

Technical Brief 3: Stakeholder engagement for gender-responsive health research

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Stakeholder engagement (SE) refers to the involvement of impacted communities and individuals as partners in—rather than merely subjects of—research. Or, in other words: the active, iterative process of “soliciting the knowledge, experience, judgment and values of [selected] individuals... represent[ing] a broad range of direct interest in a particular issue.”¹ In the context of health research, there are a diverse range of SE models, ranging from consultations (requesting stakeholders input at specific moments in the research process), to co-production (engaging stakeholders as decision-makers throughout the research process).² The more equitable the partnership, the less control academics may have over the research process, timeline and results—but the greater the potential for transformative impact.

Too often, scholarly research falls short of catalyzing positive changes or what we might call “real-world impact”. Notably, health researchers concerned with the gap between academia and practice are increasingly turning towards **SE as a mechanism for more effectively mobilizing health research for improvements in health outcomes, and in doing so, strengthening accountability to impacted communities.** Indeed, a growing evidence base indicates that SE is key to leveraging academic research for health service, program and policy change³ (and vice versa: that health-care providers' engagement with research, can also improve health outcomes⁴). This is because local stakeholders generally (a) prioritize outcomes that impact their and their communities' wellbeing (in comparison with prioritizing, for example, academic impact through publishing in peer-reviewed journals); (b) can communicate research findings to non-academic audiences; and (c) have unique insight into which particular data gaps—if closed—would have the greatest potential for impacting health outcomes.⁵ To be sure, it is important to note that stakeholders are not a monolith and the insights produced out of SE will vary depending on how and which types of stakeholders are engaged: patients, for example, may have a different perspective than policy-makers on what research questions are most relevant, or how research should be mobilized for impact.⁶

To this point, when engaging a *diverse* set of stakeholders, SE can also support more inclusive research. As noted in previous Technical Briefs,⁷ health research has a long history of excluding women, girls, and other marginalized communities from participating in research, both as subjects (resulting in biased research findings, often skewed towards the ‘neutral male’) and as partners (with

¹ [Deverka et al. 2012](#)

² [Goodman & Thompson 2017](#)

³ [Ibid.](#)

⁴ [Boez et al 2020](#)

⁵ [Tembo et al. 2021](#); [Tindana et al 2007](#); [Martinez et al 2018](#); [Wakunuma et al 2019](#)

⁶ [Cornish 2014](#)

⁷ [Berryhill & Fuentes 2021a](#); [Berryhill & Fuentes 2021b](#).

decision-making power in health research still largely in the hands of an elite minority). This exclusion has resulted in data gaps; misdiagnoses; ineffective services; and harmful research practices.⁸

Engaging a more diverse set of stakeholders in health research—such as impacted communities, rights advocates, and community-based civil society organizations (CSOs)—can help ensure that both the design and implementation of research is more considerate of the needs and priorities of marginalized communities.⁹ For example, a recent study by UNICEF on Sexual Exploitation and Abuse in the Democratic Republic of the Congo began by consulting impacted communities to identify how women and girls discuss and understand sexual exploitation and abuse, in order to then develop research tools with the appropriate language for investigating the barriers to reporting sexual exploitation.¹⁰ Likewise, consultations with community-based CSOs can help shape research questions that respond to the needs of marginalized communities, rather than academic trends. For example, the Sexual Violence Research Initiative (SVRI) develops and validates research agendas based on rigorous consultations with diverse partners, especially women’s rights organization. In doing so, the SVRI is able to financially support and advocate for research projects that more directly respond to the real needs of frontline responders and on-the-ground advocates.¹¹

Given these reasons, SE is not only critical for more impactful and inclusive health research—but also for *gender-responsive* health research. Gender-responsive health research seeks to capture the ways in which gender and other differences and power dynamics interact with health determinants.¹² However, to do so, researchers must engage with those experiencing those differentiated impacts. Furthermore, **gender-responsive health research is driven by the explicit goal of advancing gender equality.** Such a goal cannot be achieved when research is limited to academic audiences. As outlined above, engaging with stakeholders helps connect research findings with real-world impacts—whether that be through improving services for those discriminated against based on gender and other intersecting dynamics, or raising awareness around gender differentiated health outcomes.¹³

Who are potential stakeholders for gender-responsive health research?

