Women attend a meeting organised by an NGO for influential members of the local community in which reproductive health issues are discussed; with the aim of their disseminating this information within their community.
Nepalganj, Nepal. Peter Barker | Panos Pictures

A RESOURCE GUIDE FOR COMMUNITY ENGAGEMENT AND INVOLVEMENT IN GLOBAL HEALTH RESEARCH

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1 COMMUNITY ENGAGEMENT AND INVOLVEMENT:
# PEOPLE, PROCESS AND POWER

Across the breadth of global health research now funded by the National Institute for Health Research, there is a common cause that binds diverse projects together. The shared aim of the global health research portfolio is to leverage the research capacity of UK and LMIC based institutions to directly impact on the health and well-being of vulnerable and marginalised populations within Overseas Development Assistance eligible countries.

In line with the call to "Leave No One Behind" within the Sustainable Development Goals, this funding mandates that all projects include Community Engagement and Involvement (CEI) as a core component of the research strategy, planning, implementation and evaluation process.

A peer educator talking to children at a community centre in the Democratic Republic of Congo.
Giacomo Pirozzi | Panos Pictures

While the social determinants and other influencing factors of these health issues will vary widely according to cultural and geographic contexts, all CEI work will require a deeper understanding of the intersecting experiences of marginalisation and exclusion of those most affected if they are to have a 'transformative impact' (1).
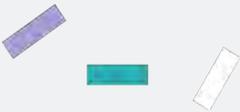
The first thing to understand about 'community engagement' and the broad goal of 'involvement' in global health research is that this is not a new way of thinking (2-6).

The meanings of community engagement, and the assumed potential of the approach to improve the health and well-being of poor and marginalised populations, has been at the heart of debates over public health planning, health systems development, and the tensions between horizontal versus vertical approaches to international public health interventions from the late 1950s.

What this means for those seeking to develop 'innovative' community engagement and involvement strategies within interdisciplinary health intervention research projects in 2019, is that there is a substantial pool of already existing knowledge on what has worked, and what hasn't (7-10).

In the decades leading up to the 1978 Alma Ata Declaration of "Health for all by 2000" (11), public health professionals, not-for-profit, private health providers and governments in both the North and South tested out new methods of community engagement.

Building on these innovations in community-centred health care, which ranged from the "barefoot doctors" in China, to the work of the Christian Medical Commission, to social medicine movements in Latin America, the Alma Ata Declaration enshrined community participation as a guiding principle of future primary health care efforts.

While vertical biomedical interventions* have nonetheless dominated the practice of global health since the late 1980s (2), there has been in recent years a renewed push for increased power-sharing, upwards accountability, and a more reflexive and deliberative way of working towards 'health for all' (12-19).

This movement towards greater horizontality in planning and decision-making within international public health efforts is – in part - a response to the growing awareness of health inequities and social determinants of health.

Community engagement is an umbrella term. It is used to describe a wide variety of approaches that in practice vary from tokenistic forms of inclusion in health research decision-making, to de-centred participatory planning, knowledge co-production and resource sharing (8-9).

Doing community engagement can be messy. There is no recipe book to follow, or model that can be brought to scale. It does not *de-facto* generate equitable health outcomes or shifts in structural inequalities (7). However, if it is done with an openness towards new ways of relating across differing positions of power, and new mechanisms of knowledge production within the otherwise hierarchical world of global health research, it has the potential to be a positive force for change.

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*By "vertical biomedical interventions" I refer to the tendency in global health, and formerly international public health, to intervene according to biomedically-specific research objectives, government mandates or the agendas of private philanthropic funding bodies (e.g. to combat HIV/AIDS, Malaria or Tuberculosis, versus spending on public health infrastructure or primary health care services that meet a range of public health needs). See Randall Packard, A History of Global Health: Interventions into the Lives of Other Peoples (1).

2 PEOPLE-CENTRED METHODS: WHO IS 'THE COMMUNITY', WHAT DO THEY NEED, AND HOW DO YOU GET STARTED?

One of the most challenging aspects of community engagement is to identify 'the community'. A common error in public health research and global health project implementation has often been to identify 'the community' in purely geographic or place-based terms (e.g. health clinic or hospital catchment areas, rural village or urban municipality boundary lines). However, geographic boundaries and social forms of belonging and identity-making do not necessarily overlap. These past decades of community engagement work have generated substantial knowledge on just how complex, dynamic, and heterogeneous social groupings can be (7, 14, 20-21).

