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# Overcoming structural barriers to sharing power with communities in global health research priority-setting: Lessons from the Participation for Local Action project in Karnataka, India

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## ABSTRACT

Community engagement is gaining prominence in global health research. But communities rarely have a say in the agendas or conduct of the very health research projects that aim to help them. This paper provides new evidence on how to share power in priority-setting in ways that seek to overcome structural constraints created by the funding environment. The five strategies were identified through case study research on the Participation for Local Action project in Karnataka, India. That project was carried out by researchers in partnership with the Zilla Budakattu Girijana Abhivrudhhi Sangha, an indigenous community development organisation representing the Solega people. The paper describes each identified strategy for sharing power in priority-setting, followed by a report of the pitfalls and challenges that arose when implementing it. Thus, the study also demonstrates that even where actions and strategies are used to address power imbalances, pitfalls will arise that need to be navigated. Given those challenges, considerations to reflect upon before employing the identified strategies are suggested. Ultimately, the paper aims to communicate strategies for sharing power during and after priority-setting and lessons on how to implement them effectively that can be used by global health researchers in the current funding environment.

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## KEYWORDS

Power; participation; community engagement; research; priority-setting; global health

## Introduction

How can researchers and communities share power in priority-setting for global health research projects? Community engagement and participation are big buzzwords in global health research these days (Reynolds & Sariola, 2018; Solomon et al., 2016; Tembo et al., 2021). But communities in low and middle-income countries (LMICs) seldom have a say in the agendas of the very health research projects that aim to help them. Typically, priorities (research topics and objectives) are defined by funders and/or by researchers, often from high-income countries. In this paper, global health research priority-setting refers to defining the research topic and study questions for individual health research projects or programs, rather than defining a set of global, national, or institutional research topics that require priority funding and implementation.

Sharing power with communities in priority-setting is essential to ensure their voices, experience, and knowledge are reflected in the research topics and objectives explored by global health

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research projects. This, in turn, can help address epistemic injustice and generate research topics and objectives that are more explicitly focused on improving access and affordability of health care and services for them (Oswald, 2016; Pratt, 2019a). It has ‘the potential to ... compensate for or resolve existing differences in power, privilege, and positionality; allow for marginalised voices and experiences to be represented in the production of scientific knowledge; and ensure that research is relevant and impactful’ (Reynolds & Sariola, 2018, p. 257).

Sharing power throughout the research process, including during priority-setting, is a key facet of co-production, which is gaining increasing recognition in global health research as a mechanism for achieving greater health impact (Beresford et al., 2021; Egid et al., 2021; Oswald, 2016; Tembo et al., 2021). As Tembo et al. (2021) affirm, ‘for research that drives change and reduces the waste of resources, co-production should start from the earliest stages, *when problems are identified and priorities defined*’ (emphasis added). Taking such an approach means researchers jointly construct knowledge with research users and beneficiaries; all parties design and conduct research together in ways that achieve the purposes of both sets of actors (Hall et al., 2016). A co-production approach aims to redistribute knowledge-based power and replace it with mutual learning between all participants in a collaboration (Tembo et al., 2021). It is a process of bringing together multiple kinds of knowledge and multiple perspectives to construct an understanding of research phenomena based on a plurality of situated knowledges (Oswald, 2016).

So far, limited guidance exists for how power sharing can be achieved between researchers and communities during global health research priority-setting. A significant amount of existing literature explores the concept of participation in contexts of power disparities, spanning disciplines like political philosophy, ethics, development studies, health policy, and community-based participatory research (see Abelson et al., 2007; Arnstein, 1969; Benhabib, 1996; Cargo & Mercer, 2008; Cornwall, 2011; Crocker, 2008; Gaventa & Cornwall, 2006; Goulet, 2006; Hickey & Mohan, 2004; Kitchin, 2000; Mitton et al., 2009; Mitton et al., 2011; Peuravaara, 2015; Wallerstein & Duran, 2006; Young, 1996, 2000). But it largely does not consider the participation of communities in the context of *global health research priority-setting*.

How to share power in co-production in global health research is starting to be discussed in the literature (Apgar et al., 2016; Egid et al., 2021; Lokot & Wake, 2021; Mannell et al., 2021), though without an explicit focus on the priority-setting phase. Strategies for power sharing include reflexivity and having explicit discussions on the meaning and impact of power within a given collaboration (Egid et al., 2021; Farr, 2018; Mannell et al., 2021; Turnhout et al., 2020); shared decision-making (Egid et al., 2021; Mannell et al., 2021); reciprocity in terms of benefits accruing to each actor in the co-production process (Mannell et al., 2021); and depoliticising co-production (Turnhout et al., 2020). There is a strong emphasis that ‘constant critical reflective practice and dialogue [about power dynamics] is essential to facilitate more equal relational processes’ (Farr, 2018, p. 623). Constantly reflecting on such matters throughout co-production processes can support a greater understanding of how to minimise the effects of different inequalities (Farr, 2018).

In relation to global health research *priority-setting*, previous research identified sixteen ‘sites of power’ that affect how processes are run, who participates in them, and who influences their outputs (Table 1) (Pratt, 2018; 2019b). During priority-setting for global health research projects, it is important to implement ways of sharing power with communities in relation to these sites. After priority-setting, it is important to demonstrate respect and accountability to such communities (Pratt, 2019b). Some suggestions and considerations for power sharing at these sites have been made in the literature on co-production in global health research.<sup>1</sup>

Yet *structural* barriers frequently make it challenging to implement power-sharing strategies at these sites during and after priority-setting. In global health research, the funding environment largely does not support community engagement prior to applying for grants (Pratt, 2019b).<sup>2</sup> This makes it difficult to include communities in the priority-setting stage of global health research projects at either the partner or consultant *levels of participation* (Table 1). Instead of engagement, there is a trend of privileging epidemiological survey methods for getting a ‘comprehensive’ idea of

