# COMMUNITY RESEARCHERS' ROLES IN ACHIEVING ARISE OUTCOMES AND LEGACY

Authors: African Population and Health Research Council (APHRC), Kenya; BRAC James P Grant School of Public Health, BRAC University, Bangladesh; CODOHSAPA, Sierra Leone; College of Medicine and Applied Health Sciences (COMAHS), Sierra Leone; Institute of Gender and Children's Health Research (IGCHR), Sierra Leone; LVCT Kenya; SDI Kenya; SPARC, India; Sierra Leone Urban Research Centre (SLURC); and The George Institute for Global Health, India (TGI), with the ARISE Consortium

## **KEY MESSAGES**

- ARISE community researchers (co-researchers) have been integral to the work of the consortium and have played a central role in driving forward the outcomes delivered by the programme. This case study draws on examples from each of the focal countries Bangladesh, India, Kenya, and Sierra Leone and celebrates the contribution of co-researchers to the programme's successes.
- From the initial stages of ARISE, co-researchers were key to identifying and connecting with vulnerable groups across the communities working and living in informal spaces, enhancing understanding of the communities to improve the relevance and targeting of the project's interventions.
- Because of their unique position at the interface between the communities, local service providers, national research organisations, and governance actors - co-researchers acted as intermediaries to establish and strengthen the trust and connections between these different groups. They supported these groups in the co-design and implementation of interventions to improve the delivery of services to promote the health and well-being of communities working and living in informal spaces.
- Training, exposure and involvement of co-researchers enabled and empowered them to approach government officials and other stakeholders with enhanced communication and influencing skills.
- Involving community representatives as 'change agents' to work for their own community can be a low-cost and appropriate approach that brings sustainable change.
- Building an environment of mutual respect, trust and equity is essential in working effectively with co-researchers.



### BACKGROUND

ARISE aimed to explore and understand the health and well-being of people and communities working and living in informal spaces, which can be influenced by a combination of factors such as residence, environmental conditions, financial status, educational attainment and social connections with friends and family. There is evidence that the close involvement of co-researchers at every stage of research projects from inception and construction, through execution, to dissemination, can help to ensure that research conducted is relevant to and owned by communities involved.

ARISE used community-based participatory research (CBPR) with co-researchers, which aims to improve accountability, and promote health and well-being as well as develop alliances for new governance arrangements for people living and working in informality. CBPR emphasises building strengths and resources by collaborating with the community in every stage of knowledgebuilding and interventions to address genuine local concerns and problems.



# STAKEHOLDER **ROLES AND RESPONSIBILITIES Co-researchers** Worked as a bridge between the community and researchers • Supported in co-producing data collection tools like interview guidelines, survey questionnaires etc. Assisted in simplifying the tools to maximise understanding • Supported researchers in arranging group discussions with the community Assisted in identifying participants for events like consultation workshops, service and stakeholder analysis and in-depth interviews • Participated in formal and informal capacity-building training • Participated in events arranged by the implementation partners, mobilised the community to participate if needed and take observation notes and share with the researchers • Participated in reflexivity sessions to provide in-depth information to researchers • Data collection and validation • Shared community and intervention updates GIS mapping • Captured photos, image analysis, captioning and narrative development • Communication of community concerns through a variety of local, national and global channels and outputs Arranged and participated in webinars • Co-analysis of data **Field Research** • FRAs are co-researchers who have been promoted to full-time paid staff Assistants (FRAs) • Played all the roles and responsibilities of co-researchers to a greater extent • Provided support in documenting ARISE activities by typing up the information they and their peer co-researchers collected (as many are unable to type) • Provided more in-depth data on their community • Supported researchers in understanding the community by clarifying facts Supported in transcription Community-• Empowered co-researchers by providing formal training with community leaders based • Informed and involved co-researchers in all ARISE activities organisations • Catalysed an enabling environment for co-producing solutions by creating platforms, capacitating (CBOs) the community, mobilising the community and stakeholders and organising, facilitating and coordinating the necessary actions • Held researchers and professions accountable to the community (e.g. Federations of Slum Dwellers) **ARISE** partners • Capacitated the co-researchers through formal, informal and hands-on training (Research and • Mentored co-researchers by providing technical, professional, financial and psychological support Community to strengthen their skills and sustain their efforts Development • Created a non-hierarchical and respectful environment for co-researchers within the wider team **Organisations**) • Shared the research platform with community members joining as co-researchers • Supported co-researchers in negotiations with duty-bearers where necessary • Facilitated exposure of co-researchers by sharing different national and international platforms with them, turning them into community ambassadors for addressing local issues • Fostered a two-way learning environment to exchange knowledge and document community health and wellbeing • Created opportunities for sharing across groups of co-researchers

