SABIN VACCINE INSTITUTE | VILLAGE REACH®

CO-CREATING HEALTH SOLUTIONS

PARTICIPATORY RESEARCH AND HUMAN-CENTERED DESIGN FOR IMMUNIZATION PROGRAMS

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ACRONYMS

BeSD	Behavioral and Social Drivers of Vaccination
CAB	Community Accountability Board
CBPR	Community-Based Participatory Research
CHW	Community health worker
CoP	Community of practice
EPI	Expanded Programme on Immunization
HCD	Human-Centered Design
HPV	Human papillomavirus
LMIC	Low- and middle-income country
SBRG	Social and Behavioral Research Grants Program
VARN	Vaccination Acceptance Research Network
WHO	World Health Organization

Photo credit: Januário Bila

EXECUTIVE SUMMARY

This technical paper offers a comprehensive and practical guide to conducting participatory research and design within global health immunization initiatives.

Drawing on the experiences of the Sabin Vaccine Institute, VillageReach and partners, this paper provides practical guidance on establishing a foundation for participatory qualitative methods aimed at understanding and addressing immunization challenges. The focus is on principles that center community engagement, inclusivity and leveraging local knowledge.

By integrating established frameworks such as UNICEF's Journey to Immunization and the World Health Organization's Behavioral and Social Drivers of Vaccination, this paper ensures a structured approach to participatory research design, data collection, analysis and solution development.

A central theme of this paper is the application of Human-Centered Design (HCD) and Community-Based Participatory Research (CBPR) to generate actionable insights, engaging communities directly in co-designing solutions. It also outlines essential steps for building and supporting a research team, securing institutional support, selecting study sites, recruiting participants and adapting existing tools and frameworks to suit specific research needs.

Additionally, the paper provides resources for disseminating findings and fostering peer-to-peer learning, ensuring that the knowledge generated is shared effectively and has practical value for all stakeholders, particularly at the community level. It also addresses practical considerations such as budgeting for participatory research efforts.

After reading this paper, we hope you will:

- **Understand** the core principles of participatory research and design
- **Use and adapt** immunization frameworks for data collection and analysis
- **Build and support** a research team
- **Engage** stakeholders and secure institutional support
- **Explore** options for participant recruitment and verification of vaccination status
- **Select and implement** participatory data collection methods
- **Apply** participatory data analysis processes
- **Facilitate** participatory design workshops with communities
- **Involve** communities in disseminating findings
- **Identify** key budget inputs and resource requirements for participatory approaches

INTRODUCTION

Participatory research and design are powerful methodologies that place the perspectives and lived experiences of community members at the heart of both understanding and addressing complex issues.

Participatory research engages those directly affected by an issue, ensuring their insights and knowledge shape the entire research process. This approach not only generates a deep understanding of the issue, but also fosters trust and collaboration between researchers and community members. Participatory design, in turn, focuses on co-creating solutions with the people most affected by the challenges. By involving community members in the design process, it acknowledges that they are the best suited to identify and develop solutions that are relevant and effective in their specific context. When combined, participatory research and design form a comprehensive framework to identify barriers and develop practical, community-driven solutions.

These methodologies are crucial for improving equitable global immunization efforts. Traditional immunization strategies often fail to meet the specific needs and preferences of parents and caregivers, leading to gaps in vaccine coverage and uptake. By employing participatory methods, immunization programs can develop solutions that are more responsive to the needs of the communities they serve. Evidence demonstrates that involving communities in co-creating solutions fosters greater engagement, adherence to implementation plans and support from government stakeholders at various levels.[1] This approach ensures that immunization systems are not only more effective but also sustainable and embraced by the communities they aim to protect.

By employing participatory methods, immunization programs can develop solutions that are more responsive to the needs of the communities they serve.

Participatory research also facilitates the collection and use of different types of knowledge, extending beyond those produced by conventional health research. Knowledge is multifaceted and includes both theoretical knowledge of a topic, and practical, experiential and intuitive understanding. Traditional health research, typically conducted by and for academic audiences, often focuses on theoretical knowledge derived from quantitative studies.[2] However, this

approach can fail to capture the full context of an issue, in particular the sociocultural and lived experiences of those affected. Further, academic research findings may be too abstract and technical to be understood and translated into actions that can improve the lives of people and the community.

In contrast, participatory research captures broader forms of knowledge, incorporating practical, experiential and intuitive knowledge from people and communities. It builds a fuller picture of an issue by integrating local narratives and collective experiences, bridging gaps between lived experiences, scientific research and policymaking.[2] This approach recognizes that those being researched hold valuable knowledge and enables the co-creation of knowledge with those in the participating group and community. In this way, participatory research redefines the traditional research paradigm, empowering the researched to become researchers themselves.[3]

Participatory design, often referred to as Human-Centered Design (HCD), sits at the intersection of behavioral sciences and design thinking. These approaches create actionable insights that are specific to the context in which solutions will be implemented and that are well-positioned to target social and behavioral barriers.[4] They also embrace an iterative process to problem-solving in which participants work together to rapidly and repeatedly brainstorm, test and refine solutions.[5] Within the global immunization landscape, there is growing recognition of the importance of human-centered approaches to designing health systems that effectively reach vulnerable and marginalized populations.[4]

While participatory research and participatory design approaches can be used independently, they are most powerful when combined. Participatory research produces detailed, nuanced insights that are rooted in community perceptions and experiences. These insights provide an excellent foundation for the participatory design process, which transforms those research findings into actionable and people-centered solutions.

This technical paper provides a comprehensive guide to implementing participatory research and design methodologies within the context of global immunization efforts. It draws on the experiences of VillageReach and the Sabin Vaccine Institute in supporting and implementing similar projects over the past four years. To illustrate the application and impact of these methods, the paper includes case studies that highlight successful initiatives in various settings.

WHAT TO EXPECT IN THIS PAPER

1. Laying the Foundation for Participatory Research & Design
2. Principles and Practices for Meaningful Community Engagement in Research and Design
3. Participatory Research Process and Tips
4. Participatory Design Process and Tips
5. Dissemination Strategies
6. Budgeting Guidance

Participatory Research and Design Case Studies

Participatory research and design have been deployed in diverse settings globally to develop solutions for routine immunization that are both impactful and responsive to specific community needs. Throughout this paper, we present examples from the following projects involving Sabin and VillageReach:

- **India:** Community-based participatory research was used to improve vaccine delivery and acceptance in an area with extremely low vaccination coverage.[6]
- **India:** This project utilized photovoice to enable the transgender community and persons with disabilities to capture and share their lived experiences, highlighting structural inequities in COVID-19 vaccine uptake.[7]
- **Pakistan:** Community-centered co-design was used to design and implement socio-behavioral interventions to counter COVID-19 related misinformation among marginalized populations living in squatter settlements in Karachi.[8]
- **Sierra Leone:** Academics and the Ministry of Health piloted a community-led ethnographic approach, where community health workers were trained in qualitative social science methods to collect data on vaccination experiences and perspectives of community members.[9] The project provided insights into the social dynamics of vaccine confidence and local drivers of trust.
- **Guatemala:** A transdisciplinary team-building approach was used to address vaccination hesitancy among Indigenous Mayan communities. The transdisciplinary team utilized a co-creation process and knowledge translation with local key stakeholders to solve societal challenges.[7]
- **Malawi and Mozambique:** Community researchers were engaged in the "Let's Talk About Vaccines" study to identify barriers and solutions to address dropout from the routine, under-2 immunization schedule. This study was conducted through a 3-phased approach: participatory research to identify barriers to immunization from the perspective of health workers and caregivers of children under two years old; participatory co-design with health workers and government officials to design solutions based on findings from Phase 1, followed by piloting those solutions for 1 year; and lastly, an evaluation of the effectiveness of these solutions and the community engagement approach.[10,11]
- **Malawi, the Democratic Republic of the Congo, Nigeria and Pakistan:** Participatory research and design is taking place to identify and address causes of dropout from the immunization schedule prior to the delivery of the first dose of measles-containing vaccines.