Furthermore, we know a lot more about how participatory methods necessarily create tensions in the 'in-between spaces' of differently situated actors with differing levels of power (22, see also this blog post), including the researchers themselves. The act of opening up the decision-making processes of health research to include individuals and groups who might have different, and potentially competing, ideas about what their communities need is just one facet of the negotiations that will necessarily emerge from involving communities in more meaningful ways.

Refugees watch a performance in Dosseye camp by people living with HIV who use theatre to educate about the disease, address stigmatisation, old myths about the disease and the need to seek medical treatment. Dosseye, Chad | Robin Hammond | Panos Pictures

In light of these complexities, we recommend using an 'empowerment framework' and 'learning by doing' approach. What this means in practice is that instead of a target-oriented, top-down approach to getting specific community members to engage as 'beneficiaries of programs with the objective of improving health services delivery' you 'mobilize community members to participate in decision-making, planning, implementation, and evaluation of programs' with the aim of empowering marginalised groups to have greater control over the decisions that most affect their lives (15 p.25, see also 16-19).

'Learning by doing' requires building in reflexivity and flexibility into the design of project activities, therefore creating the necessary space in the timeframe of the project to step back and reflect together with community members about what is working, what isn't, and how to address shared challenges.

A good place to get started to better understand what these approaches look like in practice are both EQUINET's "Participatory Action Research in Health Systems: A Methods Reader" handbook, and ActionAid's "Transforming Power: Participatory Methodologies Forum" report. Both offer helpful guidance and a range of potential tools and methods that can be used from inception period through to the evaluation and co-production of research findings.

In addition to these published materials, we suggest learning more about the "ethics framework for community engagement in global health research" currently being developed by Dr. Bridget Pratt at the University of Melbourne (**see Box 1**). Thinking through ethics concerns in an iterative, reflexive way, together with those individuals and groups being directly targeted by health research, is one concrete way to encourage power-sharing.

Beyond these starting points, there exists a much broader range of 'communities of practice' and published reflections on participatory and community engagement methods in health and development (23-26).

Here are a few links we recommend for inspiration, ideas, resources and support.

- **Participatory Methods** – The IDS hosted website for 'people working together around the world to generate ideas and action for social change'
  https://www.participatorymethods.org

- **COPASAH** – Community of Practitioners on Accountability and Social Action in Health
  https://www.copasah.net

- **Participedia** – A global community sharing knowledge and stories about public participation and democratic innovations
  https://participedia.net

- **Participate** – The IDS hosted website for the Participate project which focuses on mobilising 'knowledge from the margins for the SDGs'
  http://participatesdgs.org

- **Transformative storytelling for social change** – this site includes handbooks, case studies and supportive resources to use transformative storytelling within the context of a community-engaged research practice
  https://www.transformativestory.org

- **MESH** – an online network for people working in community engagement in global health
  https://mesh.tghn.org

Box 1 Sharing power when setting research agendas

Extracted from "Giving Communities a Voice", by Bridget Pratt, University of Melbourne, bridget.pratt@unimelb.edu.au

What's needed to give marginalised communities a voice in agenda-setting for health research projects? Recent research shows several key considerations apply before, during and after agenda-setting.

Before setting an agenda, several ethical considerations apply. For example, researchers and their partners need to assess whether the foundations for shared decision-making exist or can be built with community members. Building these foundations can take time, and may not align well with current short-term funding models. During agenda-setting, researchers and their partners need to employ strategies to share power with disadvantaged and marginalised communities in areas like leadership, space, level of participation and facilitation amongst others.