#### TABLE 1: The range of roles and responsibilities across key stakeholders involved in the work of co-researchers

### **ENLISTING COMMUNITY MEMBERS**

At the beginning of the ARISE project (2019), community members were enlisted as 'community researchers' (coresearchers) from the communities working and living in informal spaces where the research was taking place. These co-researchers have diverse socio-economic backgrounds and some face additional forms of marginalisation and exclusion, including living with a disability, belonging to single female-headed households, having married early, having a short formal education or being part of ethnic minority communities. Across the ARISE country teams there were 16 co-researchers enlisted in Bangladesh from the nine urban informal settlements; 15 in Sierra Leone; 23 trained in India; and 204 in Kenya. There were a range of approaches to payment of co-researchers for their time and input, ranging from stipends to expenses to contracting as paid staff.

#### TRAINING IN RESEARCH METHODS AND TOOLS

Co-researchers received comprehensive training from ARISE partners in research methods - such as CBPR, photovoice and social mapping - as well as training on how to use research tools such as NVivo and GIS mapping (a more comprehensive list of training is provided in Table 2). Soft skills such as public speaking and leadership were also developed so that coresearchers could identify the different needs and challenges faced by community members, prioritise issues by analysing data collaboratively with community members and gain legitimacy to represent these groups' interests in engagements with service providers and duty bearers. Embedding coresearchers within research teams and building their skills in research tools and approaches provided the co-researchers with tools to deepen their own understanding of their communities and facilitated bi-directional learning between co-researchers and research teams.

TABLE 2: The range of training and skills building of co-researchers.

TRAINING NAME	TRAINING DETAILS
Leadership and implementing social accountability tools	Co-researchers received periodic leadership training along with the community leaders, which provided the necessary knowledge and confidence to take leadership roles and community action. They also received training on implementing social accountability tools for effective community-led project monitoring and management.
Qualitative data collection (transect walks, social maps, venn diagrams, service maps and analysis, Ripple Effect Mapping, in- depth interviewing and case study development)	Qualitative data collection training sessions aimed to provide co-researchers with the essential knowledge and abilities required to conduct qualitative research proficiently, utilising a range of methods. Training was delivered through interactive discussions, practical exercises, mapping training and group activities. Co-researchers in fieldwork were also supported with constructive performance evaluations to enhance their proficiency in practical implementation.
Quantitative data collection	Co-researchers gained skills in survey design, piloting, basic quantitative data collection, monitoring, analysis and reporting. They were also trained in tool development and validation, and setting respondent selection criteria.
GIS mapping	During this training, the co-researchers learned how to document the location of health, water, sanitation and hygiene (WASH), and other services inside or near the community's geographical area.
Social mapping	Co-researchers were trained to support community members to draw social maps depicting specific social dimensions that they believe to be relevant and important.
Venn Diagramming	Co-researchers were trained to facilitate Venn diagramming to identify and discuss the range of formal and informal governance actors and institutions responsible for health and wellbeing, from whom accountability might be sough, how they interact with each other and how accessible they are to diverse community members