EXPERIENCE OF SABIN AND VILLAGEREACH WITH PARTICIPATORY RESEARCH AND DESIGN

Participatory research and design are central to the work of both the Sabin Vaccine Institute and VillageReach. Both organizations lead, support and facilitate participatory research to improve access to routine immunization across low- and middle-income countries (LMICs).

Since its establishment in 2019, Sabin's Social and Behavioral Research Grants Program (SBRG) has funded locally led, participatory research to explore the social and behavioral drivers of vaccine acceptance and demand in LMICs.[12] Grant partners conduct innovative research projects to illuminate critical, community-level questions on vaccination access, acceptance and demand to co-create, pilot and evaluate potential solutions. Collaborative partnerships between academic researchers, local communities and decision-makers — from local to global levels — are central to this program.

This approach creates a direct link between local, community-based research and policy makers, enabling research that drives action. All former and current grant partners are also part of Sabin's Grant Partner Coalition, which is a platform for real-time, peer-to-peer engagement and learning around social and behavioral research-related opportunities and challenges on vaccination.[12] A participatory approach is embedded across the SBRG program and is key in facilitating impactful research.

VillageReach aims to reduce inequities in access to quality primary health care by working with governments to design and sustain responsive systems that deliver products, information and services when and where they are needed even for the hardest-to-reach communities. It aims to develop systems that can adapt to changes in demand, absorb shocks and stresses and factor in and respond to the needs and preferences of the communities they serve.

Increasingly, VillageReach employs participatory research and design approaches as a key strategy to achieve these goals. The research and design methods presented in this technical paper have been applied to studies and projects related to routine immunization services, COVID-19 vaccination delivery, adolescent health, digital tools and telehealth services. We have also applied learnings from these studies to the development of a ***Community Insights to Action framework***, which aims to drive systems-level change by routinely capturing, analyzing and integrating insights from under-reached communities into primary health care systems.[13]

LAYING THE FOUNDATION FOR PARTICIPATORY RESEARCH AND DESIGN

GUIDING PRINCIPLES FOR PARTICIPATORY RESEARCH AND DESIGN

In participatory research and design, establishing clear guiding principles is essential for achieving meaningful and impactful outcomes. These principles, not only shape the research process, but also foster trust and legitimacy among community participants. Transparent and well-communicated principles encourage community members to engage openly as community members feel confident that their input is valued and respected.[8]

This transparency is crucial for establishing credibility and fostering long-term partnerships between researchers and communities.

Best practices in participatory research emphasize the importance of inclusivity, respect for local knowledge and continuous feedback loops to maintain trust and relevance throughout the research process.[14] From our experience, we've identified the following guiding principles as essential for participatory research and design.

Best practices in participatory research emphasize the importance of inclusivity, respect for local knowledge and continuous feedback loops to maintain trust and relevance throughout the research process.

Photo credit: Januário Bila

GUIDING PRINCIPLE	DESCRIPTION	BENEFIT
Establish a diverse, transdisciplinary core team	Involve stakeholders from various fields (e.g., health care, religious leaders, education) as core members of research and design teams	Ensures that research findings and interventions reflect the diverse perspectives and stakeholders involved in implementing change
Include community researchers	Include community members who are representative of the study population as part of the research team by compensating and training community members to be researchers or research leads	Facilitates ownership of research within the community, helps incorporate different perspectives and nuanced understanding of findings relevant for the community and enables the design of sustainable, community-led interventions
Engage leadership and other stakeholders	Build relationships and engage with leaders from health facilities and both lower- and national-level EPI in addition to community leaders and organizations known to and trusted by the community	Ensures that recommendations and solutions align with local and national immunization strategies and are absorbed into immunization policies and practices and generates community buy-in to solutions
Address power dynamics	Conduct empathy-building and power balancing activities to manage power dynamics between research leads, community researchers, study participants and government representatives	Generates rich and authentic data and facilitates co-creation of appropriate solutions that meet the needs of all stakeholders
Incorporate reflexivity/ self-reflection	Evaluate how researchers' subjectivity may influence research design	Helps design research that minimizes bias and is responsive to community needs
Utilize accessible research methods	Ensure that all methods/ tools are designed appropriately to reach marginalized, under-researched areas and 'hidden' populations	Helps ensure that traditionally marginalized populations are included in research, improving the comprehensiveness of research findings and reach of solutions
Embrace continuous learning and iterative adaptation / prototyping	Continually review and monitor data, learn from the evidence and make adaptations when collecting data or when developing prototypes and implementing solutions	Enhances adaptability and effectiveness of solutions through ongoing refinement and responsiveness
Build capacity and skills	Incorporate training and skills-development for health workers and other important immunization system actors into solution implementation strategies	Strengthens local capacity and improves the long-term sustainability of solutions

FACTORS THAT CONTRIBUTE TO THE SUCCESS OF PARTICIPATORY RESEARCH & DESIGN

Benefits of Following Participatory Research and Design Principles in Mozambique and Malawi

An external evaluation conducted by the University of Western Cape found that the CBPR and HCD approaches employed in the Let's Talk About Vaccines project contributed to the following outcomes:[1]

- **Effective Community Engagement:** Using caregiver researchers and innovative, photo-based data collection methods successfully engaged communities in Mozambique and Malawi, fostering trust and active participation.
- **Collaborative Ideation:** Extensive collaboration during the ideation (research) phase led to a sense of ownership among participants, which was crucial for the success of the project.
- **Context-Specific Solutions:** Tailored interventions, such as immunization education sessions in Mozambique and community-based scorecards in Malawi, were well-received and aligned with local realities, enhancing adoption and sustainability.
- **Enhanced Understanding and Capacity:** The project improved participants' understanding of vaccination barriers, increased empathy among health care workers and built local health capacity, contributing to long-term positive outcomes.
- **Alignment with Policies:** Co-created interventions aligned with existing government policies and utilized existing structures, ensuring relevance and feasibility.

IMMUNIZATION FRAMEWORKS FOR DATA COLLECTION AND ANALYSIS

Immunization frameworks are valuable tools for informing the design, implementation and interpretation of participatory research and design for routine immunization. These frameworks are critical to the development of any research protocol. Different frameworks may be useful depending on the type of research and approach.

Two particularly valuable frameworks for participatory research and design in immunization are the World Health Organization's (WHO's) *Behavioral and Social Drivers of Vaccination* (BeSD) and UNICEF's Journey to Immunization Map.

UNICEF's Journey to Immunization Framework

The Journey to Immunization Framework, developed by UNICEF, maps the different steps of an immunization journey and encourages thinking about the different, intersecting factors that affect people's attitudes towards vaccination **(Figure 1)**.[4] The steps along the framework encourage consideration of the key factors that affect a patient's immunization experience. These include:

1. **Knowledge & awareness** of the disease, vaccination and immunization services.
2. **Intent to vaccinate:** The gap between intention and behavior and underlying factors such as attitude towards vaccination, subjective norms and perceived behavioral control.
3. **Preparation for vaccination:** Logistical factors such as transportation, childcare and mitigation of opportunity costs.
4. **Cost & effort** of traveling and accessing immunization services.
5. **Point of service,** referring to the immunization service experience, interactions with health workers and health center experience.
6. **After service,** encompassing short-term factors such as understanding next steps following vaccination and getting home from the clinic and longer-term factors, such as side effects, reminders and reinforcement of vaccination as a social norm.