**Table 1.** Sites of power.

Site of power	Definition
Leadership	Who takes the lead on the key aspects of research priority-setting: planning, implementing, ensuring outputs are fed back and used.
Scope	What issues can be brought into the priority-setting space and what issues are not allowed; What information is presented or shared with participants at the start of the priority-setting process.
Empowerment	What goals are set for the priority-setting process: instrumental and/or empowerment. Power sharing is promoted where engagement processes aim to <i>empower</i> community partners and members as researchers and to be involved in research priority-setting respectively.
Stage of participation	When community partners and members participate in the health research priority-setting process. Entry from the start of the priority-setting process is associated with deeper participation.
Level of participation	The mode of participation assumed by community partners and members during health research priority-setting. <i>Decision-making</i> means being responsible for making key choices in priority-setting, e.g. process planning choices, research topic selection, research question selection. <i>Consulting</i> means giving input but having no assurance that it will be used by those who decide.
Diversity within the community	The range of people engaged from the community.
Representation	Being present or represented during health research priority-setting.
Mass	Numbers of community partners and members of the wider community relative to academic researchers.
Space	The physical setting in which health research priority-setting is undertaken.
Ground Rules	Rules under which health research priority-setting is undertaken. They specify who can and cannot be present, who can speak, when individuals can speak, what roles individuals play in the process, how different individuals' views are used, and how a decision or closure is reached.
Facilitation	Whether facilitators and chairs of discussions and meetings ensure everyone (researchers, community partners, community members) has an equal opportunity to speak and draw out quieter voices.
Listening	Whether researchers engage in dialogue (ask questions and for clarifications) about what community partners and members say <i>and</i> document what community partners and members have said.
Being heard	Whether the views of community partners and members are taken on board and the information they provide is acted upon. Ideally, a joint product is created with inputs from researchers and those engaged.
Resources and compensation	Whether community partners are employed as members of the research team and community members are paid for time worked, rather than covering their expenses.
Unintended harms	Possible harms that could eventuate for community partners and members from being part of a priority-setting process.
Accountability	Responsibilities of researchers, research institutions, and community partners after priority-setting.

communities' priorities. This reflects the overwhelming prevailing trend of doing scientific research using quantifiable epidemiological methods versus doing community development using participatory approaches, which is evident in public health theory and practice (Galea & Link, 2013; Krieger, 1994).

The current funding environment also typically obstructs researchers and communities from having an open *scope* to set research priorities together (Pratt, 2019b). An 'open' scope means no or very few research topics related to health are off the table. In practice, research projects' topics are often already defined by the funder and/or by researchers before community engagement occurs. Engagement typically occurs when reviewing or developing study instruments, consent documents, ethics applications, recruitment materials, and/or intervention-related materials. This is often how community advisory boards function in global health research (Zhao et al., 2019). Ellis and Kass (2017) found that even in research funded by the Patient-Centered Outcomes Research Institute, engagement was uncommon at the earliest stages of research. This makes it challenging to ensure community health and research priorities inform global health research project agendas.

Power sharing in relation to *space* can be difficult because researcher-initiated collaborations are more common than collaborations initiated by community partners in the current system of knowledge production (Tremblay, 2015). Research funders' eligibility and selection criteria strongly

favour academic researchers and research institutions. When academic researchers receive research grants, they then invite community partners and/or communities to enter decision-making spaces. In these invited spaces, unequal power dynamics are recreated between community and academic researchers and can give rise to tokenism: presence without voice and voice without influence (Pratt, 2018).

Power is often built unfairly into research projects in relation to *compensation* too. Traditionally, many NGOs which have undertaken activities that address health issues in LMICs are service-oriented NGOs and concentrate their efforts on implementing ‘action’ programs. This type of NGO finds it difficult to access resources that would allow them to conduct research and must seek out academic collaborators (Delisle et al., 2005). Lead applicants and administering organisations are usually academic researchers and research institutions respectively, often from high-income countries (Reynolds & Sariola, 2018; Tremblay, 2015). Principal investigators (academic researchers) then have more knowledge about the project resources available and control access to them, while community partners do not. Principal investigators often closely guard the details of project budgets and dictate how grant money is spent without having to account to collaborating partners (Matenga et al., 2019). Finally, power sharing after priority-setting in terms of *accountability* to communities is not common. Funding arrangements and research institutions’ policies typically fail to require or create accountability mechanisms between researchers and host communities beyond the life of the original study.

This paper reports five strategies for sharing power in global health research priority-setting that seek to overcome the structural barriers discussed above. The strategies were identified through case study research conducted on the Participation for Local Action (PLA) project in Karnataka, India. The PLA project was carried out by researchers from Vivekananda Girijana Kalyana Kendra (VGKK), a non-governmental organisation that has been working for the development of Solega people since 1981, and the Institute of Public Health (IPH), a research institute in Bangalore, in partnership with the Zilla Budakattu Girijana Abhivrudhhi Sangha, a district-level community development organisation representing the Solega and other indigenous people<sup>3</sup> in Chamarajanagar district. The Solega are an indigenous population who have lived in the Biligiriranga Hills and surrounding forested regions of Southern Karnataka for centuries (Agnihotr et al., 2021). They are among several indigenous communities in India, who refer to themselves as *Adivasis*, an umbrella term for multiple distinct communities (first citizen in many Indian languages). The Solega, like other Adivasi communities, have been socially, politically, and historically marginalised both during the colonial period and in post-independence India (Xaxa, 2016). The Solega are an indigenous population designated as a *Scheduled Tribe* under the Indian Constitution’s statutory provisions to recognise vulnerable groups for affirmative action. Despite decades of public health interventions and health service strengthening, the Solega people’s health status remains poor (Seshadri et al., 2019; Thresia et al., 2020; Xaxa, 2016). The PLA project comprised participatory action research that was essentially a priority-setting process: the problems the Solega people faced in accessing maternal and child health services and interventions to address them were identified and prioritised.

