findings. The idea of empowering research participants to

## Summary box

- ▶ Community participants, in most studies in low-income and middle-income countries (LMICs), are merely used as data collectors and have no active input into study design.
- ▶ There are very few examples where researchers have carried out a formal public consultation and community participation before undertaking research in global surgery.
- ▶ Community participation is a way in which research participants in LMIC can contribute to the study design, analysis and implementation of research findings.
- ▶ We propose that global surgery studies in LMIC should have mandatory community participation, with the exception of a few clinical studies.
- ▶ Implementing a robust system of community participation in global surgery may increase global South-South engagement and eventually obviate the need for high-income countries (HIC) investigators or short-term humanitarian missions.
- ▶ We suggest an international consensus conference of key organisations in HIC, LMIC and journal editors to insist on accurate reporting of community participation in global surgery research.

provide input on how outcomes will affect them has been extensively discussed in global health, but less so in global surgery literature. In Quebec, the CARTaGENE project, designed to investigate the role of genetic determinants in global health issues, undertook a large-scale public consultation to understand public perceptions of genetic research. They collected qualitative and quantitative data that provided insight into the population's concerns about genetic research.<sup>8</sup> Tindana *et al*<sup>9</sup> described the Navongo model in Ghana, where researchers from HIC held consultations with the community's leaders and residents. However, the methodology of community participation with LMIC partners remains poorly defined.

Brear *et al*<sup>10</sup> conducted a scoping review of community participation in the global health literature. After developing a framework



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<sup>1</sup>Department of Surgery, University of York, York, UK

<sup>2</sup>Department of Surgery, Uniformed Services University, Bethesda, Maryland, USA

### Correspondence to

Dr Rahul M Jindal;  
jindal@msn.com

consisting of nine distinct aspects where participants can contribute to research, only 66 studies described at least one aspect of participation, while less than half of these studies had study population providing input on five of the nine distinct aspects; research methodology and design, research instrument and design, ethical review, data management and disseminating results. Data collection saw the highest participation from the community, but in most studies, participants were merely used as data collectors and had no active part in designing, dissemination or implementation of the findings.

### STANDARDISATION OF TERMINOLOGY

Literature in global surgery has used varying terminology such as ‘community participation’, ‘participatory health research’, ‘public consultation’, ‘shared decision making’, ‘allyship’, ‘empowerment’, interchangeably to describe a wide range of activities, which researchers have undertaken to gain input from the community. More recently, the term ‘coproduction’, has been proposed in which there is a consultation of people who use services from the start to the end of any project that affects them. This can pose confusion as a lack of precise and widely accepted definition means that there is no lower threshold for what qualifies as adequate and robust community participation. Furthermore, terms, such as allyship and empowerment have also been used in the literature to describe relationships with local collaborators. Allyship should not be approached as simply improving or helping others; but should be respectful relationship building and addressing power imbalances,<sup>11</sup> in particular by giving due authorship to investigators in LMIC. Empowering of investigators in the Global South should be viewed as supporting instead of leading.

### IMPLICATIONS OF COMMUNITY PARTICIPATION

It is important to involve the local community in all aspects of studies including study conceptualisation, design, implementation, data collection, analysis and dissemination. Research should be prioritised based on the needs of the local community which can be achieved through community participation before commencing any research. By engaging in community participation throughout the study, researchers will be able to effectively account for nuances within a culture, and address potential class, racial and gender disparities.<sup>12</sup> Finally, engaging in community participation will result in research teams having an ethical obligation to disseminate their results locally, as opposed to presentations in conferences in the Global North. Community participation will educate LMIC communities of their surgical needs, allow them to understand what needs to be done to address surgical shortfalls and open avenues for advancing preliminary research findings. Overall, implementing community participation will improve the quality of research by ensuring that the interventions that are being tested are feasible, culturally acceptable and equitable, adhere to

human rights, and are accessible to all segments of the local community.<sup>13</sup>

Community participation will also enable accountability.<sup>1 4</sup> It is an accepted fact that there are limited supervisory systems, regulating poor outcomes after medical and surgical missions in LMICs. Community participation will discourage untrained teams to embark on missions beyond their abilities. The research agenda should be presented in the local language, coherently conveying arguments for the value of global surgery and return on investment. It should also hold people, governments and organisations accountable for the value of research and potential solutions.<sup>1 4</sup>

To implement community participation within global surgery research, governing bodies within LMIC must make community participation mandatory, in addition to obtaining IRB. While not all global surgery research may be applicable for such input, the appropriate studies must be identified and advised to seek community participation.

### METHODOLOGY OF COMMUNITY PARTICIPATION IN GLOBAL SURGERY+

How do we implement community participation in global surgery research? To begin with, a more robust framework needs to be established on what community participation is and what it entails. Activities of community participation need to be of a ‘higher order’, where the communication between local populations and research teams are truly bilateral, and the decision making, and output of research projects are entirely community driven.<sup>14</sup> We suggest that the 12-activity Community Engagement in Research Index be a starting point for understanding community participation.<sup>15</sup> We also suggest an international consensus conference of key organisations in HIC and LMIC, and journal editors insist on accurate reporting of community participation in Global Surgery research.

Within global surgery, there are several publications around partnership and collaboration. Hedt-Gauthier *et al* highlighted the importance of ensuring that collaborators from LMIC are involved in all aspects of research and that all opportunities arising are equitably shared.<sup>16</sup> However, there are only a few examples where researchers have described the methodology of carrying out community participation in global surgery.