Mapping a patient's journey using this framework can help identify barriers and enablers to vaccination and places where changes could be made to improve the patient experience.[4]

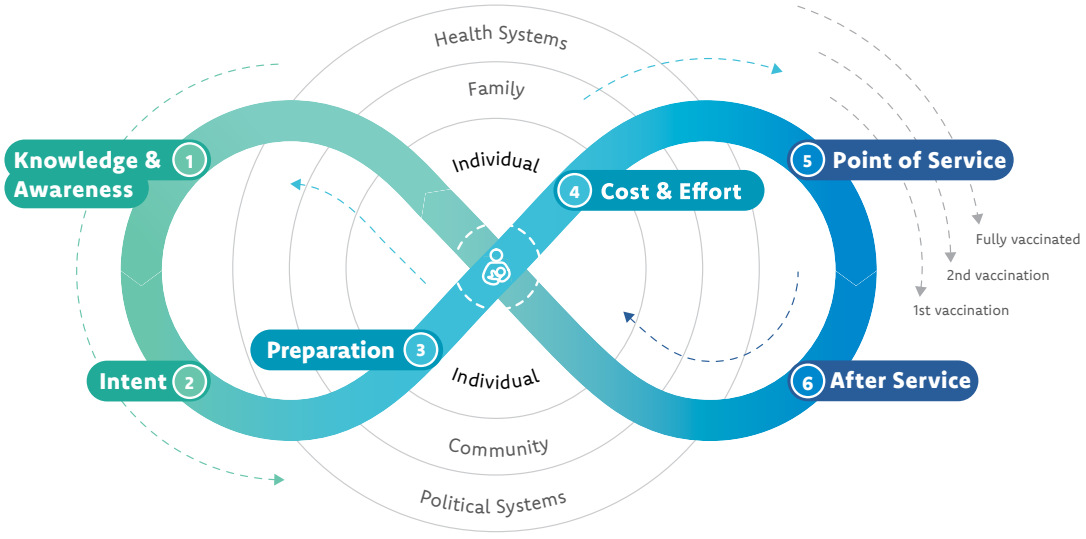


Figure 1. UNICEF's Journey to Immunization Framework

The Behavioral and Social Drivers (BeSD) of Vaccination Framework

The BeSD of Vaccination **Framework** is another valuable tool for understanding the drivers of vaccine uptake and designing interventions informed by socio-behavioral insights.[15] The framework and toolkit are particularly useful to inform the collection, analysis and use of data for immunization program planning and evaluation.

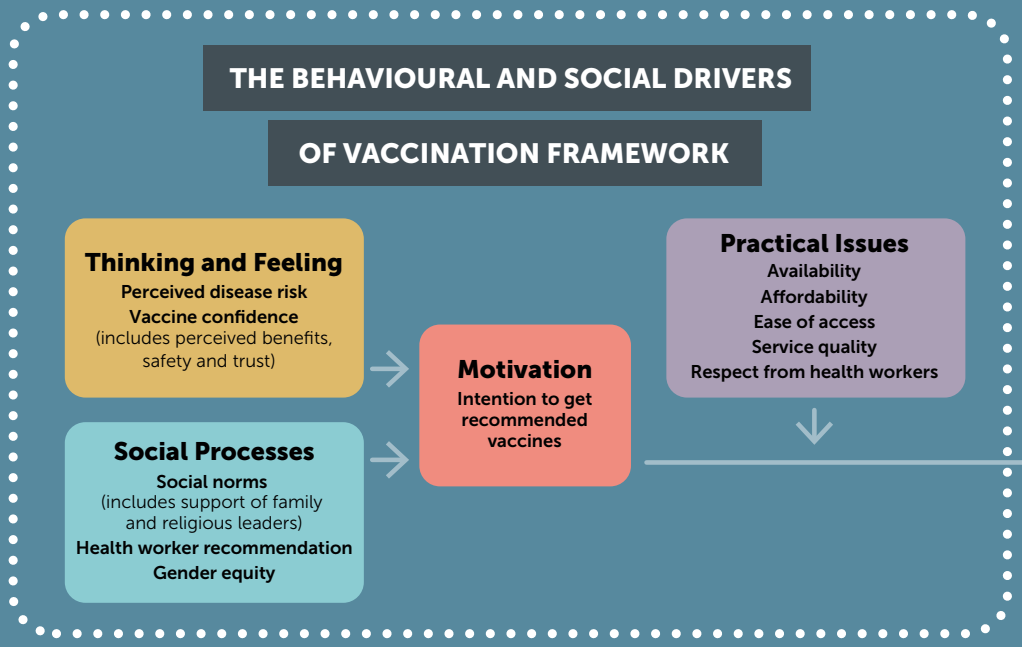
The BeSD of vaccination refers to beliefs and experiences specific to vaccination that can potentially be modified to increase vaccine uptake. The BeSD of vaccination are measured across four domains **(Figure 2)**:

1. Thinking and feeling about vaccines;
2. Social processes that drive or inhibit vaccination;
3. Motivation (or hesitancy) to seek vaccination;
4. Practical issues involved in seeking and receiving vaccination.

When deployed as part of participatory research and design, tracking of BeSD data can provide deeper insights into community beliefs and experiences around vaccination to develop impactful program interventions. WHO has developed a series of validated tools to provide programs and partners with the resources to design, collect and interpret the reasons for low vaccine uptake and systematically design, implement and evaluate interventions.

The surveys and in-depth interview guides can be used as standalone assessments or integrated as part of other data collection activities. The surveys can be administered verbally or adapted to different formats, including online or in-person interviews. When using the surveys as part of CBPR, WHO recommends that at least five BeSD priority indicators should be incorporated, in addition to other questions that are relevant to the community and research objective.

Figure 2.
The BeSD Framework



These tools are available on TechNet-21 along with guidance to support the application of the BeSD framework.[16]

Source: The BeSD working group. Based on Brewer *et al. Psychol Sci Public Interest*. (2017).

Photo credit: Greg Bodwell

Quantitative BeSD questions and response options should not be revised, to maintain validity and comparability, though qualitative questions can be adapted to fit the research context. For example, the Indian non-profit Sangath's iHEAR team adapted the BeSD framework to map the unique needs of the transgender and intersex community and people living with disabilities around access to vaccination.

ESTABLISHING AND SUPPORTING YOUR RESEARCH TEAM

Establishing the right research team is critical when using participatory methodologies. In addition to qualitative researchers and immunization specialists, teams should include a representative from the national level Expanded Programme on Immunization (EPI) and community researchers (as community leaders or community representatives). Engaging national EPI in the team is important to ensure that the research and design align with EPI priorities and the institutional buy-in can help to ensure that logistical aspects of the study or solution implementation proceed smoothly.

Establishing the right research team is critical when using participatory methodologies.

Community researchers should represent the key study population(s) and meet similar inclusion criteria as participants. This representativeness enables community researchers to build rapport with participants, making them feel more comfortable sharing their experiences and perspectives while also ensuring that findings are interpreted appropriately.[17] While experience in qualitative research can be helpful, it is often less important than having researchers who represent the study population and are enthusiastic and willing to engage with the research topic.

Another key consideration for community researchers is their language skills. They should be able to communicate with other study team members and be comfortable working in the languages spoken by participants. In areas with multiple local languages, it's helpful to ask health workers at the selected study sites to provide insights on which languages the study population tends to use.

Recruitment for community researchers can begin after study sites have been identified or narrowed down to specific lower-level administrative areas. Job postings for community researchers can be posted on online platforms, but should also be advertised through more accessible channels, such as flyers at health facilities and markets or announcements by community leaders or other community groups in the study sites.

Tips for Hiring Community Researchers

Depending on your organization or institution's hiring policies, community researchers may be hired as contractors with the expectation that their hours of work will likely vary over the course of the study. One potential risk is that community researchers may feel that they do not have job security and may leave the research team to pursue other, more permanent employment opportunities. To mitigate this risk, consider the following strategies:

- **Be transparent and clear** when describing the expectations for the position so that community researchers fully understand their roles and nature of their contracts.
- **During slower periods of the study,** allow community researchers leeway to pursue other part-time employment if it doesn't interfere with their work.
- **Shortlist twice as many candidates** as there are community researcher roles, include all shortlisted candidates in the researcher training (compensating them for their time in training) and hire the best-performing candidates from the training for the researcher positions. This strategy ensures that if a community researcher leaves the team part-way through data collection, there is a potential back-up candidate who has already been trained and can more easily be on-boarded.