In this paper, the community refers to the Solega people (and other indigenous people) living in Biligiriranga Hills. Definitions of ‘community’ can be based on geography; on special interests or goals; or on shared experiences, characteristics, or ethnicity (Molyneux & Bull, 2013). Often, what is referred to as a community may be a heterogeneous group of various actors with different levels of power, position, and influence. The Solega who are part of the Zilla Budakattu Girijana Abhivrudhhi Sangha [district Sangha], for example, likely have greater influence than some of the other members of the Solega community. Although the Sangha leaders are Solega, where the terms ‘Solega community’ and ‘wider community’ are used in the paper, they refer to members of the community who are not part of the community organisation. The terms ‘community leaders’ and ‘Solega leaders’ refer to leaders of the district Sangha. The Sangha is several decades old and has a federated and representative organisational structure that goes down to every Solega settlement in

the Biligiriranga Hills. It aims to improve the lives of the Solega people and has successfully fought to secure forest and land rights for them (Tatpati & Pathak-Broome, 2016). District Sangha leaders are not elected. They change over every three years and geographical location is considered when selecting leaders along with several other traits such as having demonstrated a desire to do social service and help others. The district Sangha is comprised of 21 members (district Sangha leaders), with four to five from each sub-district. The district Sangha leaders thus reflect Chamarajanagar district's geographic diversity. Sangha organisations also exist at sub-district and village levels.

In-depth interviews were conducted with the researchers, district Sangha leaders, and field investigators from the Solega community who conducted the PLA project. Their interviews generated rich data on how power was shared with the community organisation and Solega community in the face of structural barriers. They also showed that power sharing was diminished to some extent due to challenges and pitfalls implementing the strategies. In the paper, each identified power sharing strategy is described, followed by a report of the pitfalls and challenges that arose when implementing it in the PLA context. The pitfalls are drawn from both the study data and the authors' reflections on it. Given those challenges, considerations to reflect upon *before* employing the strategies are proposed in order for them to be more effectively implemented by others. Ultimately, the paper aims to communicate strategies for sharing power during and after priority-setting, and lessons for how to effectively implement them, that can be used by global health researchers in the current funding environment.

## Methods

### *The case under study*

The case study of the PLA project was performed as part of a larger ethics research program that examines sharing power with marginalised communities in health research priority-setting. Cases of priority-setting processes were selected that aimed to meaningfully engage marginalised communities in choosing research projects' topics and objectives and in designing interventions. The PLA project was one such case. Key dimensions of deep inclusion or meaningful engagement identified in the philosophy and development studies literatures are representation (range and mass) and voice (having a say and being heard) (Cornwall, 2011; Crocker, 2008; Young, 2000). In the PLA case, researchers sought to achieve meaningful engagement by partnering with a community organisation and soliciting information from the diversity of the Solega community as part of the priority-setting process. Community leaders and members thus participated in the priority-setting process as decision-makers and consultants.

The PLA project ran from January 2015 to September 2016. Its research team consisted of eight members: a principal investigator from VGKK, one co-investigator from IPH, one co-investigator from the Zilla Budakattu Girijana Abhivrudhhi Sangha [district Sangha], two co-investigators from other Indian research institutions, one co-investigator from a Belgian university, and two co-investigators from the Government of Karnataka. The PLA project was undertaken in partnership with the district Sangha. Although VGKK and the district Sangha had not partnered in this way before, they had a strong pre-existing relationship. VGKK helped establish the district Sangha and supports it to lead community initiatives.

The PLA project essentially comprised a priority-setting process. Introductory meetings were first conducted in 2015 between the VGKK and IPH researchers and district Sangha leaders. Once a decision to participate was made, a participatory action research process was designed and undertaken. The district Sangha recruited ten field investigators (five men and five women from the Solega community) and a field supervisor to visit the district's 148 Solega villages and collect survey data about the problems that households faced in accessing maternal and child health services. Data were jointly analysed by three district Sangha leaders, the 10 field investigators, and one of the principal investigators, and six core themes were identified. In June 2016, a



deliberative workshop was held and attended by 60 Sangha leaders (from district, sub-district, and village levels) to reflect on the six themes, to prioritise amongst them, and to develop community-led solutions to address them. A health navigator intervention (a mobile helpline for health queries and support for Solega patients hospitalised at district and higher levels of care) was selected for implementation.

### **Case study methods**

As part of the case study research, data were collected through in-depth interviews (December 2018 and April 2019). Sampling was purposive; it sought to capture the perspectives of all types of stakeholders involved in the PLA project: researchers, Sangha leaders, and field investigators from the Solega community. Sangha leaders and field investigators were suggested for interview by the district Sangha leader who supervised the field investigators. Efforts were made to select Sangha leaders and field investigators across genders and all four sub-districts, and field investigators with and without Sangha affiliation, but this proved difficult.

A total of fourteen semi-structured in-depth interviews were conducted with researchers (four interviews); Sangha leaders who participated in the introductory meetings and/or the deliberative workshop (five interviews); and field investigators (five interviews). Most field investigators who were interviewed were affiliated with the Sangha as either leaders or volunteers. In total, four women and eleven men were interviewed. To some extent, this reflected the fact that there were fewer female co-investigators than male and far fewer female Sangha leaders than male. Only three female Sangha leaders attended the initial meetings and deliberative workshop. Of the ten Sangha leader and field investigator interviewees, six were from Yelandur sub-district, three from Kollegal sub-district, and one from Chamarajanagar sub-district. Seven were Sangha leaders and one volunteered with the Sangha. Two interviewees were not part of the Sangha organisation.

Written informed consent was obtained from all participants. Following the technique of thick description, interview questions were open-ended (Geertz, 1973) and a subset of the questions attempted to draw out interviewees' experience with and perspectives on sharing power during the PLA project. Interviewees were asked the following questions:

- What foundations and barriers for shared decision-making with the researchers/indigenous communities were present?
- How were the voices and the interests of the Solega community kept central in the PLA project?
- What was important to achieving shared decision-making during the PLA project?
- How did the PLA project access the diverse voices and knowledge of community members, including those considered marginalised? How were power imbalances minimised?
- Whose voices and knowledge were present in the problems that were prioritised and the interventions developed to address them?

The question guide was translated to Kannada and then back-translated to English to ensure the questions retained their original meaning.