Photovoice	Photovoice is a participatory research method that uses photography to empower people and communities by documenting and then communicating their challenges and day-to-day experiences with those who have the power to affect change. Participants learned the principles, techniques, and ethical considerations involved in Photovoice, enabling them to effectively implement this method.
Ripple Effect Mapping	Co-researchers learned to use Ripple Effect Mapping methods to document and reflect on the anticipated and unanticipated outcomes of community-led actions, including the effects on them as individuals.
Fieldnote and observation writing	Co-researchers received intensive training on taking notes and field observations. The co- researchers lived within the community and participated in different meetings and training sessions with community members.
Transcription	Co-researchers worked on transcription of the sessions with community members. Co- researchers understand the local dialect and the underlying meaning of the phrases used by the community. This transcription also helped the co-researchers with their typing skills.
IT and Communications (email writing and WhatsApp)	Co-researchers were trained where needed on how to write and send emails, as well as keep in regular communication using WhatsApp. With this technical knowledge, they can now communicate and share data more effectively with researchers. They were also trained using programs such as PowerPoint, Microsoft Word. KoboCollect, NVivo and utilising search functions and social media. These skills also improved their employability.
Presentation	Co-researchers were encouraged to speak in front of others. Following supported participation in various meetings, co-researchers gained confidence in presenting in front of the community and wider stakeholders. For example, Sweety from Dhalpur, Dhaka, spoke at the 2022 Global Health System Research Conference.
Stakeholder engagement	Co-researchers gained skills in organising and facilitating community meetings, workshop facilitation, discussion moderation, and building partnerships to formalise networks.
Research Ethics	Training was provided on safeguarding and ethical research practice. This included what communities should expect in terms of appropriate behaviour by researchers and co-researchers and how to raise concerns with the research team.
Project management	Co-researchers strengthened skills related to project conceptualisation and implementation, budget conceptualisation and organising and chairing meetings.
Teaching	Training was provided on lesson planning, presenting to students and answering questions/ explaining specific topics.



Four co-researchers from Bangladesh, Kenya and Sierra Leone attended the virtual session of the Seventh Global Symposium on Health Systems Research held in November 2022 as panellists. They discussed the problems they and millions of others face in relation to WASH while living in urban informal settlements and the ways these can be alleviated.

#### PEER LEARNING AND EXCHANGES

Exchanges across the various levels of ARISE, from the community to the global, have been key to knowledge sharing between country teams, across ARISE workstreams and between communities. ARISE's work across different communities working and living in informal spaces and CBOs has enabled a constant iteration of research design and strategy through learning from the diversity in skills and experience. Cross-city and cross-country exchanges of coresearchers have also contributed to the cross-fertilisation of ideas and approaches to develop inclusive and equitable community leadership and to engage and influence project implementers' and policymakers' attitudes.

# STORY OF CHANGE – EMPOWERING PEOPLE AND COMMUNITIES

# Serving as leaders in communities and supporting project implementation

The co-researcher model adopted by ARISE provided opportunities for members of marginalised communities to take up leadership roles, voice community priorities, establish new grassroots initiatives and represent their communities on different platforms. Co-researchers felt that their training and involvement in the work had built their confidence over time. Their participation in organising and facilitating data collection at the community level has helped them develop leadership, organisation and management skills, leading to better employment and networking opportunities.

Co-researchers refined their research skills and knowledge by engaging in the process of identification of participants, assisting data collectors with survey sampling, validating CBPR tools, co-analysis of CBPR data as well as co-facilitating CBPR sessions. They have contributed to the development of knowledge products that reflect the community's voice which ultimately contributed to understanding the health and well-being conditions of their community in detail. ARISE has nurtured the potential for co-researchers to become future leaders in their respective fields, creating a new generation of knowledgeable and capable individuals who can contribute to positive change in their communities.

"I never had any kind of exposure to the community leaders. I did not know how the development activities came to this area. However, I can now talk to the stakeholders without any hesitation as we have earned certain respect from the community as well as from the stakeholders."

Co-researcher, a woman who works in the home, 30 years old, from Rangpur, Bangladesh



Co-researcher, Sweety (now a FRA from Dhalpur, Bangladesh) participating in leadership training



Co-researcher, Tumpa (now an FRA from Shyampur, Bangladesh) conducting a Community Development Organisation meeting during the COVID period

While the co-researchers were trained through ARISE activities, it should be noted that, before joining the ARISE project, many of them had previous exposure to other developmental and organisational working sectors.