Once community researchers are hired, they will need to be oriented to the study objectives and trained in the research methods. Depending on the complexity of the study, a complete training might take between 5 days and 10 days. Key training topics should include:

- Study background and objectives
- Roles and expectations of community researchers
- Principles of qualitative research, including ethics, processes and best practices
- Orientation to specific data collection methods and review of research tools
- Transcription
- Participant recruitment
- Data management
- Piloting data collection tools

It is beneficial to incorporate practice sessions throughout the training so that community researchers can apply the skills they are learning, such as obtaining consent, establishing rapport, and asking probing questions.

GAINING AND MAINTAINING INSTITUTIONAL SUPPORT

While participatory research is community-driven, establishing and maintaining institutional support is essential to ensure solutions are implementable and sustainable beyond the research project. An important initial step is identifying institutions relevant to the research area. In the context of routine immunization programs, these institutions may include the Ministry of Health (at the national and subnational levels), EPI implementing partners, research institutions and non-governmental organizations involved in the implementation and delivery of routine immunization programs.

Engaging these organizations from the onset is critical to ensure buy-in for the project. Establishing intersectoral

collaboration with the diverse stakeholders involved in routine immunization is also an essential part of a transdisciplinary research approach. This collaboration can be strengthened by inviting government stakeholders to serve as co-investigators, ensuring the research aligns with government priorities.

At the start of a project, meetings should be convened with these key stakeholders to share the proposed approach and provide an opportunity for feedback and input into research design as part of a co-design process. This helps ensure that research and potential solutions are culturally relevant and can be feasibly implemented by the different stakeholders involved in routine immunization. Throughout the research, regular check-ins should be set up with relevant institutions (e.g. the Ministry of Health representatives) to provide status updates and allow for feedback and course correction where needed.

Informal communication channels, such as phone calls or WhatsApp messages, can also help maintain ongoing dialogue with government partners. Institutional engagement and buy-in help ensure the long-term sustainability of research outputs, leading to meaningful improvements in routine immunization practices.

TRANSDISCIPLINARY RESEARCH

Transdisciplinary research brings together people from academic and non-academic fields to collaboratively develop and use approaches from different disciplines and co-develop novel conceptual and methodological approaches.[18] This fosters social equality in research participation, allowing all stakeholders, including communities, to co-develop research and solutions. This co-creation process supports knowledge translation and helps address societal challenges through locally generated insights.[7]

Transdisciplinary Teams in Guatemala[7]

In Sololá, Guatemala, a transdisciplinary approach was used to address vaccine hesitancy in Indigenous Mayan communities facing geographical, economic and cultural barriers to health care. The project was implemented by the Universidad del Valle de Guatemala with funding from the Sabin Vaccine Institute and the Royal Society of Tropical Medicine and Hygiene, and sought to address both local needs and national public health priorities. A transdisciplinary team of social and health scientists, along with six youth leaders trained as community researchers, conducted household surveys and interviews with community members from the health sector and civil society to understand the determinants of vaccine hesitancy. The team worked with representatives from the Ministry of Health, local leaders, non-governmental organizations, research institutions and local Mayan authorities to ensure a culturally appropriate approach. Findings were shared in local languages with government health authorities, primary healthcare workers and community leaders.

CONDUCTING PARTICIPATORY RESEARCH

The participatory research process typically involves the following steps:

1. Determine study objectives, frameworks and data collection methods
2. Establish the study team, including EPI and local representatives
3. Identify study sites in collaboration with national and lower-level EPI
4. Request permission from local authorities (both institutional and Indigenous, if applicable) to conduct the research
5. Refine participant inclusion criteria, recruitment methodology and data collection tools
6. Develop and submit research protocol for ethics committee review
7. Recruit, hire and train community researchers as members of the study team
8. Orient and engage relevant health facility staff and community leaders to the study (led by community researchers)
9. Recruit and enroll participants
10. Collect data
11. Process and analyze data
12. Present data or return data to health care workers, local leaders and authorities

This is a rough outline, and the exact sequence of different steps may vary depending on ethics board requirements or other procedures for engaging different branches and levels of government and community stakeholders.

In the following section, we share recommendations and lessons for conducting these participatory research steps within the context of a study on routine immunization.

STUDY SITE SELECTION

The selection of study sites should align with the research questions and objectives. In immunization studies, this typically involves identifying health facility catchment areas. EPI coverage data plays a crucial role in site selection, but input from national or lower-level EPI officials is also valuable. These officials can provide insights on other ongoing immunization projects or contextual factors that may impact the research.

PARTICIPANT RECRUITMENT STRATEGIES

Participant recruitment strategies and inclusion/exclusion criteria depend on the specific research questions and study objectives. However, in the context of immunization research, inclusion and exclusion criteria involve some consideration of children's immunization records and ages.

Identifying Potential Participants

In some cases, potential participants can be identified using an electronic immunization record or health facility vaccination registers. When facility vaccination records are available, it can be helpful to get insights from the health workers about how often caregivers in that community visit other facilities for vaccinations, as this will then impact the completeness and data quality of any individual facility's registers. Engagement with district and facility-level stakeholders early on can help to ensure access to health facility register books.

In cases where facilities do not track individual children's vaccination records (for instance in urban areas with much bigger catchment populations or where it is more common for children to receive vaccines from multiple facilities), other methods are needed to identify a pool of potential participants. Community health volunteers may be able to help in these cases as they are often familiar with young children in their communities and can facilitate introductions to potential participants.

Verifying Vaccination Status

Three main methods for identifying a child's vaccination status are: (1) health facility vaccination registers, (2) vaccination cards and (3) caregiver recall. Health facility registers are most useful for identifying potential participants who meet your inclusion criteria. However, in most cases, vaccination cards, when available, are the best record of vaccination status; if a child's vaccination card conflicts with the health facility records, then we recommend that the card should be considered more accurate, especially in communities where caregivers visit multiple facilities for their children's vaccinations. In cases where there are no health facility registers and the child's health card is missing, then researchers need to use caregiver recall to determine a child's vaccination status.

TIPS TO IMPROVE CAREGIVER RECALL

- Help caregivers recall their child's vaccination visits by relating them to specific developmental milestones.
- Prompt caregivers with reminders of notable events or seasonal activities that may coincide with vaccination visits.
- Provide visual aids showing vaccines administered at different ages and the location of injections on the child's body.