Different stakeholder groups will be relevant for different research initiatives, depending on the research topic, location, and projected scale of impact, among other factors. However, for gender-responsive health research, there are several key groups that should be included in any initial stakeholder mapping.

- 1. Impacted communities.** This may include patients, target beneficiaries, or the public more generally. When considering how to engage impacted communities, it is important to (a) work with a trusted local stakeholders who better understands which sub-groups are more marginalized and thus at risk of being overlooked in research; (b) consider ways in which working with marginalized groups may help visibilize their perspectives, but also how such

⁸ [Gupta et al 2019](#); [Criado-Perez 2019](#)

⁹ [Campbell 2019](#); [Tindana et al 2007](#); [Martinez et al 2018](#)

¹⁰ [UNICEF Social Sciences Analytics Cell \(CASS\) 2021](#)

¹¹ [SVRI.org](#)

¹² [Berryhill & Fuentes 2021b](#)

¹³ [Cookson & Fuentes 2021](#)

visibility may also create additional risks of harm; and (c) analyze potential barriers to participation impacted communities may face, and brainstorm—with communities—when and how these barriers can be addressed.

2. **Rights advocates.** By rights advocates, we refer to community leaders or other civil society actors that are dedicated to advancing human rights and social justice amongst marginalized groups. These individuals can be key partners for gender-responsive health research, and help connect research to broader agendas for social, economic and political change.
3. **Civil society organizations.** This can include both community-based CSOs, or larger national or international organizations representing the needs and rights of impacted communities. When engaging with CSOs, research partners should consider ways to compensate them for their time and expertise, recognizing that many smaller organizations, especially grassroots women’s rights organizations, are chronically underfunded, despite their often significant contributions and leadership around gender equality themes.
4. **Service-providers.** For health research, service-providers may include government or non-government entities that are providing relevant health services. Service-providers can provide a unique perspective on health issues, speaking both to the needs of service users as well as to the limitations and constraints faced by service-providers.
5. **Policy-makers.** The inclusion of policy-makers can be especially useful for connecting research findings to active policy agendas, or using research to catalyze new policy agendas. However, engagement with policy-makers may also face certain limitations: such as political sensitivity and ever-changing political contexts and thus priorities.

How are IDRC’s Global South AI4COVID partners engaging with local stakeholders to support more gender-responsive health research?

- Makerere University’s research project, **End-to-end AI and data systems for targeted surveillance and management of COVID-19 and future pandemics affecting Uganda (COAST)**, seeks to (a) advance more usable and equitable AI-related datasets; (b) develop AI-driven tools for improved patient care and management; and (c) evaluate COVID-19 interventions for targeted government responses.

Recognizing the importance of stakeholder engagement, the COAST project’s steering committee is composed of senior government officials as well as representatives from the Kampala City Council Authority (KCCA), Uganda Communications Commission (UCC), and Makerere University’s Infectious Diseases Institute. These partnerships have helped facilitate **access to COVID-19 related data**, while also **bringing together diverse perspectives** to reflect upon the project’s progress and **problem-solve together**.

For example, over forty spoken languages (with varying accents) are spoken in Uganda. This presented a challenge to the COAST team’s attempt at collecting audio and textual data from community-based radio stations. However, through problem-solving with the project’s steering committee, the team was able to identify effective techniques for more accurate transcription, which will help **contextualize the collected data** based on different regions.

- The Centro Interdisciplinario de Estudios en Ciencia, Tecnología e Innovación’s research project, **Argentinian Public Health Research on Data Science and Artificial Intelligence for Epidemic Prevention** (ARPHAI), seeks to investigate and pilot new models to leverage electronic health records for (a) supporting early detection of the coronavirus and other diseases, (b) improving data collection in vulnerable communities, and (c) supporting with the Argentinean Ministry of Health’s strategies for managing and containing the coronavirus disease.

For the ARPHAI team, engaging with stakeholders has been key for **developing more inclusive data systems**. The team developed working groups to explore methods for safely including data on individuals with nonconforming gender identities in electronic medical record systems. These working groups included private and public sector experts, including representatives from the Ministry of Health and the Ministry of Women, Gender and Diversity in Argentina.