# COMMUNITY-LED ADVOCACY AND THE USE OF EVIDENCE TO INCREASE VISIBILITY

Community ownership of the data generated by ARISE strengthened community agency and understanding of the importance of evidence to raise awareness around health and wellbeing. This has increased the visibility of their physical existence and the challenges that they face in negotiating with local authorities and decision-makers. The capacity and increased potential for communities to assess their own challenges and propose and implement feasible solutions has been acknowledged by decision-makers.

Different types of data and methodologies complemented and reinforced each other to inform the actions of different groups. While the ARISE experience has demonstrated the power of art-based approaches to build a common understanding of issues and ownership of solutions, communities and coresearchers also recognise the importance of quantitative data to support their advocacy with governance actors by 'speaking to them in their own language'. For example, in Kenya, the survey provided waste workers with numbers and statistics as a basis for negotiations with governance actors. In Mumbai, India, involvement of co-researchers from the Mahila Milan grassroots women's organisation in a health and wellbeing survey identified and began advocacy with health services for the support needs of people with tuberculosis. In Sierra Leone, the health and wellbeing survey highlighted systemic deficiencies in essential service provision within these communities such as the prevalence of inadequate water and sanitation infrastructure, coupled with disparities in healthcare access and utilisation.



Data collection in Moyiba Community, Sierra Leone

Co-researchers have worked with communities to identify policy levers to demand action and mobilise for change, highlighting that data does not need to be published before it can be used for advocacy and discussion with local governments. Co-researchers have played a role in aligning these different entry points for action to the language and needs of governance actors to link to their agendas and mobilise them towards action. For example, in Nairobi, data collected by co-researchers fed into the Mathare Special Planning Area Research Collective and were used to advocate for settlement upgrading with the government. One of the needs identified was electricity provision, which was used for advocacy, resulting in tangible improvements in electricity infrastructure and service delivery in the settlement. Young co-researchers took the initiative to write to and meet with stakeholders on their own, highlighting their increasing leadership skills and confidence to engage with authorities independently.



"These electricity connections are illegal, we call them sambaza...The wires are not high enough. Outside my house the wires sometimes stretch from a pole and touch, producing sparks when it rains." - Image from the Kenya Photovoice exercise, taken by a child heading a household.

# INCREASING UNDERSTANDING OF INTERSECTING INEQUITIES WITHIN COMMUNITIES

Co-researchers from diverse backgrounds used their local knowledge and lived experiences to enable a deeper understanding of the intersecting social, economic, cultural and physical factors shaping the realities of urban marginalised communities. Purposively recruiting coresearchers with different positionalities – in terms of age, gender, disability, caste, and livelihood - has helped ARISE gain nuanced insights into how intersecting social identities and power structures shape vulnerabilities and well-being within communities. This diversity and the inclusion of different perspectives on marginalisation have contributed important insights into the nuances of community demographics and structures and challenged perceptions of community homogeneity. A strong emphasis on intersectionality has been central to the design and adaption of research processes to ensure responsiveness to diverse community needs and realities. Co-researchers helped to translate different research realities and world-views, facilitating researchers' access to communities to deliver deeper insights on community dynamics, increasing the credibility of the research process and the feasibility and utility of proposed solutions.

The enhanced local understanding of co-researchers is acknowledged across all country teams as a key success factor of ARISE research and an important driver to the sustainability of the processes. Co-researchers' cultural sensitivity has helped facilitate appropriate communication with communities to identify and prioritise challenges and in the design of actions.

For example, in Korogocho and Viwandani in Nairobi, ARISE engaged child-heads of households, the elderly, and persons with disabilities as co-researchers, who were identified as vulnerable groups through initial exploratory participatory research. Their lived realities uncovered intersections of age, gender, disability status, and household headship. ARISE supported the creation of new CBOs led by diverse coresearchers, demonstrating their leadership in establishing independent grassroots groups.