Photo credit: Januário Bila

ADAPTING TOOLS AND FRAMEWORKS FOR RESEARCH

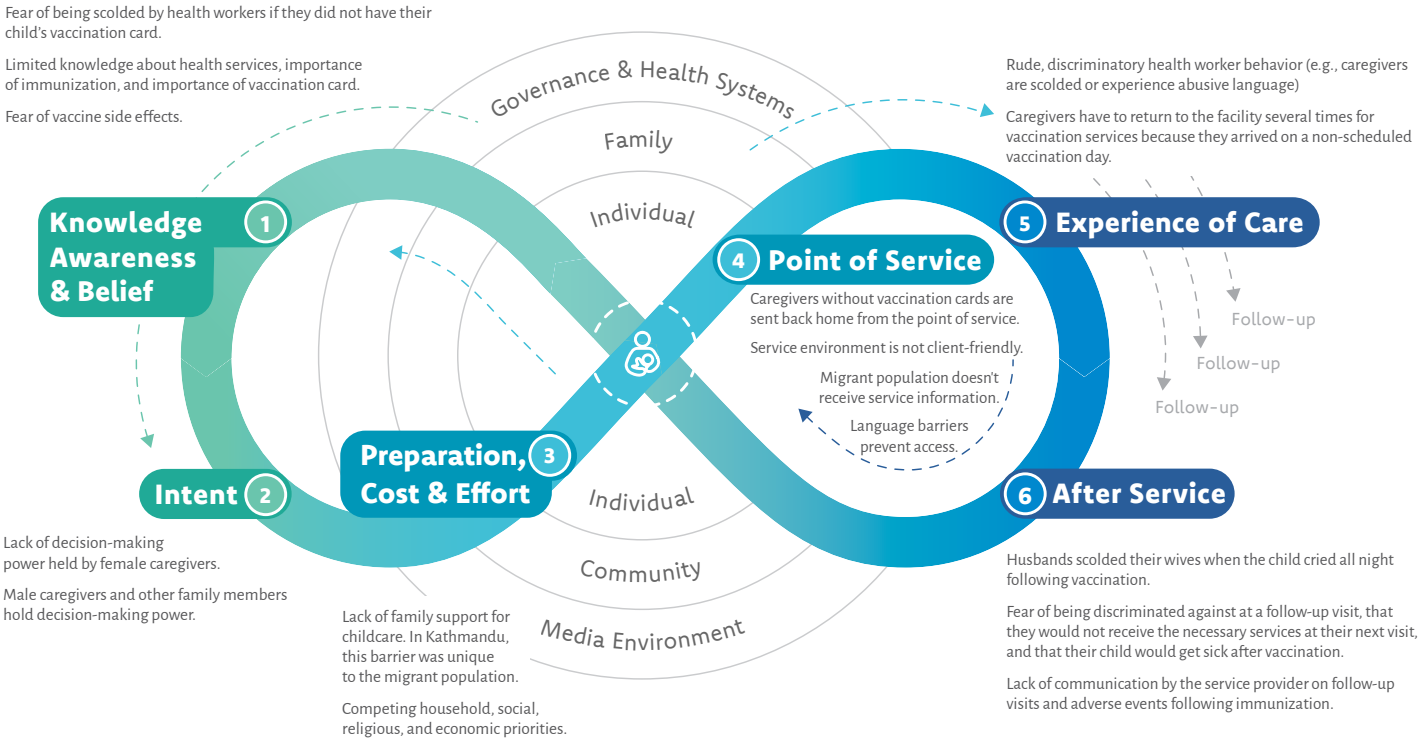
When preparing participatory research protocols, it may be necessary to combine elements from multiple frameworks, such as UNICEF's Journey to Immunization and the BeSD framework, to suit specific study contexts and generate more nuanced findings.

Combining the Journey to Immunization and BeSD Framework in Nepal

In Nepal, the two frameworks were applied to understand where the immunization and health journey could be improved.[19,20] BeSD of vaccination were collected from caregivers, healthcare workers and community health volunteers in Kathmandu and subsequently mapped onto the "Journey to Immunization" framework, providing a comprehensive understanding of the immunization landscape as shown in **Figure 3**.

Several interventions were subsequently implemented to address the identified barriers, including training health care workers on respectful care, HCD and social and behavior change communication and home-based counseling.

Figure 3. Enablers and Barriers Across the Immunization and Health Journey in Nepal



Application of Adapted BeSD Framework in Mozambique[10]

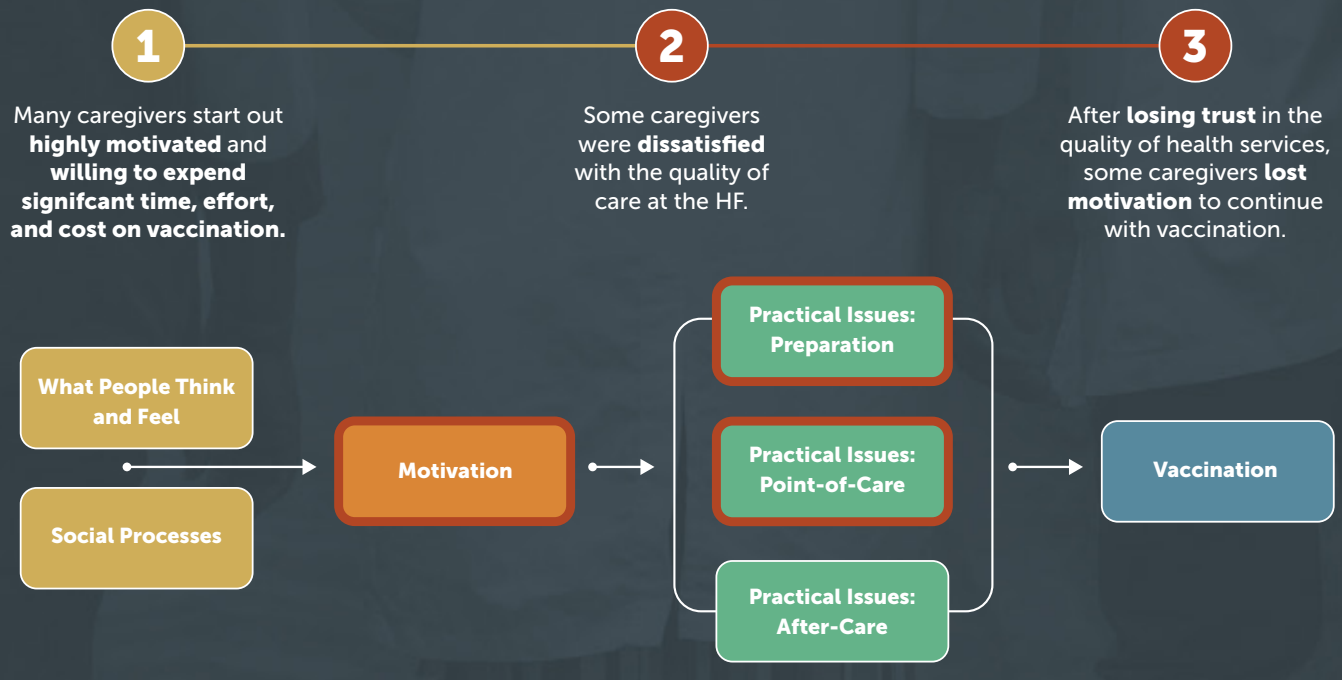
As part of a community-based participatory research project funded by Wellcome, VillageReach, in partnership with the Zambézia Provincial Health Directorate, conducted interviews with caregivers of children under 2 years old and health workers in two districts of Zambézia Province, Mozambique, to identify key influences on immunization dropout. The BeSD framework, along with UNICEF's immunization journey framework, guided data collection and analysis and informed the development of the interview questions and codebook. The BeSD framework was expanded to break down the "practical issues" domain into three phases that were drawn from the UNICEF journey framework: preparation, point-of-care and aftercare.

Applying this adapted framework, the findings revealed four main themes:

1. Social norms and limited family support place the burden of vaccination on mothers, compounding the challenges of accessing vaccination services.
2. Perceived poor quality of health services reduces caregivers' trust in the health system.
3. Concerns about side effects, exacerbated by perceived "accumulation" of vaccines, lead to hesitancy.
4. Power dynamics at the health facility make caregivers hesitant to seek and advocate for vaccination services.

These insights informed two HCD workshops where caregivers, health workers and community members validated the findings and developed solutions.

Figure 4. Adapted BeSD Framework Highlighting a Key Finding: Perceived Poor Service at Health Facilities Reduces Caregivers' Trust in the Health System



EMPLOYING PARTICIPATORY DATA COLLECTION METHODS

Below are summaries of four participatory data collection methods that can be used with caregivers and health workers. Complete details are provided in the appendix. These methods, based on successful experiences from VillageReach and Sabin's cohort teams, may need adaptation depending on the research questions and study context. Data management processes should be in place to maintain research ethics, as these methods generate data stored on cameras, phones and voice recorders. Devices must be secured in the field and data uploaded to a protected folder before devices are wiped clean.