Thanks to this multi-sectoral collaboration, the ARPHAI team has developed recommendations to develop a data model which integrates nonconforming gender identity categories, and has documented this proposal considering local and international experiences. These recommendations are **now being considered for the Ministry of Health’s Integrated Health History system**—illustrating a significant advancement towards fulfilling the aspirations of the country’s 2012 Gender Identity Law. The ARPHAI team now plans on ground-truthing these proposed recommendations with impacted communities, including CSOs representing the LGBT+ community and researchers specialized in trans-gender studies.

- The **Africa-Canada Artificial Intelligence and Data Innovation Consortium’s (ACADIC)** works across 9 African countries: Botswana, Cameroon, Eswatini, Mozambique, Namibia, Nigeria, Rwanda, South Africa and Zimbabwe. In each of these countries, the ACADIC team has engaged closely with local community leaders and policy-makers to **co-develop research questions and solutions relevant to local needs**.

For example, when reviewing data on COVID-19 hotspots in Cameroon, stakeholders and researchers recognized an irregularity: communities with a higher percentage of internally displaced persons were not categorized as COVID-19 hotspots—which was concerning, given that healthcare resources largely depended upon hotspot identification. **As members of these communities, stakeholders knew that this statistic was not representative of their local reality**. Further investigation illustrated the cause of this misrepresentation: data on internally displaced refugees (mostly women and children) was largely missing.

Based on this finding, ACADIC worked with community leaders to co-develop a solution: they developed awareness raising campaigns and volunteer networks to facilitate greater access to COVID-19 testing centers. Reported rates of COVID-19 for these communities began to increase, resulting in the community being identified as a hotspot. This intervention had **significant policy and resource implications for impacted communities, such as being prioritized in the national vaccination rollout strategy.**

Challenges to stakeholder engagement in health research

1. **Time.** Successful partnerships require trust. However, trust-building takes time—especially if project partners are geographically dispersed. Additionally, engaging with local stakeholders may require flexibility. For example, if political contexts change (as they often do), stakeholders may recommend new research directions, or express new priorities. These dynamics do not always align well with academic funding timelines, which are generally much slower and static.¹⁴

→ *To overcome this challenge:* Partners should set clear expectations around timelines, respect each others' unique time limitations, and keep communication open in the case of any changes. Where possible, flexibility should be built into the research plan.¹⁵

2. **Competing priorities and opinions among stakeholders.** Academic and non-academic stakeholders may have significantly contrasting priorities, which can create tensions for collaborations. For example, Boez et al's (2021) analysis of a health projects' experience with SE found that "the importance of academic publications 'trumped' stakeholder engagement at every turn." Stakeholder partners also reported that "academics were more inclined to submit 'safer' projects—which were less reflective of stakeholder need, due to the funding process and job security."¹⁶

→ *To overcome this challenge:* Expect and prepare for these contrasting priorities, and leverage them for the project's success. Ask from the beginning: What are each partners' priorities and where can we map out areas of alignment? Where there is not alignment, how can different priorities be leveraged to create a more comprehensive research project, instead of a point of conflict?

3. **Power inequalities.** Competing priorities may become of greater concern when coupled with power inequalities among research partners. Past experiences indicate a few common areas in which inequalities can become especially apparent and potentially limit the potential for SE: health research projects may create or reinforce inequalities between 'technical experts' and 'local experts' when non-academic research is treated as 'less objective' and thus of less

¹⁴ [Martinez et al 2018](#); [Boez et al 2021](#)

¹⁵ [Harrison et al 2019](#)

¹⁶ [Boez et al 2021](#)

quality and value for the project; or when non-academics' time is not compensated equally to academics' time.¹⁷

→ *To overcome this challenge: To address power imbalances between researchers and stakeholders, particularly impacted communities, it is important to include experiential knowledge and participatory methodologies.¹⁸ It is also important for project leadership to consider, from the beginning: How might our research project reinforce existing inequalities? How might it create new inequalities? What protocols or policies can ensure stakeholders are treated as equals? How can setting clear expectations from the beginning, or creating spaces for safe, open communication, help overcome these challenges? These conversations should include all levels of the project team, to ensure a shared commitment to SE.*

- 4. Lack of sustained commitment.** Relatedly, sustained commitment across the project team to the chosen model of SE is key for a research projects' success. If team members (even a small minority) lack interest or willingness to engage with stakeholders throughout the project, then it may be difficult to develop trust among stakeholders, thus limiting their engagement as well. Without intervention, lack of commitment may grow throughout the project, especially if SE appears to require certain trade offs (for example, SE might require slower or delayed timelines, and greater project flexibility).