All interviews were conducted in person in the Biligiriranga Hills and Bangalore, thirteen by BP and one by NSN. Interviews with researchers were performed in English. Interviews with Sangha leaders and field investigators were performed in Kannada with the assistance of a research assistant (NSN). Interviews' duration was 63–126 min.

Interviews were transcribed verbatim and, where necessary, translated from Kannada to English. Thematic analysis of interview transcripts was undertaken by two coders in the following five phases: initial coding framework creation, coding, inter-coder reliability and agreement assessment, coding framework modification, and final coding of entire dataset (Campbell et al., 2013; Hruschka et al., 2004).

Ethical approval was obtained from the University of Melbourne Medicine and Dentistry Human Ethics Sub-Committee and the Institute of Public Health (Bangalore) Institutional Ethics Committee.

### ***Authors' positionality***

The paper's first author is an ethics researcher from a high-income country. She was not a member of the PLA project team. This case study was her first introduction to the Sangha and its processes and the Solega people, their history, and their way of life. She does not speak Kannada or Solega-nudi, which are the primary languages of interaction among the Solega in Chamarajanagar. By not being embedded in the case under study or having a relationship with the Sangha, she gathered and analysed study data with an 'outsider' lens. While this avoided certain biases an 'insider' positionality might generate, it also meant that she was more likely to misunderstand and misinterpret the data and did not interpret them from an Adivasi lens. Partnering with collaborators embedded within the Solega community and spending several weeks in the Biligiriranga Hills sought to mitigate the former risk. Additionally, follow-up interviews were conducted to ensure accurate understanding where initial interview transcripts were unclear, and the meaning of English translations of transcripts was checked with NSN where BP was unsure if she interpreted them correctly.

The remaining two authors were part of the PLA project research team. Both are medical doctors and have worked in primary care at VGKK hospital. In 2014, they set up a long-term tribal health research field station embedded within the Solega community to address health inequities of tribal communities through research and action (Seshadri et al., 2019). They thus are embedded within the Solega community as health workers and yet remain 'outsided-ness' as non-Solega. They have purposefully limited their participation in designing and conducting the case study in order to ensure that their voices were not privileged over Sangha leaders and field investigators in this study. They provided input on the case study's recruitment scripts, Plain Language Statement, Consent Form, and Question Guide to ensure that they were appropriate and would be understood by study participants. Neither they nor the Sangha were involved in data analysis. After data were thematically analysed and an outline of this paper was written, they provided feedback. They then provided comments on a first draft of the paper. They also summarised the draft to the Sangha leadership, documented its members' responses, and shared those responses with the lead author.<sup>4</sup>

## **Results**

Ways of sharing power and their associated pitfalls and challenges were identified at five sites: scope, level of participation, space, compensation, and accountability (Table 1).

### ***Scope***

#### ***Dual agenda***

There was not an open scope to focus the PLA project on what the district Sangha viewed as the Solega people's priorities. The project's topic – access to maternal and child health services – was already set by the funding call.<sup>5</sup> So how could the community organisation's voice be reflected in the project's topic and objectives?

After consulting with the co-investigator from the Sangha, he and the principal investigator organised an open discussion with the district Sangha. At the discussion,

we mentioned that look this is our focus in the project we're trying to build. Now you might have some other focus, we will not interfere with, so we will be able to bring in resources in the form of supporting data collectors, now if you want to bring your own agenda on what these data collectors are likely to do when they visit and when they have these conversations we do not restrict those things.



This proposal was agreed to and actualised, with the district Sangha building their own agenda into the PLA project. Its leaders were interested in identifying what other problems the Solega people were experiencing and in determining whether the Solega could access relevant government benefit schemes and their forest rights. They would have ownership of that data and ultimately chose not to share it with the researchers. The PLA project survey thus had two components corresponding to the project's dual aims. Those aims encompassed *both* the research topic set by researchers, which aligned with the funding scheme and was something they felt the Solega community would get behind, *and* the agenda of the district Sangha, which sought to improve the overall well-being of the Solega community in Chamarajanagar district. Ultimately, the barriers to access identified by the project and the health navigator intervention implemented to address them encompassed but were not specific to maternal and child health.

### Pitfalls

During initial meetings between the researchers and district Sangha and at the deliberative priority-setting workshop, the scope of discussion was not restricted to maternal and child health. The topic of alcoholism came up 'quite overwhelmingly' according to the researchers. Although the data considered at the workshop focused on maternal and child health, Sangha leaders, especially women, called for addressing alcoholism in the Solega community in workshop discussions. Yet recommendations for interventions to combat alcoholism could not be taken forward due to the nature of the PLA project funding. The researchers reported having to exercise their power at the workshop:

It was all readily obvious that alcohol was the main choice for what they considered a big problem. I think during the facilitation I remember already dropping hints that this we will have to do it outside of our project space because we're already committed to this project being on maternal and child health and I, at that point immediately sort of occurred to me that there's no way I can justify an intervention now on alcohol ... So then we exercised our power in sort of saying that we'll take this separately.

By making space for priority-setting discussions beyond maternal and child health, topics and issues were raised that the PLA project could not act upon. There were limitations as to what community priorities could be the focus intervention development and testing during the PLA project.

### Level of participation

#### Using PAR as an priority-setting process

The PLA project utilised participatory action research (PAR) methods to ensure community participation in priority-setting and identify a community-driven research agenda in relation to maternal and child health. Such methods also made it possible for the district Sangha to participate as a *partner* in the priority-setting process. According to many interviewees, the district Sangha served as the *lead* partner in implementing data collection and analysis. It created a sub-committee to oversee the PAR process, recruiting ten field investigators (five men and five women from the Solega community) and a field supervisor to collect data about the problems Solega households faced in accessing maternal and child health services and other government benefit schemes. Data was jointly analysed by three district Sangha leaders, 10 field investigators, and the principal investigator. Following the deliberative workshop, a subset of the district Sangha leaders met with the research team to further prioritise and identify an intervention(s) that would be taken up in the district. Thus, PAR methods facilitated Sangha leadership in identifying health topics of importance to the Solega community and in designing and implementing interventions to address them.