Vora *et al* described community participation in their study of unmet surgical needs in a slum in India.<sup>17</sup> They translated the questionnaire in the local language, identified community leaders; conducted a pilot study and a town-hall meeting to explain the purpose, data collection methodology, privacy, and potential outcomes. This allows the local population to directly communicate with researchers in a language they understand and contribute to the value of the research and likely will be more receptive to the implementation of research findings. As an alternative to formal town-hall meetings,

communities could be engaged in informal community hubs, press conferences,<sup>18</sup> regional caucus sessions and annual forums.<sup>19</sup>

The UK Global Health Research Unit on global surgery<sup>20</sup> has pioneered community participation in preparation for launching randomised clinical trials investigating capacity building in district hospitals in Ghana. Their study proposed techniques of hernia repair and shortfall of trained surgeons in rural areas. Similar to Vora *et al*,<sup>17</sup> their team conducted interviews discussing, feasibility and acceptability of the proposed study, confirming the importance and relevance of their research and highlighting aspects that are important to patients and the community. The GlobalSurg collaborative has employed an indirect technique of community participation in their projects. They recruit and train local healthcare professionals in the steering committees of respective projects. Noteworthy examples are the Global Neurotrauma Outcomes Study, a prospective, multicentre, international cohort study of outcomes following emergency surgery for traumatic brain surgery, the CovidSurg Cohort Study,<sup>21</sup> aiming to assess the outcomes of surgery in patients with SARS-CoV2 infection, and The CovidSurg-Cancer Study<sup>22</sup> focusing on patients with a tumour that requires surgical treatment during the pandemic.

A new era has been initiated with South-South collaboration. This is defined as collaboration and exchange of expertise between two or more LMIC.<sup>23</sup> Initially, this type of collaboration was seen in the field of global health. The Haiti-Lesotho collaborative model<sup>24</sup> is a good example of such a type of collaboration in which the HIV equity initiative established in Haiti was adopted in Lesotho. Another more recent example has been India's efforts in manufacturing and distributing COVID-19 vaccinations to other LMICs due to its ability to produce high quality vaccines at low cost.<sup>25</sup> Only recently has the South-South partnership extended to surgical problems. The African Surgical Outcomes Study was initiated in South Africa in collaboration with several other African countries.<sup>26</sup> This study investigated postoperative outcomes and found that patients in Africa were twice as likely to die following a surgical procedure vs the global average, despite having a low-risk profile and low complication rates. This study is built on the successful collaboration of 25 African countries consisting of 11 500 patients, and over 1000 African clinicians. This is a step in the right direction, nonetheless, we believe that direct community participation will help identify nuanced differences and disparities between and within LMICs.

### LIMITATIONS TO COMMUNITY PARTICIPATION IN GLOBAL SURGERY RESEARCH

There are several limitations to consider in community participation. First, community participation in LMICs is still a fairly new concept. Local communities often do not have prior experience of interaction with researchers

from HIC and are unaware of the benefits research can bring to their community. While community participation may provide a platform for the local community to build a strong sense of trust and improve coordination with the research team, getting the local community to engage with the project in the first place may be a challenge. This will require a strong network of local academic collaborators and researchers who appreciate the local culture, language and practices and have empathy for the community irrespective of educational or financial status. Second, community participation may cost both time and resources. It is imperative that researchers from HIC put an effort not only in finding local academic collaborators and researchers who can afford the time to engage in meaningful public consultations, but also take an additional step to create allyship and empower their collaborators.<sup>10</sup> It is local academic collaborators who will have the experiential knowledge of how to identify and train appropriate local champions who can be the voice of the community and ensure unbiased feedback. Funding agencies will have to allocate adequate funding for this exercise.<sup>27</sup> Third, community participation may not apply to all studies. For example, the role community participation plays in a randomised control trial of drug intervention may be limited. However, the CARTaGENE project has shown that engaging the community in even complex genetic research may still prove beneficial. Finally, care must be exercised that mandatory community participation is not tokenistic, with researchers attempting to tick a box as opposed to meaningful engagement.

### CONCLUSIONS

It is necessary to reframe the focus of global surgery research from measuring the problem to identifying, evaluating and implementing solutions.<sup>28</sup> We believe that this is possible through community participation, which should be a formal and mandatory component of any global surgery research methodology, with a few exceptions for clinical studies. However, there is a need for defining the terminology, methodology, and benefits of community participation,<sup>29</sup> which may vary from country to country. This can be addressed through a 'consensus conference' of key stakeholders.

Implementing a robust system of community participation within global surgery will allow for bidirectional flow of communication, data dissemination and create a platform for meaningful change. South-South engagement should be nurtured by funding agencies so that eventually there may not be a need for HIC investigators or short-term humanitarian missions. Global South is no longer a passive recipient of ideas but now brings important lessons to share with their peers to eradicate poverty, address inequality, economic growth challenges, including treatment and management of surgical diseases.<sup>26</sup> Despite these positive developments, community participation is still 'indirect' in the form of training healthcare workers and surgical leaders, participation in steering committees

and journal authorship. We urge direct community participation in global surgery research, but care should be taken that it is not 'tokenistic'.<sup>14</sup>

**Twitter** Vigneshwar R Veerappan @raj\_vigneshwar

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#### ORCID iD

Rahul M Jindal <http://orcid.org/0000-0002-8731-0671>

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