→ *To overcome this challenge: Boaz et al (2021) found that project team members with positive past experiences with SE better understood and could advocate for the benefits of SE. Those who considered SE as an important part of their personal and professional values were also more likely to support and advocate for SE.¹⁹ From the beginning of a research project's planning period, it is recommended, therefore, to have team members share their positive experiences with SE, in order to help build stronger buy-in to the chosen SE model. It is likewise important, at the outset, to create a safe environment for team members' (including stakeholders) to share any doubts or concerns.*

Recommendations for engaging stakeholders in gender-responsive health research:

Formalize partnerships as integral into your research framework, rather than an 'add on' to enhance the project's quality.

Any 'add-ons' are less likely to be sustained throughout a project's lifecycle, or create significant impacts in the direction or results of a research project. This is both true when it comes to integrating a gender perspective into research,²⁰ and when considering how to engage stakeholders. Instead, SE should be seen as integral to your research framework, or part of your frameworks' central methodology and theory of change. This is most effectively accomplished when stakeholders are engaged from the beginning of the project's design and inception.

Build space for communication, feedback, and iteration formally into the research plan. Formalizing communication and feedback methods can help ensure open, ongoing, and more equitable engagement among partners—especially when these methods are co-designed alongside partners.

¹⁷ [Martinez et al 2018](#)

¹⁸ [Tembo et al. 2021](#)

¹⁹ [Boez et al 2021](#)

²⁰ [Berryhill & Fuentes 2021b](#)

Likewise, given that stakeholders' inputs should inform research processes and findings, it is important to establish spaces for program iteration and adaptation. For example, this might include a monthly check-in meeting with stakeholders, in which the research plan is reviewed and adapted, if and as needed. While this is also dependent on donor requirements, formalizing these processes in the research framework and plan from the beginning can help illustrate to donors the importance of program flexibility for SE and the project's broader impact. It is also important to note that the more stakeholders involved in a research project, the greater the flexibility needed to ensure that input can be adequately received and responded to as needed. This is critical when working in more dynamic or unstable contexts.

Identify potential barriers and enablers to stakeholders participation. A long-standing criticism of SE is the failure of SE advocates to consider “the macro-social power inequalities that drive poor health, often lying beyond the reach of local community efforts.”²¹ In order to facilitate stakeholders' participation in health research projects, macro-social inequalities—and the many barriers that come from these inequalities—must be addressed. This requires having open conversations with stakeholders at the beginning of the projects' design, in order to identify potential barriers to participation. Likewise, this process should identify potential enablers to their participation: What would allow the selected stakeholders to engage in the research project? These conversations may identify logistical factors (for example, the language in which meetings are held), or more macro-issues (such as inequities between academic and non-academic participants). Along with identifying these barriers and enablers, project leadership should continuously check in with partners throughout the research process to see how barriers and enablers have changed, or how successfully the identified barriers and enablers have been addressed.

Recommended tools and resources:

- [Practical Guidance for Involving Stakeholders in Health Research](#) (Concannon et al. 2019)
- [How to engage stakeholders in research: design principles to support improvement](#) (Boaz et al. 2018)
- [Patient stakeholder engagement in research: A narrative review to describe foundational principles and best practice activities](#) (Harrison et al. 2019)

²¹ [Campbell 2019; Cornish 2014](#)