### Pitfalls

Using PAR to identify research priorities and to design interventions created two levels of priority-setting. At the first level, funders and researchers set the PLA project topic (maternal and child health) and research objective: to facilitate contextualisation of the safe motherhood programme of the Indian government's National Health Mission with the Solega population in Chamarajanagar

district in order to improve its implementation. At the second level, a PAR process was used to identify the problems the Solega community faced in accessing safe motherhood services and to identify actions to address them. The district Sangha partnered with the researchers at the second level only, creating different stages of entry to priority-setting for the research team and the community organisation. Earlier entry into decision-making is associated with higher quality participation (Crocker, 2008).

The PLA project also achieved different levels of participation for the district Sangha and the wider Solega community. Over the past two decades, VGKK has engaged with the Sangha as a partner and supported the Sangha organisation to consult with the wider Solega community. This existing relationship was adopted in the PLA project because it was the first time the two organisations had partnered to do research and the awarded funding was for a short period. As such, the district Sangha were engaged as *partners* and decision-makers in the PLA project.

The wider Solega community's participation (apart from field investigators) was largely restricted to *consultation*. Community members provided input about what challenges they faced accessing maternal and child health services and then that data was synthesised by Sangha leaders, field investigators, and the researchers to generate a set of core problems to prioritise amongst. Prioritisation and intervention development were slightly more inclusive, as some members of the Solega community were invited to participate as decision-makers at the priority-setting workshop by the district Sangha. The workshop, however, did not broadly involve the Solega community.

The researchers attributed the limitations to the district Sangha and Solega community's stage and level of participation to several factors: a lack of time (the project was funded for one-year), lack of resources, Sangha implementation of the PAR process and workshop, and difficulty engaging with the wider community to design a PAR process. The latter reflected most community members' lack of training in research and language barriers between them and the researchers. The researchers suggested that, as PAR is a sustained process, a second cycle could address some of these limitations.

Finally, community partners questioned the use of PAR methods. A researcher reported that:

[A] Sangha member with training in research methods queried why aren't we being more objective with our research approach. That person felt hey listen but if we are investing money in talking about our problems shouldn't we be investing in something that is considered objective and that is considered high quality by everyone ... Whether right or wrong what the larger world considers as high quality evidence, shouldn't we be investing in that instead of doing this.

Some tension existed between setting community-driven priorities in a participatory way and respecting community voices that called for employing other (less participatory) approaches to generate 'higher quality' evidence (according to current ways of valuing different types of knowledge) of community needs that were more likely to be taken up by government officials. This tension was resolved through a deliberative discussion. That discussion ended with the Sangha leader agreeing to the use of PAR methods in the PLA project and accepting the researchers' offer to develop technical reports that would carry more 'quantitative' evidence and summary statistics to address his concern. The researchers further promised that, in the future, other types of methods could be used to investigate other issues affecting the Solega community.

## Compensation

### *Promoting community organisation control and transparency*

Power is often unfairly built into budgeting for research projects in terms of transparency and control. Ensuring transparency in relation to the entire PLA project budget was thus very important to the researchers. At initial meetings with the district Sangha, the researchers went through the PLA project budget with them by line item:

In terms of fairness to the people there in the room, I think we put our cards on the table, so we, we were very clear that there is this kind of money. We mentioned how much money is there ... We also said we can raise more.

A member of the district Sangha was a co-investigator and he had access to a copy of the entire budget as well.

To ensure the district Sangha had control over the budget allocated to them to implement the PLA project, a memorandum of understanding (MOU) was created between the district Sangha and VGKK (the lead organisation on the project). This meant the district Sangha was not allocated resources on a reimbursement basis. As part of the MOU, district Sangha leaders and the researchers agreed on deliverables and timelines. The Sangha got a first instalment of money to start things off and then a second and third instalment based on certain deliverables being met. As a grassroots NGO, VGKK's policies were quite flexible and permitted this type of arrangement, which was a key facilitating factor. (In contrast, research institutions like IPH often have clear but rigid financial and administrative policies that do not allow it.) That such policies were *acted* upon likely reflected the trust and long-standing relationship between VGKK and the Sangha. The funder was flexible with the arrangements as long as they were requested in advance with sufficient explanation and documentation.

PLA project investigators also recognised that ensuring community organisation control over the budget could go farther than it did in the PLA project. In a second cycle of collaboration, the district Sangha should be the lead organisation who administers the budget. Changes to funding structures are needed to support this iterative type of project approach. Ideally, to navigate the power differentials,

If I'm a funder, I would okay create – because that's how as a funder I can really make a change – so I would fund this project [the PLA project] where researchers, epidemiologists, some kind of people are engaging with the Sangha. After these eighteen months, I would study it and then the next cycle I would start shifting some of the funding from the researchers so like, for example, funding a researcher in the Sangha itself, or funding a young tribal to play a researcher role and evaluate the intervention within the Sangha.

Current research funding mechanisms are not set up to fund multiple cycles of research collaborations. Each cycle must be submitted as a new project and is subject to a separate assessment from the original project. A subsequent proposal for follow-up research written by the district Sangha was shared with the PLA project's funder, but it was ultimately not awarded money.

### **Pitfalls**

The PLA case shows that, while transparency is important, tensions can still arise in relation to aspects of the project budget that are beyond researchers' control – namely, the length of the award. The PLA project was a one-year award, though the researchers stretched the budget over three years via a request for a no cost extension. However, several Sangha leaders and field investigators voiced their desire for a longer-term project, lasting five or more years. A Sangha leader noted that they [Sangha leaders] and even people within the Solega community were 'unsatisfied' because the PLA project only ran for a year. A field investigator emphasised that longer projects are necessary to achieve benefits and development for the Solega community:

If we do the project for six or seven months, the community cannot develop. Even if we do for one year, it is of no use. If we do the project for at least five years, then people will know they are getting benefit from the project.

### **Space**

#### ***Making an invited space into a created space***

The PLA project was researcher-initiated and thus an invited space. Much of the decision-making about the PLA project happened at meetings held at a research field station in the Biligiriranga Hills.