Photovoice: Participants are provided with cameras and take photos to convey their perspectives and experiences in response to a prompt. This method can lead into an in-depth interview (IDI) and can be used to help build rapport with the participant and help them to more accurately remember their experiences.

PROS

- Generates rich data that showcases personal stories and perspectives
- Generates powerful collateral for advocacy and disseminating findings
- Can be engaging and empowering for participants

CONS

- Resource-intensive (requires purchasing cameras)
- Time-intensive (requires 3 visits to each participant)
- Additional ethical issues may arise
- May not be socially or culturally acceptable to take photos in all communities

LOGISTICS

Practical issues: Requires at least 2 visits to each participant, typically about 1–2 weeks apart. We also recommend a 3rd visit to provide the participant printed photos to keep and to recruit for the design phase of the study/project.

Materials: Cameras (including batteries and cables); memory cards

ETHICAL CONSIDERATIONS

- Document consent from all identifiable photographed individuals
- Ethics committees may have additional requirements for ethical approval
- Most journals will likely not allow photos to be published.

Photo-elicitation/Photo Narrative: Participants are shown a set of photos and they select and describe which photos depict their perspectives or experiences. This method can be used at the start of an IDI.

PROS

- Less time- and resource-intensive than photovoice methods
- Visual tools can help participants to reflect on and share their views

CONS

- Not as rich data as photovoice since participants are limited by the available photos

LOGISTICS

Practical issues: This method only requires one data collection visit to each participant.

Materials: A printed set of photos or other kinds of images

ETHICAL CONSIDERATIONS

- Fewer ethical issues than photovoice, but still need consent from anyone depicted in the photo set

SMS Exchanges: Participants regularly send SMS messages to describe their observations or experiences in response to a prompt. Researchers reply and probe for more detail. This method can be used prior to an IDI so that researchers can then probe on notable points that arose during SMS exchanges.

PROS

- Back-and-forth exchange allows researchers to respond to participants' messages and probe for additional detail
- Participants can also send photos or audio recordings for richer data
- Researchers can send regular reminders to participants to encourage them to send messages

CONS

- Network or charging challenges can disrupt regular exchanges of messages
- Not ideal for participants with lower literacy levels

LOGISTICS

Practical issues: This method requires at least two trips to each participant. Use a platform (e.g. Telegram or WhatsApp) that allows you to export the completed message exchanges.

Materials: Phones and data bundles

ETHICAL CONSIDERATIONS

- Participants should be instructed to not send identifiable photos of people. If they send photos of a vaccination card or register books, then any children's or caregivers' names should be covered.

Voice Diaries: Participants use voice recorders to record diaries in which they talk about their observations or experiences in response to a prompt.

PROS

- Can work effectively for users with a wide range of literacy levels
- Allows participants to record their diaries at a time convenient to them
- Works well in geographies that don't have good network

CONS

- Does not allow researchers to react to or probe for more information until after they collect the recorders
- Researchers have no way to track progress or quality of data until after the method is complete

LOGISTICS

Practical issues: This method requires at least 2 visits to each participant.

Materials: Simple voice recorders

ETHICAL CONSIDERATIONS

- No additional ethical considerations beyond normal participant consent

Photo credit: iStock

CONDUCTING PARTICIPATORY ANALYSIS

Community participation in research does not end after data collection; it is equally important to ensure that the data analysis process is participatory to ensure that findings are properly interpreted and relevant to the study community. Including community researchers in the analysis process is one way to ensure that community perspectives are taken into consideration.

Tips for Engaging Community Researchers in Data Analysis

- Conduct **weekly data debriefs** with community researchers to give them an opportunity to provide updates on the data collection progress and to discuss preliminary findings.
- Provide community researchers with an opportunity to **review and validate code books** (including codes, their definitions and exemplary quotations that those codes would be applied to) to ensure alignment in how codes are defined and interpreted within the study contexts.
- Include community researchers as active leaders in developing themes based on the coded data, for instance through a **participatory analysis workshop** facilitated by a study team lead, but with discussion driven by community researchers.
- Present findings back to participants and give them an opportunity to weigh in and adjust or validate the findings. One way to do this is through developing **user personas and journey maps** that represent the key themes and allowing participants to reflect on them during follow-up HCD workshops (discussed in the 'Conducting Participatory Design' section).

Practical examples of participatory analysis in action are shared below.

COUNTRY EXAMPLE 1

Transdisciplinary Team Building to Address Vaccine Hesitancy Among Indigenous Communities in Guatemala[7]

In Guatemala, a transdisciplinary team building approach was used to address vaccination hesitancy among Indigenous Mayan communities. The approach utilized the Youth Participatory Action Research framework, creating a transdisciplinary team of social and health scientists and six youth leaders trained as community researchers. The transdisciplinary team divided into ethnolinguistic groups (Tz´utujil, Kaqchikel and K´iche) to carry out community household surveys and semi-structured interviews with individuals from both the health sector and civil society to understand determinants of vaccine hesitancy.

The team applied a pluri-epistemic data analysis approach, for three types of data:

1) Historical aspects
2) Cultural-linguistic aspects and
3) Contextual aspects of the COVID-19 pandemic and related vaccination strategies.

Six steps were followed for data analysis:

1. Exchange of field notes and collective reflection of the data collection phase.
2. Separate analysis of data and reporting-out per ethnolinguistic group, followed by a synthesis process presenting research findings to all during a transdisciplinary team workshop.
3. A collective analysis of key research findings around historical, cultural-linguistic and contextual determinants.
4. Creation of a joint narrative using storytelling for linking findings and shared results with a culturally pertinent overview.
5. Co-creation of data presentation between scientists and community researchers with the aim of sharing information with key stakeholders in local languages.
6. Presentation of research findings with governmental health authorities, primary health care workers and community leaders.

Photo credit: iStock.com/ltsabby94

COUNTRY EXAMPLE 2

Community-Led Ethnography and Trust-Building in Immunization Programs in Sierra Leone[9]

In Kambia District, Sierra Leone, a community-led ethnographic approach was used to train community health workers (CHWs) in qualitative social science methods, with an emphasis on participatory methods. The project aimed to understand experiences and perspectives of vaccination in the study region to support programming for routine and emergency vaccination.

Led by a team of social scientists and the Kambia District Health Management Team, CHWs received a tailored training program covering qualitative social science, participant observation, ethnographic notetaking, in-depth interviews, focus groups and participatory methods like power mapping and rumor tracking. CHWs practiced these methods in the field with close support from the research team (comprising social scientists/researchers and data analysts).

After collecting data, CHWs reconvened for a collaborative analysis workshop, involving the health management team and lead social scientists. The analysis workshop opened with unstructured discussions about findings, leading to a systematic approach to creating themes through participatory activities and close readings of transcripts and observation notes. The workshop considered how each theme from the collective analysis could be translated into concrete recommendations for improving community engagement around vaccination. CHWs also reflected on their experience as researchers and how it changed their perceptions of vaccine hesitancy. A second phase of the project evaluated local perceptions of the new strategies to improve community engagement.

Photo credit: iStock

COUNTRY EXAMPLE 3

Community-Oriented Approaches for Strengthening Vaccine Delivery and Acceptance in India[6]

In Mewat (Nuh) District, Haryana, India, community-oriented approaches, including participatory analysis, were employed to improve vaccine acceptance and delivery. This area has low vaccination coverage and unique barriers to vaccine uptake. CHWs and leaders were deeply involved in the design, implementation and evaluation of interventions aimed at increasing vaccine uptake.