Sharing power means that locally-based researchers, community organisations and key informants are among those initiating and leading agenda-setting. It's important to undertake agenda-setting in physical locations that promote the presence and voice of marginalised groups. As one community engagement research affirmed, the choice of location can radically influence the outcome of engagement efforts:

> " If you hold (a meeting) in the health department building, there's a particular set of behaviours and languages that are associated with that building, and people who dominate those behaviours and languages will dominate the meeting…[when] we did a meeting in the traditional meeting house and we got people from the ministry and the World Bank to go there…it completely changed the dynamic. "

To encourage community members' participation, sharing power means involving marginalised groups as decision-makers, not just as part of a consultation process. So researchers, partners, and community members deliberate together, integrating their knowledge to generate the final research objectives. By way of contrast, consultation is characterised by community members being invited to give their input to agenda-setting, but having no assurance it will be used. To facilitate deliberations, a certain approach is required to ensure the least powerful voices get as much opportunity to be heard as the most powerful. Explained one public health researcher:

> " You can set people up to be even further disenfranchised in that sort of process where you assume they've been engaged in the design of something, but in fact they've just been silenced by internal power dynamics within a group. "

After agenda-setting, it is important to demonstrate respect and accountability to marginalised groups by feeding back research topics and goals for their comment, and by acting on the final research priorities. The goal of inclusive and meaningful citizen engagement in priority-setting demands an iterative and deliberative approach to understanding, and therefore mitigating, unequal power relationships in global health research. The attentiveness to power and inclusion is key to moving beyond shallow, or tokenistic forms of community engagement in global health research.

Based on this research, an ethical toolkit is being developed to assist researchers and their partners (community organisations, policymakers, health care providers) to design priority-setting processes where power is shared with communities. For the most up-to-date version of the toolkit please contact Bridget directly. The current version consists of three worksheets to be completed by researchers and their partners in collaboration, and a companion document.

The global health research portfolio of the NIHR calls for interdisciplinary research consortia to tackle health issues for which there is a potential for 'transformative' outcomes. With thematic areas of work that range from health policy and systems-focussed interventions, to Neglected Tropical Diseases (NTDs) and Antimicrobial Resistance among others, a commitment to community engagement and involvement is a prerequisite to achieving measureable impacts.

As one example of this commitment, the NIHR Research and Innovation for Global Health Transformation (RIGHT) programme foregrounds a CEI approach in its portfolio which includes research on severely stigmatising skin disease, epilepsy and infection-related cancers. It is clear from the paucity of existing literature on community engagement in LMIC specific research on these specific health issues that there are gaps in knowledge and practice to be filled (27,28). For the broader category of mental health (NIHR RIGHT call 2) there is more experience to build on, though much of it derives from models of community engagement first established in High Income Country (HIC) settings (for exception, see 29–31). Across the NIHR's Global Health Research portfolio it is clear that standardised practices of community engagement borrowed from HIC contexts will not be sufficient.

To effectively tackle health issues shaped by culturally, geographically and health-systems specific experiences of stigma, marginalisation and exclusion, contextually-grounded approaches will be needed. To generate a CEI approach for these 'stickier' health concerns, it will necessarily be more challenging to find ways to integrate 'knowledge from the margins'.

Inside the maternity ward, Dr Veena Kundra is Shivpuri District Hospital's only gynaecologist. Since 2004 the number of institutional births in health facilities in Madhya Pradesh has doubled. Safe delivery and new born care is reducing the number of women and children who die as a result of child birth – and infant deaths have reduced by 14% since 2004.
Nick Cunard / Department for International Development | CC BY-NC-ND 2.0

In Cyril, Smith, Possamai-Inesedy and Renzaho's systematic review on the role of community engagement (CE) in improving the health of marginalised populations, they found the greatest impact where these approaches '...included incorporating the voice and agency of indigenous and ethnic communities in the research protocol, real power-sharing, bidirectional learning, and needs assessment' (7, p.7).

Door-to-door community awareness campaigners educate the residents of a local slum about tuberculosis (TB) in Chennai (Madras), Tamil Nadu State, India.
Atul Loke | Panos Pictures

By contrast, those that did 'not improve health behaviours were affected by lack of community involvement in formative research and inadequate needs assessment' (Op. Cit). Key to the successful examples identified in this systematic review, and those reported elsewhere, is the prioritisation of a deliberative approach. To be 'deliberative' requires repeated efforts to check, test, and readjust the assumptions that the research team has brought with them into their project design against the lived realities of those people at whom their research is meant to benefit.