The researchers therefore sought to increase Sangha ownership of both these meetings and the field station. When they moved on to the campus, they invited the district Sangha to feel free to use the space for their meetings. Doing so made the space feel like it was both theirs and the researchers, rather than solely the researchers' space. It was also a natural continuation for the district Sangha. Prior to becoming the research field station in 2014, the campus had been used by a forest conservation organisation that employed the Sangha co-investigator on the PLA project, so the community organisation had held its meetings there for many years.

The researchers also purposefully conducted many of the PLA project meetings within district Sangha meetings:

Normally I think there is a certain local meetings happen in a certain way, we didn't break from that too much ... So we wanted it to be a session within their meetings so we blended ourself into their meeting so that we could also engage with it as theirs, not as a researchers activity. Because I've seen very often that because they also attend a lot of these awareness training programs and things like that given by officials where it's a teacher student relationship so they come to listen and then an expert teaches ... . An entirely different format would have made that meeting into our meeting and we didn't want that.

### **Pitfalls**

Making the field station the primary project meeting space had implications for who came to the PLA project meetings. Sangha leaders from more distant sub-districts were less likely to attend and were thus less involved in the PLA project. Alternative locations may have facilitated greater participation by Sangha leaders from Gundlupet and Chamarajanagar sub-districts.

Blending into Sangha meetings also meant that the norms and dynamics of those meetings were recreated in PLA project meetings. As a result, few women were present and those that attended were not very vocal. The district Sangha has fewer female leaders (25%) than male leaders (75%). Women's participation in the Sangha decreases from village to sub-district and district levels due to the distance from home.

Within the district Sangha, while all have an equal opportunity to speak at meetings, women are less likely to take that opportunity. Their not speaking may reflect not wanting to speak. However, female leaders may do so because they feel they have less knowledge about what is going on in the district relative to men because domestic responsibilities restrict their travel. According to a female Sangha leader,

whatever we know, we should speak that, otherwise we have to keep quiet, so we will speak only what we know ... Everybody was given a chance, all spoke. They said whatever problems you have you tell it here, everybody had a chance, but some, like our [male Sangha leader name] they speak a lot, because he interacts with the people in the haadi [village] more. So he knows more about it. Since we are females, we have restrictions to roam around a lot. Since they are men, they can go anywhere at any time.

Female leaders lack of participation at Sangha meetings does not reflect gender norms in the wider Solega community. Solega women are quite vocal and larger numbers are involved in socio-political movements at the village level.

### **Accountability**

The PLA project identified several overlapping ways researchers can make themselves accountable to community organisations and communities in research priority-setting.

### **Feeding back**

PLA project findings on the health problems faced by the Solega people were comprehensively fed back to the district Sangha. A Sangha leader affirmed that doing so is part of 'bringing forward our Solega community'. Where researchers share the results, 'you join hands with us, we will be knowing what the community needs, our leaders will be knowing that. If they [the researchers] give you the report, you can send this further up to the government.' Another affirms,

we can use it [the report] at the policy level, based on the outcome and solution and recommendation by that researcher and then we can use that research and recommendation things to the policy level and we can do the action things.

Sangha leaders viewed feeding back from the PLA project (and research in general) as especially important because it enables them to know what community problems to address and to go to policymakers and health care providers with evidence about the specific needs of the Solega people. They can advocate for the government to address those problems that their organisation cannot. But this cannot happen when results aren't shared with them.

### *Acting on data*

The data generated by the PLA project has been used in two main ways: (1) to advocate for change and (2) to develop and test interventions. During the PLA project, the district Sangha issued complaints to district health officials, taluk medical officers, primary health centres, and mobile clinic units regarding specific instances where doctors and/or Accredited Social Health Activist (ASHA) workers were not regularly visiting villages deeper in the forests of the Biligiriranga Hills. Such complaints were addressed and a field investigator noted that it was important to raise them so that the 'feelings of the people will directly reach the concerned persons.'

At the end of the PLA project, the district Sangha shared its final report with the district government health department and tribal welfare department:

We have given the report when the ministers come, and we have also written to them from our organization and also we have given them petitions in the meetings, so even government has woke up now. And now they have given ambulances which have all the equipments. They can conduct the [baby] delivery on the spot. Lab is also there, every facility is there in it. They have given one [ambulance] for each taluk [sub-district] ... so like this it helped us a lot.

Yet using information on health problems and priorities for advocacy is not enough. Sangha leaders and field investigators felt strongly that interventions or 'actions' to address identified priorities must be designed and implemented:

I feel whatever data we have collected should be used for planning the solutions to the problems identified in the project ... It should not be only documentation it should be action. When it becomes action it will help more.

One leader noted that this was the opinion of 'most of our people' at the deliberative workshop. By using PAR methods, the PLA project did develop and implement an action component. A health navigator intervention was designed and ran for one year using project money. It addressed some of the main problems identified during data collection: poor access to appropriate information about maternal health and government benefit schemes available in general and especially during emergencies. The intervention is now being implemented for indigenous communities in five districts by the Karnataka state government, with technical support from the Sangha and the researchers.

### *Promise keeping*

The researchers made promises to the Sangha that they would conduct subsequent research projects with the Sangha on the Solega community's other health priorities: alcoholism and tobacco control. Taking such priorities forward in subsequent projects is an important way of listening to community voices when the scope of the first project is restricted to focusing on certain priorities.

### *Pitfalls*

In the PLA project, some field investigators who weren't Sangha leaders said that they had not received the project's final report and didn't know what the project had ultimately found. They affirmed that they would have liked to have a copy of the report and suggested that, at the end

of the project, a meeting should have been arranged with all the field investigators to share the results with them.

Beyond feeding back to the community organisation and field investigators, interviewees stated it is also important to ensure that project results reach the wider community. Sharing them with the village Sangha is a key way for them to reach participants in the PLA project, though the extent to which this was done after the PLA project is unclear.