In Bangladesh, the recruitment of co-researchers from ethnic minority groups in the Responsive Fund project in Rangpur enabled access to important information about the different ethnic and marginalised communities. Previously, the research team had limited knowledge and access to the internal circle of information which is crucial for deeper exploration and building trust within the community to enable smooth implementation of the research activities. Real-time updates from the co-researchers in the form of photos and narratives highlighting the WASH-related challenges of their community have provided researchers with a deeper understanding of community dynamics.





Co-researchers discussing the timeline and outcomes during a synthesis workshop

# ESTABLISHING AND STRENGTHENING RELATIONSHIPS

Co-researchers with non-governmental organisations (NGOs) Co-researchers were actively involved in coordination with local NGOs and CBOs to leverage their reach, local knowledge and sustained presence to facilitate community engagement. In some cases, these partnerships helped to expand the scope of support that CBOs and NGOs provided to communities, as well as embedding new ideas and approaches that contribute to the long-term legacy of ARISE work. In India, ARISE researchers and community members worked closely with the NGO Dalit Bahujan Resource Center (DBRC) in Vijayawada and Guntur, which supports oppressed caste communities including waste workers. This collaboration established communication channels between the community and governance actors that supported waste worker communities to obtain documentation to claim government housing entitlements. In multiple sites, ARISE Kenya embedded its work in NGOs affiliated with the Slum Dwellers International (SDI) network, ensuring sustainability by contributing to SDI's longstanding agendas.

### Within communities

Co-researchers built trust in the research and advocacy process within their communities through sustained interactions over the years and by harnessing existing traditional power structures, such as incorporating village elders into co-created actions. For example, co-researchers in Sierra Leone built trust and consensus within the community by involving village elders who provided cultural guidance and mediated conflicts, highlighting the intersections of traditional power structures and local knowledge within communities. Mechanisms such as Community Learning Platforms created spaces to empower communities to share their data and discuss emerging insights and priority actions.

Co-researchers Esha and Billal assisting in drawing the social map of Kallyanpur along with community members



Community researchers Manuja and Arif engaging in community mapping

These workshops were a space for dialogue and validation of emerging insights, strengthening relationships between coresearchers and communities to foster collaboration and trust. The use of creative communication approaches such as street plays, songs and skits allowed co-researchers to disseminate findings back to the community in accessible formats, building rapport and a sense of a shared agenda.

Working with ARISE has contributed to co-researchers gaining social recognition in their own communities and expanding their social and professional networks, which they can capitalise on beyond ARISE.

# "I think we have gained greater recognition among our community people, and our social standing has significantly improved due to work and our association with such a wellknown and reputable organisation."

Woman co-researcher, 35 years old and the head of a household from Greenland, Khulna in Bangladesh

#### Between communities and service providers

Co-researchers played a key role in establishing connections and facilitating communication between communities and relevant duty bearers and service providers to discuss emerging evidence and explore potential solutions. Convening different governance actors helped to strengthen intersectoral coherence and coordination, creating opportunities for local governance actors to increase their agency to improve the effectiveness and reach of health services in communities working and living in informal spaces. This convening power has, in many cases, built upon the social capital of national research teams and existing relationships to identify allies in government, with a strong emphasis on identifying the right decision-making level.



COVID-19 awareness sessions run with primary groups in Shyampur, Bangladesh

ARISE has placed a strong emphasis on engaging at the most appropriate governance level and acknowledging that national-level policy change is frequently not a pre-requisite to delivering solutions for people living and working in informality. Different spatial settings require different levels of change with examples of engagement with City Councils, County Assembly and Ward Authorities as key gatekeepers to improve services within informal spaces. There are also different levels of political will from government and city authorities to make changes to legal rights and support service access for vulnerable groups. Additionally, this political will is in constant flux as political cycles evolve, creating new dynamics that can either undermine trust and commitments or create new opportunities for community engagement in political spaces.