This might mean multiple rounds of community consultation that are built into the decision-making process of the research programme, leaving open the potential of changing tack or adjusting the research approach in accordance with what emerges from the consultation process. This could include consultations with community members subdivided according to the particular forms of marginalisation and exclusion relevant to the health issue (rather than lumping people associated with one geographic space all together). Whatever the degree of 'robustness' of the CEI approach that is taken, it will require an investment of time and project resources. Perhaps most importantly, it requires a human resources investment. Community engagement works best if within the interdisciplinary team there are sufficient team members that have the necessary 'soft skills' to do relationship-building work and to navigate complex relationships of power. One good example of the deliberative approach in action has been the work of the Kenya Medical Research Institute Wellcome Trust Research Programme centred on the Kilifi County Hospital and the surrounding communities of 280,000 residents (32,33). This research group embedded multiple cycles of community consultation and adaptation in their research, which created multiple opportunities for the project to adapt in response to the needs, values and demands of community members (see **Box 2**).

Box 2 Deliberative approaches to community engagement: A case study from an international collaborative health research programme in Kenya

By Vicki Marsh, Noni Mumba, Salim Mwalukore, Sassy Molyneux and Dorcas Kamuya

At the Kenya Medical Research Institute (KEMRI) Wellcome Trust Research Programme on the Kenyan Coast, many studies focus on a geographically defined 'community' of around 280,000 people living around the County Hospital where the programme is based. Over time a multifaceted platform of engagement activities has been developed, recognising the complex, layered and dynamic relations and structures within this population.

Deliberative engagement approaches are part of the platform, specifically developed to bring diverse community voices into ethical and practical policy-related debates about whether and how more complex, often novel and sometimes sensitive research or research-related activities should be planned and implemented in this setting.

To date, deliberative engagement methods have centred on a range of research-related policies and issues, including sharing incidental genetic findings; study benefit sharing; research data sharing and governance; the use of routine clinical data in research; involving children and young people in research; and research and clinical sample bio banking at the centre.

In developing deliberative approaches, we draw pragmatically on three core literatures and fields of practice, including practical applications of deliberative democracy in the global north, the related literature on deliberative ethics and the methodological grounding of constructivist and critical forms of social science. Core lessons from our experience concern processes of sampling, engagement and analysis.

We use purposive sampling approaches to include diverse voices, relevant to the issue at hand and sensitive to marginalized positions. In relation to engagement processes, carefully developed (piloted) approaches that build mutual respect, manage group dynamics and ensure that all views and underlying reasoning are heard are foundational.

In particular, we build tailored participatory approaches that draw on co-learning to promote wider understanding of core issues, and ensure reflexivity around researchers' own ethical values. For example, during the bio banking engagement, it was important to show participants the freezers where biobank samples are stored and the measures used to anonymize these.

In discussing study benefits, we avoided 'ring fencing' discussions by introducing terms such as 'undue inducement' and 'exploitation' from the research ethics literature, but explored and then drew on participants' views on any limits that should be placed around levels of study benefits.

For more complex and novel areas, it has been critical to allow for repeated discussions to give time to explore and reflect on new areas introduced; we have worked with a series of small group discussions and larger workshops followed by small group discussions.

During analysis, we've used summary analysis charts to capture forms of individual reasoning, including changes over time, in and across groups, supplemented by traditional software supported inductive framework analysis to draw out meaning from the data.

Analysis and interpretation of the data is a team process, building normative arguments by drawing on the wider literature, including relevant areas of social science and bioethics. There are many challenges in this process. Some are practical, such as finding the skills to develop and run these activities, blending skills in ethical analysis and qualitative and participatory research approaches; all of which are time consuming and require a funding commitment.

There are also important challenges in bringing the outputs of engagement to bear on policy in practice, given the complexity of policy development. However, our experience has been that the careful mapping of diverse views and values across a community in relation to well explored ethical issues provide a strong basis for a normative analysis that has the depth and flexibility to be carried forward throughout a policy development process.
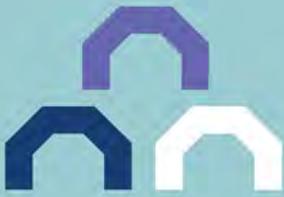
This reader in community engagement concludes with some thoughts on power and accountability in global health interventions. The emphasis given by the NIHR to a community engagement and involvement approach is absolutely key to achieving the "Leave No One Behind" agenda. We know that in spite of over six decades of concentrated investment in global health, the seemingly intractable problem of health inequities remains unsolved (34). As health researchers, it is a moral imperative to seek meaningful engagement with the very people whose lives this new knowledge seeks to transform.