Phase 1 of the project recruited community leaders to form a Community Accountability Board (CAB), which included CHWs, religious leaders, teachers, council leaders and village elders. The CAB provided input on community acceptance of vaccines and helped design the intervention. The study team conducted qualitative interviews with CHWs and CAB members, as well as surveys with community members, to understand barriers to vaccine acceptance and inform the design of the intervention. Subsequently, two HCD workshops were conducted via Zoom with the CHWs and CAB members to jointly design and refine a proposed intervention from the study team to improve vaccine acceptance. After implementation, the CAB met monthly to review and monitor progress, with feedback incorporated to improve the initiative.

Photo credit: iStock.com/Sudarshan Jha

CONDUCTING PARTICIPATORY DESIGN

CBPR focuses on engaging communities to identify and understand issues related to the research question. By incorporating participatory design into CBPR, the trust and collaboration built during the research phase are extended into the development of practical solutions for the identified challenges and opportunities.

HUMAN-CENTERED DESIGN

HCD principles have increasingly been used to integrate participatory design into CBPR. While comprehensive toolkits for HCD in health and immunization programs are available, the emphasis here is on providing actionable tips for implementing participatory design within CBPR.

Participatory design, rooted in HCD, places people at the center of solution development to ensure that outcomes are meaningful and effective for users. The HCD process typically involves three iterative phases: inspiration, ideation and implementation.[21] In CBPR, the research phase acts as the inspiration phase, focusing on understanding the community's challenges and aspirations. The ideation and implementation phases then involve collaboratively creating and executing solutions to address these challenges and capitalize on the identified opportunities.

The resources in the call-out box provide comprehensive guidance on implementing HCD. By integrating these principles into CBPR, researchers can turn collaborative research insights into tangible interventions and solutions while continuing to build on the trust and respect developed throughout the CBPR process.

Human Centered Design Toolkits and Field Guides

The following toolkits and field guides provide detailed guidance and tools for conducting human-centered design in health programs.

- Human Centered Design 4 Health (UNICEF)[4]
- The Field Guide to Human Centered Design[5]
- Human Centered Design for Tailoring Immunization Programs[22]
- Scope Impact HCD toolkit[23]

BUILDING ON CBPR TO MOVE INTO THE PARTICIPATORY DESIGN PHASE

After completing CBPR research and analysis, the next step is moving into the participatory design phase. Typically, this involves conducting several workshops with stakeholders, including government officials, health workers, community leaders/influencers and most importantly, end users, such as those providing or receiving immunizations, or those caring for them (caregivers). These workshops and sessions usually include:

- **Presenting research findings** to the group and brainstorming ideas to address challenges and seize opportunities.
- **Refining ideas** and prioritizing those that should be implemented.
- **Designing prototypes** and developing implementation plans.
- **Testing prototypes** with users and incorporating feedback.

The toolkits mentioned in the call-out box provide valuable guidance and activities for each phase of this process.

Tips for Conducting Participatory Design

PHASE	TIPS
Preparation for inclusive design workshops	• Ensure diverse participation in the workshops by including government officials who need to provide buy-in, as well as end users like health workers, community health workers and community members. • Anticipate the needs of community members and end users to enable meaningful participation. For example, provide childcare when involving mothers of young children and consider using non-writing activities for participants with lower education levels to allow them to express their ideas and opinions.
Facilitating successful design workshops	Workshops with diverse participants often involve power dynamics. To ensure everyone has a voice, facilitate activities that foster empathy and mutual respect. Consider the following strategies: • **Reflect on Research Results:** Present personas and journey maps from different perspectives to help participants understand various viewpoints. • **Use Icebreakers:** Encourage participants to share their expectations and potential biases upfront. • **Set Workshop Norms:** Establish norms at the beginning to create a respectful environment. • **Facilitate Inclusively:** Ensure all participants have a voice and moderate discussions to balance contributions. • **Consider unique needs:** Offer translation services and non-writing activities for those who might not speak the primary language or feel intimidated by others.
Refining solution/ implementation ideas	To refine ideas into something that is feasible to implement — work with government stakeholders to identify which of the solutions ideated meet the following criteria: • Feasible to implement within stipulated budget • Aligned with government priorities • High potential for impact • Will address multiple barriers/solutions identified in the CBPR phase
Engaging Stakeholders	• Invite a government representative to be a co-investigator on the study team and invite government stakeholders to participate in design and prototyping workshops to foster ownership and buy-in from government • Participate in routine government meetings where project updates or planning are happening. Use these opportunities to provide updates and solicit advice - the key is to not work in a silo. • Engage multi-sectoral stakeholders (e.g. community leaders, religious leaders, other branches of government, partner organizations, etc.) in the design and prototyping process - try to include anyone who might end up playing a role in implementing the co-designed solutions.

Co-Designing Solutions to Address Causes of Vaccination Dropout in Mozambique

In Mozambique, VillageReach conducted participatory research to identify the causes of dropout from the routine immunization schedule from the perspectives of caregivers and health workers. These findings were used in a participatory design process where caregivers, health workers, district and national EPI representatives and other community stakeholders co-created solutions to improve vaccination coverage. VillageReach facilitated two HCD workshops, one in each study site. Each two-day workshop followed these steps:

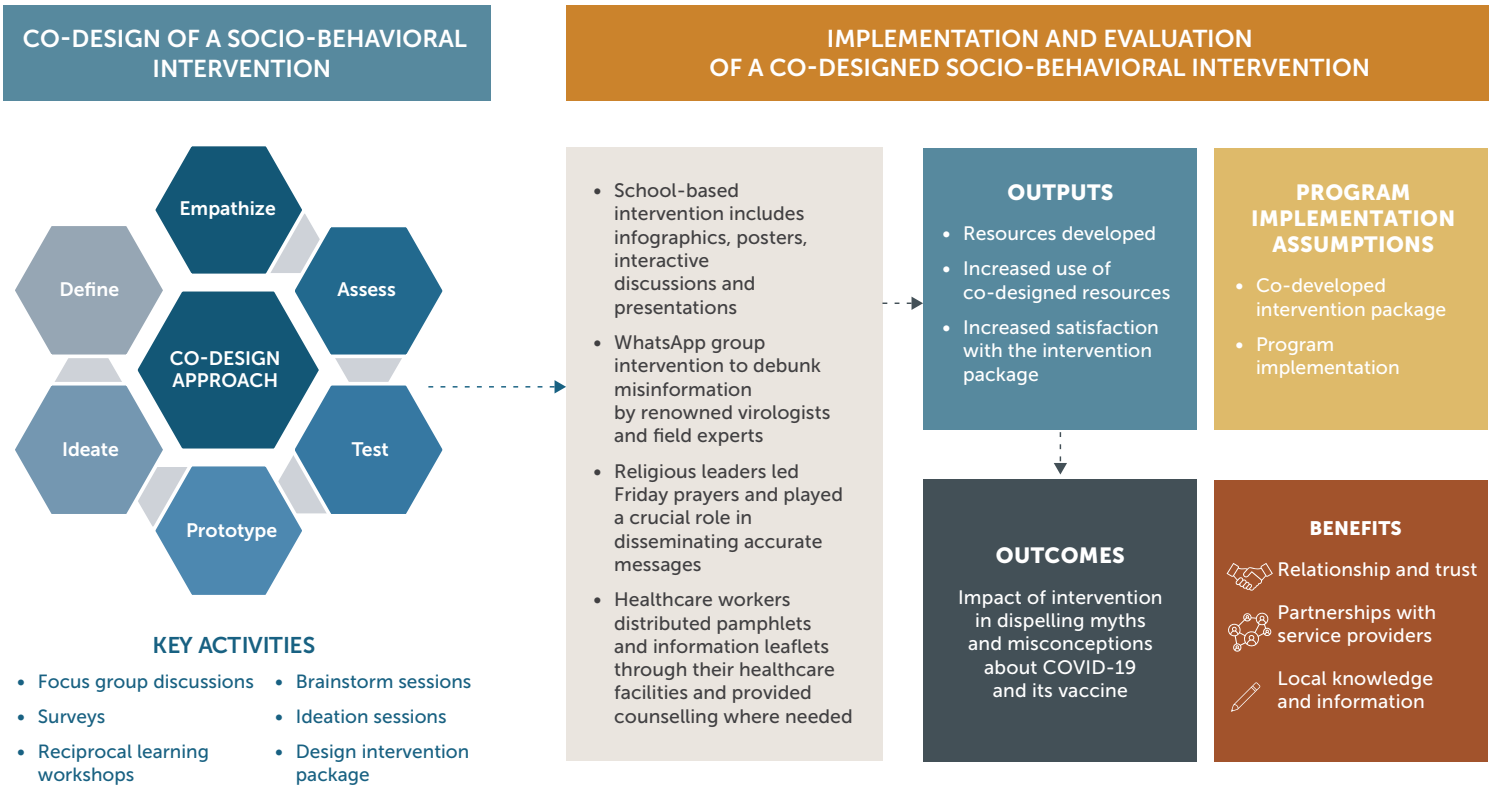
- **Introduction:** An overview of the study was presented, along with the aims of the workshop and importance of community participation.
- **Power Dynamic Balancing Activity:** Participants engaged in an activity designed to acknowledge power dynamics and misconceptions between health workers and caregivers and to create an open and non-judgmental space for co-creation.
- **Personas and Journey Maps:** Findings from the research were presented to the workshop participants in the form of caregiver and health worker personas and journey maps that represented the key themes identified during the research. Participants then reviewed, discussed and validated those findings.
- **Problem Statements:** Facilitators presented three different problem statements/"how can we" statements that were used to guide the solution creation activities.
- **SWOT Analysis:** Participants reviewed the personas and journey maps and identified the personas' strengths, weaknesses, opportunities and threats to identify common strengths and challenges relating to the problem statements.
- **Idea Centers:** Participants moved around the room and visited each of the three "idea centers", where they reviewed the problem statements and SWOT analysis and used sticky notes to either add new ideas or build on existing ideas for solutions to the problem statements.
- **Impact vs. Feasibility Matrix:** Participants discussed the impact and feasibility of ideas generated from the idea centers and facilitators placed each idea in an impact vs. feasibility matrix. For each problem statement, participants voted on 1–2 ideas that had high impact and high feasibility.
- **Prototypes:** Participants worked in smaller groups to generate prototypes for each of the top ideas. They presented these prototypes to the larger group to solicit feedback and then incorporated feedback and refined their ideas into solutions.