Although project data was acted upon, potentially unrealistic expectations of what could be achieved arose. In the PLA project, one intervention was supported with available funding: the health navigator program. However, field investigators and Sangha leaders said they hoped the program could be implemented beyond Chamarajanagar district, as tribal peoples other than the Solega were facing the same challenges. They also wanted the project to implement more interventions than the health navigator program.

Finally, at the time of data collection in 2019, it was over a year after the PLA project and researchers still hadn't been able to take on the research topic of alcoholism. A Sangha leader raised this issue as a point of concern during interview. Although the investigators are committed and want to do subsequent projects in the Solega community on its self-identified needs, finding a funding source and successfully being awarded funding can be a long and arduous process. It ultimately took over five years in this case. In 2021, the full team of the PLA project in partnership with medical colleges has initiated a multi-institutional research and action center that will study and act on tobacco and alcohol addictions as well as explore ways for organising cessation services for addictions.

## Conclusions

Community engagement is gaining prominence in health research. But communities rarely have a say in the agendas or conduct of the very health research projects that aim to help them. This paper contributes to the limited knowledge base on sharing power with communities in priority-setting for global health research. It provides new evidence on how to share power in priority-setting in the face of structural (funding) constraints. Given the increasing emphasis on undertaking global health research as the co-production of knowledge (Tembo et al., 2021), such evidence is timely and can inform current priority-setting practice. In their work on co-production in global health research, Egid et al. (2021) reiterate that power is pervasive, and that while many researchers are intentional about engaging with power, actions and available tools must be used more systematically to identify and address power imbalances in co-production and participatory research partnerships in order to contribute to improved equity and social justice outcomes. We agree with this finding and, as such, sought to share detailed strategies for sharing power and lessons for how to effectively implement them for use in global health research priority-setting at the project level.

Drawing from the PLA project experience, this paper has presented five strategies for power sharing with community partners and their wider community during and after priority-setting. The strategies are dual scope priority-setting, using PAR as a priority-setting process, establishing budget control and transparency for community partners, making invited spaces into created spaces, feeding back, acting on data, and keeping promises. They share power in relation to five sites of power in priority-setting: scope, level of participation, space, compensation, and accountability (Table 1) (Pratt, 2018; 2019b). The importance of sharing power at these sites is emphasised in the emerging literature on co-production in global health research (Egid et al., 2021; Farr, 2018), though in-depth discussion of particular strategies is lacking at present.

The strategies discussed in detail in this paper are particularly important to impart because they, to a certain extent, bypass existing structural barriers to power sharing with communities in research priority-setting. Such barriers are thus not a sufficient reason for researchers to fail to share power with community organisation partners during priority-setting. We recommend that researchers employ the power-sharing strategies, where applicable, in their practice.



Yet our study further demonstrates that even where actions and strategies are used to address power imbalances in global health research priority-setting, pitfalls will arise that need to be navigated. The PLA case shows that implementing the five identified strategies comes with challenges and limitations that researchers should be aware of. These challenges and pitfalls can potentially diminish the effectiveness of the power sharing strategies, as seen in the PLA case. As such, we also recommend researchers *reflect* upon certain considerations *before* implementing the power-sharing strategies identified in this paper. Before using a dual scope approach, it is important to think about whether priorities are likely to be identified that the research team cannot take forward as part of the current study and, if so, what will happen. If the research team makes promises to take on those priorities after the current study or to find others who can, it will make them accountable for doing so. (This matter is discussed further below.)

Before using PAR as a priority-setting process, it is essential to consider whether disparities in the stage of entry will be created between academic researchers and community partners and/or whether disparities in the level of participation will be created between community partners and the wider community. Before using PAR as a priority-setting process, it is also necessary to consider what to do in the event community partners do not want to use participatory processes to identify community health and research priorities. In the PLA case, a Sangha leader questioned relying on a such processes, but he ultimately agreed to the use of participatory methods. It is thus possible that two ways of sharing power with communities – control and level of participation – may come into conflict, where community partners prefer to undertake priority-setting processes that afford lower levels of participation to themselves and community members.

Before seeking to promote community partner's understanding of the budget, it is necessary to consider whether doing so will reveal aspects of the budget that are not acceptable to community partners and what to do if those budget aspects are beyond researchers' control to alter. In relation to space, it is important to consider how invited spaces that become shared or owned by the community partner could still be exclusionary in terms of who is present and who is heard. Where local power dynamics exclude certain marginalised populations, our experience suggests that creating spaces that problematise these exclusions and bring them into reflective dialogue can be a useful mitigation measure. This is consistent with suggestions that co-construction processes in global health research be reflexive about power (Egid et al., 2021; Mannell et al., 2021). Rather than taking exclusionary local norms head-on, this approach entails entering into a conversation about those norms. The idea is for researchers to ensure such reflective practice spaces are created within research cycles. Over time, we have found that when researchers bring in the idea of reflective practice, this creates spaces for co-evolution both of the community partner and the research partner. In the PLA case, the researchers' presence and constant problematisation of gender within the district Sangha has spurred an alternate women's chapter discussion in the community organisation. In turn, their pressure to act on alcohol and tobacco has pushed the researchers to pursue channels of funding that they were earlier unaware of in order to fulfil their promises to the Sangha and Solega community. As previously mentioned, securing such funding has taken time.

In relation to accountability, a key consideration is whether feeding back project results will occur at several levels (community partner, field investigator, and the wider community). It is also important to consider how to manage expectations regarding whether and how quickly future projects on other community priorities can eventuate. Transparency and honesty about how difficult it may be to find funding sources for future projects, for example, could assist to manage expectations. It can help reduce the likelihood that community partners see academic researchers as not following through on their promises when that is not in fact the case. Additionally, we have found the need to be very clear that the research team is an ally of the community but not the solution itself. This kind of a priori articulation of the research team's wider social position within community dialogues is very important to avoid building unrealistic expectations, e.g. that all issues and interventions identified by priority-setting will be addressed by researchers. Here, it can be useful to make open declarations at meetings and discussions that some of the identified solutions

cannot be implemented/realised by the research team due to being outside their mandate and, at the same time, reinforce, wherever possible, that some of the things that come up in these discussions are indeed rights of citizens and thus responsibilities of the State. Often, there are other local actors who are also State actors (e.g. local government/Panchayat) who can potentially be allies. Making links with relevant State actors is facilitated by working in multi-actor collaborative research teams that include them or other State actors.