With both the Sustainable Development Goals 'Leave No One Behind' agenda, and the World Health Organization's revamped commitment to a Universal Health Coverage and so-called Alma Ata 2.0 agenda, it is crucial that those involved in global health research recognise and grapple with the unequal levels of power and the dynamics of exclusion that have for so long defined the field (see **Box 3**).

The emphasis given by the NIHR to a community engagement and involvement approach is an important priority, alongside many other allies working in the broad field of global health, towards more equitable and ethical practices of research. The gold standard should be a self-reflexive way of working. If the global health research community does not hold itself accountable to the 'target groups' it seeks to understand, or look for ways to creatively leverage collective influence to push for change at higher levels of power, then this work risks compounding the very health inequities that are the subject of investigation.

Tin Naing Soe, a volunteer health worker explaining to residents at the Kwali Camp about importance for malaria testing. Kwai Camp residents live and work on a rubber plantation where malaria is spread and severely affects the population. Mayan Chaung, Mon State, Myanmar.
Vlad Sokhin | Panos Pictures

Box 3 How to make a diagnosis of marginalisation in the health sector

Extracted from "How to advocate for an 'Leave no one behind' approach in the health sector" by Erica Nelson, on behalf of the Swiss Agency for Development and Cooperation

By definition, to be marginalised is both a cause and an effect of poor health; that is, being in a state of poor health (broadly defined) can lead to social exclusion, economic hardship and political marginalisation; and social exclusion, economic hardship and political marginalisation are contributing factors of ill health. Health systems are highly politicised social systems.

Across all levels and activities within a health system, social rules and norms contribute to different levels of exposure to disease, or vulnerability to ill-health, and to different levels of access to preventive, curative and rehabilitative care.

Intersecting patterns of social difference - e.g. economic status, geographic location, gender, religion, ethnicity, race, disability, age, health status, educational status – play a substantial role in determining both individual and group means to achieve good health, to prevent ill-health, and to treat ill-health.

1 Disaggregated data collection

The first step towards a better understanding of the scope and nature of marginalisation and exclusion within the health sector is to begin to build in disaggregated data collection at the planning, implementation and evaluation stages of a given health research intervention.

Disaggregated health data – by sex, age, socio-economic status, ethnicity, education status among other possibilities – can help to identify where patterns of social difference contribute to poor health outcomes.

Subsequently, this data can help to ensure that community engagement and involvement activities are reaching out to, including, and better understanding those who are most marginalised and excluded.

The World Health Organisation is building up a health inequalities monitoring database on a country-by-country basis, which can allow for a broad brushstrokes understanding of patterns of marginalisation in health systems.

However, this data is not of sufficient detail when it comes to intersecting patterns of marginalisation and exclusion at sub-national, regional or local level.

It will not be feasible to address the whole range of possible social identifiers of difference, but depending on the nature of the intervention a good place to start is to pick at least two or three categories of marginalisation relevant to the project design and track change over time across these categories.

2 Gender and intersectionality analysis

The starting point of a gender and intersectionality analysis is to understand that health systems – that is the nationally-specific contexts in which the NIHR's Global Health Research will be carried out - are not 'gender neutral'.

Health systems are defined by unequal and assymetrical power relationships, of which gender is one important category of difference.

Gender analysis, and the related endeavour of intersectionality analysis (which accounts for intersecting patterns of social difference such as race/gender/education status), is recommended as an integral part of health research interventions at all stages of the process (36).

With regards to CEI, this means critically examining all aspects of a proposed strategy to ensure that marginalised voices are heard, potentially within the the context of separate and safe spaces.

Box 3 continued

3 Stakeholder analysis and accountability mapping

Accountability is increasingly being instrumentalised as an intervention to improve health outcomes. To understand how relationships of power can constrain or open up pathways to change in global health, it is necessary to map out the key stakeholders of a given health intervention and the relationships of accountability that structure their interactions (37).