There are several examples of how ARISE co-researchers acted as key interlocutors in the creation of platforms that brought communities, service providers, municipal authorities, NGOs and other governance actors together to share perspectives, understand mutual limitations and roles, and identify collaborative strategies to promote coherence in governance approaches to assessing and responding to community needs and priorities related to health and well-being. For example, in Freetown, co-researchers engaged the Ministry of Health through City Learning platforms to present community representatives and duty-bearers. This space was used to present community concerns and recommendations to advocate for tackling the emerging health crisis related to the widespread use of 'kush' (an addictive illegal substance).

### REFLECTIONS

Co-researchers are equal partners in ARISE research teams and have been key to the success of the consortium in identifying the issues of greatest concern to communities and implementing strategies for change. Through their participation in ARISE, co-researchers have gained research and soft skills. Co-researchers have demonstrated their ability to work together with communities to build a common understanding of the issues that they face, articulate solutions and then engage with decision-makers and other relevant stakeholders to strengthen their accountability for the implementation of interventions. At each stage in the research process, co-researchers have used these soft skills to sensitise different stakeholders, from communities to decision-makers, to build buy-in to processes and identified solutions. Co-researchers' accomplishments demonstrate the importance of involving communities in research to better understand local realities of health and wellbeing challenges and governance practices, especially when there is limited understanding of the local context. It is hoped that even after the ARISE project's completion, the knowledge and skills acquired by co-researchers will persist.

# Sweety Akter, a 21-year-old woman from the Dhalpur informal settlement in Bangladesh who worked as a co-researcher for ARISE shared her story.

"Working with ARISE has transformed my life goals and aspirations. Before joining here, I had to halt my education due to my family circumstances, being one of four sisters with no male support after my father's death. My mother worked tirelessly to provide for us, but as I reached the 9th grade, the expenses for my education became a heavy burden. Despite the desire to continue my studies, I couldn't continue. However, later on, I joined ARISE as a community researcher, which was a great achievement in my life. I decided to continue my education by returning to school and also began working outside the home, successfully overcoming the gender norms that existed within my family. Although my mother supported this, my conservative family members did not.

From now on, my goal is to become financially independent, advocate for justice and change societal perceptions. Recently, I have resumed my studies by enrolling in the 9th grade. Also, I have been promoted to a FRA in BRAC JPG School of Public Health, covering my educational costs and contributing to my family's finances. In my opinion, this opportunity has been transformative for me, offering a path to a brighter future and the ability to make a positive impact on my society."

#### **FURTHER RESOURCES**

- ARISE (2023) ARISE India learning exchange: Waste work and workers in Shimla, Vijayawada and Guntur, ARISE Video, <u>https://www.ariseconsortium.org/learn-more-archive/arise-co-researchers-working-collaboratively-to-build-capacity/</u>
- ARISE (2022) Ripple Effect Mapping film, ARISE Video, <u>https://www.ariseconsortium.org/learn-more-archive/ripple-effect-mapping-film/</u>
- Omondi, J. et al. (2024) How to conduct community-led action oriented data collection, ARISE Blog, <u>https://www.ariseconsortium.</u> <u>org/how-to-conduct-community-led-action-oriented-data-collection/</u>
- ARISE (2022) Session report: Accountability from below? Learning from Participatory Research processes on water and sanitation in informal settlements, ARISE Consortium, <u>https://</u> <u>www.ariseconsortium.org/learn-more-archive/session-report-</u> <u>accountability-from-below-learning-from-participatory-research-</u> <u>processes-on-water-and-sanitation-in-urban-informal-settlements/</u>

#### ACKNOWLEDGEMENTS

Thank you to Nazia Islam, Louise Clark, Sweta Dash, Kate Hawkins, Jiban Karki, Leah Murphy, Anthony Mwaniki, Hayley Stewart, Joe Taylor and Sia Tengbe for developing and editing this output, published in 2024.



The UKRI GCRF Accountability for Informal Urban Equity Hub is a multicountry hub with partners in the UK, Sierra Leone, India, Bangladesh and Kenya which we call ARISE. The Hub works with communities in slums and informal settlements to support processes of accountability related to health. It is funded through the UKRI Collective Fund.