We further note that some of the identified challenges may be addressed through subsequent PAR cycles. The PLA project comprised a first PAR cycle between researchers and the district Sangha. Subsequent cycles may be better able to involve the community organisation in the early stages of priority-setting (e.g. writing the funding application), achieve a greater level of participation for the wider Solega community, and shift control of more of or all the budget to the district Sangha. Community partners and community researchers can acquire greater power and greater responsibility as the partnership matures.

Power sharing can, of course, also be aided by addressing structural constraints. Creating spaces for LMIC community organisations and representatives within agenda-setting by funders and adequately resourcing their participation at the priority-setting level are key. Although the strategies we report are meant to circumvent structural barriers, we do not mean to suggest that such barriers should not ideally be removed. At the funding level, research and funding organisations need to include community organisations and members who have been engaged in research projects (as partners, consultants, advisors, etc.) in developing funding priorities and grant structures. They should also be part of grant review panels that determine funding allocations. Pre-award funding to undertake priority-setting with community partners or representatives should be much more common and easily accessed, particularly at the start of researcher-community collaborations.

The case study had several limitations. Members of the Solega community who were consulted as part of the data collection phase were not able to be interviewed because records of their identities were not kept. Ideally, more women, more Sangha leaders from Chamarajanagar and Gundlupet sub-districts, and more non-Sangha field investigators would have been interviewed. The latter were sought to offer more impartial perspectives on whether the community organisation was a good representative of the Solega community. Efforts were made to interview individuals in these categories but finding available interviewees proved difficult.

Given the case study was carried out more than four years after the PLA project started, several interviewees had poor recall of what happened during the project's initial meetings. Where this happened, it was noted in the field notes for the particular interview. It was then taken into account when coding. Parts of interviews were excluded where an interviewee did not remember an event or were coded under the category 'general Sangha processes', where an interviewee described how things generally happened in Sangha meetings rather than what had happened in the PLA project meetings with researchers.

Since Sangha leaders and field investigators were not involved in the research process, data were not interpreted from an Adivasi lens. Our findings thus lack an Adivasi gaze, which is an epistemic limitation of the study. The decision not to involve the Sangha in the research process of this case study was made because, in the experience of the two co-authors who work with them, the Sangha are less interested in being involved as co-researchers in research that is pre-dominantly a global health academic inquiry. They want to participate as researchers when studies are directly related to improving the well-being of the Solega, which is their main objective. Given this circumstance, we sought to partially mitigate the effect of their lack of involvement by soliciting Sangha leaders' feedback on the first draft of this paper. We also chose not to involve the two co-authors who were part of the PLA project in the data analysis process so that their voices and the Sangha's voices were not unequally represented in the study.

Future research should capture the perspectives of more community partners and members who have been engaged in health research on ways to share power with them in the face of structural constraints. Additional case studies should be done to generate a larger knowledge base on such power

sharing strategies – namely, more strategies in relation to the sites discussed in this paper and strategies in relation to other sites of power. Future research should also expand the knowledge base on the structural factors that obstruct power sharing, e.g. normative barriers in relation to research culture, social norms in particular contexts, and institutional barriers created by funders and research institutions. In the Indian context, this entails exploring how caste affects power sharing in research (Sabharwal et al., 2020). Finally, research is needed investigate how researchers and community partners might navigate the pitfalls and challenges described in this paper. Doing so is essential to implementing the power sharing strategies as effectively as possible.

Ultimately, despite this case study's limitations, we hope that the strategies and lessons presented in this paper are useful to global health researchers seeking to share power and decision-making with community partners and community members in priority-setting.

## Notes

1. In relation to the site of power, 'level of participation', Egid et al. (2021) emphasise the need to establish governance structures and processes that share decision-making with community partners and to enable community partners to set the agenda for the research and choose which approaches to implement. In terms of 'compensation', Egid et al. (2021) identify co-researcher compensation, both economic and in other forms (recognition and prestige in their community, learning new skills), as an action to address power inequities. In relation to 'space', Farr (2018) mentions that using 'community spaces' encouraged people who may be deemed 'hard to reach' to get involved and contribute their experiences, skills and resources. Farr (2018) has further developed a series of questions to support practitioners considering different power dynamics within co-production processes. These include questions related to the diversity of who from the community is involved and whether changes are made due to their perspectives in a given co-production process. The former relates to the site of power 'diversity' and the latter relates to the site of power 'being heard'.
2. Some current and former funding schemes for global health research support seed funding to put together a full grant proposal or an inception phase for funded projects but these are not common and may emphasise engagement with policymakers as opposed to engagement with marginalised communities and organisations that represent them (Pratt & Hyder, 2018a, 2018b).
3. There are indigenous tribes in Chamarajanagar district other than the Solega, but 90% of indigenous people in the district belong solely to the Solega tribe.
4. A minor change was made to the paper based on the comments received from the Sangha leadership. Specifically, the following sentence was added to the Space sub-section: 'Within the district Sangha, not speaking may reflect not wanting to speak.'
5. In choosing this topic within the funding call, the principal investigators had done so with the Solega people in mind, drawing on their experience as doctors serving the community:

'when you're talking maternal health or when you talk children (yeah) it's a community issue. So the minute you say pregnancy, you say childbirth or you say children, even the men have an opinion and even they are interested so I realised that maternal health was something that they would engage, come forward as a community.'

Had the PLA project focused on a disease like TB, the researchers thought they would have struggled to get community participation because it's a disease and the Solega people would assume that only a small population in their villages would actually have it. The underlying causes of poor access to maternal and child health services were the same as other issues facing the community, so the researchers also felt addressing those causes would be attractive to the Solega people.

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this paper. However, we believe that the nature of their involvement was not of a kind to raise concerns about the validity of study findings.

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## Data availability statement

The data that support the findings of this study are available from the corresponding author, BP, upon reasonable request.

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