For example, one common approach to improving health outcomes at the local level is the use of a "community scorecard" to identify, track and remedy issues of poor or inadequate service provision. For a better understanding of what one approach to a community-scorecard process might look like, see the "Enabling Community Action for Maternal Health" photo story by Vaishali Zararia, Renu Khanna and Sophie Marsden. This photo story describes a collaborative project between three non-governmental organisations (SAHAJ, ANANDI, and KSSS) in Gujarat, India, that worked together to promote community action and social accountability for improved maternal health services.

This approach runs the risk of putting increased pressure on the least powerful actors (e.g. community health workers) who cannot control the resources they are allocated, or the support they are given to perform their roles. A stakeholder and accountability mapping approach, using the Brinkerhoff matrix as a starting point (38), can help to begin to identify how relationships of power play out at multiple levels of health policy making, health resources allocation, and within public health governance structures.

While the NIHR global health research funds are not necessarily targeted at accountability-specific interventions (e.g. research that aims to improve public health governance and the responsiveness of health duty-bearers) it is worthwhile to consider what community engagement and involvement work is being done by front-line health rights activists (Box 4).

The more overtly politicised and political work done by these activists is useful for what it can tell us about the relationships of power that structure and shape how marginalised groups interact with public health services and health systems, and how their voices (and by extension, their needs) are easily silenced (34-35,37).

Community health workers demonstrate the use of mosquito net in Kisumu, Kenya.
Sven Torfinn/WHO | Panos Pictures

Box 4 Health Accountability and Adaptive Action Cycles:
Learning from the Centro de Estudios para Equidad y Gobernanzo en Sistemas de Salud (CEGSS)

One great example of an 'Adaption Action Cycles' approach to community engagement in public health is that done by the Centre for Health Systems Equity and Governance (CEGSS) based in Guatemala.

CEGSS uses 'action-reflection-action' cycles to allow them to continuously check-in and reassess how their strategic approach to improving indigenous health equity is working, and perhaps more importantly, how to respond to the push-back from health authorities or conflicts that their articulation of health rights can generate.

In contrast to the ways in which SMS technology is more commonly used to collect data in geographically dispersed settings, the CEGSS teams use teams of trained local 'health defenders' who listen and collect complaints related to poor health services, denial of treatment and verbal abuse (all common issues for indigenous populations in Guatemala) and then logs this according to a detailed classificatory scheme via SMS. In this way, the CEGSS team can geo-reference complaints and build a more detailed picture of where health rights are at greatest risk.

Once there is sufficient data to collate and then present to health authorities, they move their demands higher up the decision-making hierarchy.

Based on the response from health authorities, they return to the communities involved and reflect on which actions are producing the desired results (e.g. improved health services) and whether they need to seek out new alliances, different points of leverage, or collect alternative forms of data.

As they write, 'from our initial technical approach to accountability through supporting implementation of a legal mandate for participatory monitoring and planning of health services, CEGSS' support has evolved to focus on adaptive cycles of accountability action.

Through close engagement with the indigenous citizens, communities, and grass roots organisations on the front lines, we have observed that it is not the information generated by monitoring that influences accountability, but the process through which citizens gain and confront power.

With a central focus on activating citizens' latent power and their power as a group, reading the response in the political context and adjusting strategies accordingly guides adaptive cycles of gathering evidence and advocating with public officials.'

The community engagement links, resources, references and learning offered here are an attempt to give research teams and funding applicants a starting point for thinking critically about the assumptions and expectations they might carry with them as they embark on what might be a new way of working, or a well-honed way of working that is being tested in a new geographic context.

The good news is that beyond something as static as this piece of paper, there are lots of already existing networks that applicants can tap into as they begin their work. Do not hesitate to reach out – there is much to be learned.
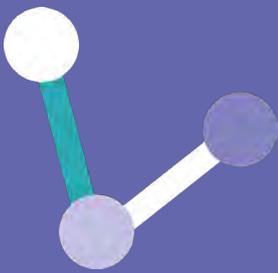
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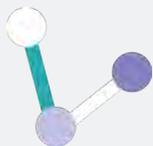
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