Design principles for stakeholder engagement

**Adapted from Boaz et al 2018.*

Organizational

1. **Map stakeholders, identifying their potential roles in the research project.** In doing so, make sure to have a diverse range of stakeholders (including those from marginalized, impacted communities). Through a two-way dialogue with stakeholders, begin to match stakeholder strengths and capacities with the objectives of stakeholder engagement. Ask: where would they like to be engaged in the research project?
2. **Clarify the objectives of stakeholder engagement.** For example, objectives might include co-designing research questions and tools, supporting the interpretation of results, or increasing awareness of / advocacy around key findings. The objectives should be shared and well understood among all parties, and most importantly, upheld (failing to uphold these expectations can undermine trust with stakeholders).
3. **Embed stakeholder engagement in your model for research uptake.** How does SE fit within your model of research and impact? There are a number of existing models that show how SE benefits health research, or based on the unique specificities of your project, you may want to consider developing your own framework.
4. **Identify the necessary resources for stakeholder engagement.** What additional resources will be necessary to ensure meaningful stakeholder engagement, or to address any potential barriers to engagement? For example, will stakeholders need to be compensated for their time? Are additional resources needed to find a shared physical space to engage in the research together? What about digital connectivity or transportation costs?
5. **Formalize organizational learning and rewarding mechanisms that encourage stakeholder engagement.** For example, this may include periodic evaluation of stakeholder engagement; creating a mechanism for ongoing stakeholder feedback and discussion of this feedback; or adding stakeholder engagement as an assessment criteria in organizational or project reviews.

Values

6. **Foster shared commitment to the values and objectives of stakeholder engagement in the project team.** Ideally, there should

be commitment and buy-in from the start of the research project.

7. **Share understanding that stakeholder engagement is about more than individuals.** Consideration needs to be given to stakeholders' roles where they act as *representatives*, recognizing their power, influence, and limitations within broader organizations, communities and networks—all of which may change over time.
8. **Encourage stakeholders to value engagement.** Support and build capacity for stakeholders and their organizations to engage. Where engagement is lacking, ask: why? How can engagement be encouraged, or the model of engagement be adjusted to respect the priorities and preferences of stakeholders.
9. **Recognize potential tension between time efficiency and quality of engagement.** Quality engagement may lead to greater relevance and impact, but may also have implications for productivity in meeting project objectives. Engaging stakeholders, taking into account their needs and inputs, and adjusting elements of the project in response to their feedback takes time and can slow down the research process.
10. **Generate a shared commitment to sustained and continuous stakeholder engagement.** Project teams and stakeholders see the value of links between research producers and research users to build ongoing collaborations in order to meet the objectives.

Practices

11. **Plan stakeholder engagement activity as part of the research programme of work.** That is, formalize SE activities into the project protocol or plan.
12. **Build flexibility within the research process to accommodate engagement and the outcomes of engagement.** It will also be important to build in mechanisms to allow researchers and stakeholders to feel safe and supported in articulating what is out of scope, and when adjustments are needed.
13. **Consider early on: how input from stakeholders can be gathered systematically to meet objectives.** The importance of some face-to-face contact and interactions should be considered.
14. **Consider early on: how input from stakeholders can be collated, analysed and used.** This is especially important to think about early on when working with a diverse group of stakeholders who may have conflicting or contrasting input.

15. Recognise that identification and involvement of stakeholders is an iterative and ongoing process. Trustful relationships will be fostered by taking the time and creating the structures for ongoing interaction.

Summarizing a stakeholder engagement plan						
<i>*Adapted from Concannon et al 2019.</i>						
RESEARCH STAGE	RESEARCH ACTIVITY	STAKEHOLDER GROUP				
		<i>Impacted communities</i>	<i>Rights advocates</i>	<i>Civil society organizations</i>	<i>Service-providers</i>	<i>Policy-makers</i>
Preparing for research	<i>Building research capacity of stakeholders</i> <i>Training researchers to work with stakeholders</i> <i>Prioritizing evidence gaps</i> <i>Choosing research topics</i>					
Conducting research	<i>Defining the research question</i> <i>Choosing relevant outcomes</i> <i>Designing a research protocol</i>					

	<p><i>Defining participant inclusion and exclusion criteria</i></p> <p><i>Drafting or revising study materials and protocols</i></p> <p><i>Recruiting participants</i></p> <p><i>Monitoring patient data and safety</i></p> <p><i>Collecting data</i></p> <p><i>Analyzing data</i></p> <p><i>Identifying key findings</i></p> <p><i>Interpreting findings</i></p> <p><i>Disseminating results</i></p>					
<p>Using research</p>	<p><i>Implementing evidence in practice</i></p> <p><i>Evaluating research</i></p> <p><i>Evaluating engagement</i></p> <p><i>Identifying topics for future research</i></p>					