Following the workshops, VillageReach presented the co-created solutions to EPI stakeholders to get their feedback on which solutions to move forward with. Subsequent prototyping workshops were conducted to define the solutions in more detail before they were piloted.

Community-Centered Co-Design of Socio-Behavioral Interventions to Counter COVID-19 Related Misinformation in Karachi, Pakistan

In Pakistan, a community-led co-design approach was used to evaluate misinformation around COVID-19 and develop contextual interventions to address misinformation in marginalized peri-urban slum communities of Landhi town, Karachi.[8] A wide range of local stakeholders participated in the co-design process, including pregnant and elderly women, teachers, health care providers, religious leaders, shopkeepers, youth and local government representatives. The co-design methodology followed the stages of the design thinking model (**Figure 5**), with co-design workshops held separately for male and female participants at each stage to design and test locally acceptable solutions.

Figure 5: Study Design Utilizing the Design Thinking Model



Source: Figure adapted from information provided by Qasim R, Dow University of Health Sciences, Karachi, Pakistan.

DISSEMINATION AND PEER-TO-PEER LEARNING

ENGAGING THE COMMUNITY IN DISSEMINATION

Sharing research findings with communities is a core component of participatory research. Community members should be active in the dissemination process and have a say in how findings are shared. Disseminating research insights is important not only to raise awareness and understanding among the community but also to share findings with broader stakeholders to inform actions to address challenges.

Traditional dissemination strategies, such as press releases, policy briefs and reports, often rely on passive, one-way communication from a research group to the broader public.[24] However, meaningful community engagement in the dissemination process requires two-way dialogue. This means incorporating community interpretations of the findings and considering their feedback on dissemination strategies.[19] Participatory dissemination strategies should be built into the project plans as a natural extension of the participatory approach used throughout the design and research phases.

Innovative and creative approaches can be used to co-create and share findings with the community. These may include community theater, storytelling, and contemporary media such as social media videos, podcasts and photo stories, which are gaining popularity as inspiring tools to connect with people in a human-centered way.

Examples of creative and community-focused dissemination strategies:

- **Documentaries:** As part of Sabin's SBRG program, Sabin collaborated with research teams to produce **a four-part docuseries** showcasing the work of grant partners and providing a platform to share local, community stories with a global audience.
- **Comedy film:** In a project among displaced persons of the Karen community on the Thai-Myanmar border, community members created films to improve COVID-19 vaccine demand and supply. Conducted by the International Organization for Migration with support from the US Centers for Disease Control and Prevention, community members held a **comedy film festival** titled "Prevention is Better than Cure", with films scripted, acted, filmed and edited by community members.[19]
- **Photography:** In India, a project using photovoice stories explored structural inequities in COVID-19 vaccine access among transgender persons and people living with disabilities. Participants reflected on their vaccination and health care experiences, co-producing knowledge by discussing their photos and writing their own narratives.

PEER-TO-PEER LEARNING

Learning hubs and communities of practice (CoPs) are valuable resources for those engaged in participatory research to share information and expertise. CoPs bring together individuals with a shared purpose around a community issue, providing a space for peer-to-peer learning and the dissemination of insights. In participatory research, learning hubs and CoPs elevate community concerns and support community-centric approaches in program design.

There are several learning hubs and CoPs that provide spaces to share information, learn and connect with others involved in participatory research on routine immunization. One example is the Sabin Vaccine Institute's Boost Community, a platform for immunization professionals around the world to connect with peers and access resources and trainings to enable them to grow in their careers[25]. The mission of the Boost community is to enable immunization professionals to connect with peers and experts, learn skills that build capacity and advance careers and lead immunization programs in challenging contexts.

Photo credit: Januário Bila

The Boost Community includes initiatives such as:

- **Bright Spots**[26]: A storytelling initiative highlighting grassroots-driven process improvements in routine immunization service delivery at the sub-national level. It offers immunization staff the chance to showcase innovations and explore new approaches.
- **Behavioral Science for Immunization Network**[27]: This network connects immunization professionals and behavioral science experts to explore how behavioral science tools can be applied in immunization programs. The network focuses on both global and country-level insights, sharing practical experiences to increase vaccine acceptance and uptake.

The Vaccination Acceptance Research Network (VARN) is another unique community for global leadership in the application and advancement of social and behavioral science insights, research and expertise on vaccination acceptance.[28] The network comprises multidisciplinary and multisectoral professionals working on evidence-based solutions from research and practice to optimize vaccine acceptance, demand and delivery in low-resourced settings. Many VARN partners are involved in participatory research across LMICs.

For those involved in human papillomavirus (HPV) vaccination research, the Global HPV Consortium is a transdisciplinary, public-private movement to quicken the pace of HPV prevention and cervical cancer elimination.[29] The Consortium unites governments, research organizations, civil society and community-based allies, with participatory research and design at the core of its work.

BUDGETING FOR PARTICIPATORY RESEARCH AND DESIGN

While participatory research and design approaches offer numerous benefits, they can also be resource- and time-intensive. Balancing broad stakeholder inclusion with budget constraints necessitates careful consideration of scope and resource management. To adhere to participatory research and design principles, it is essential to allocate budget for activities and materials that enable meaningful community engagement and ensure that community researchers are fully integrated into the study team.

Photo credit: Januário Bila

Key budgeting considerations include:

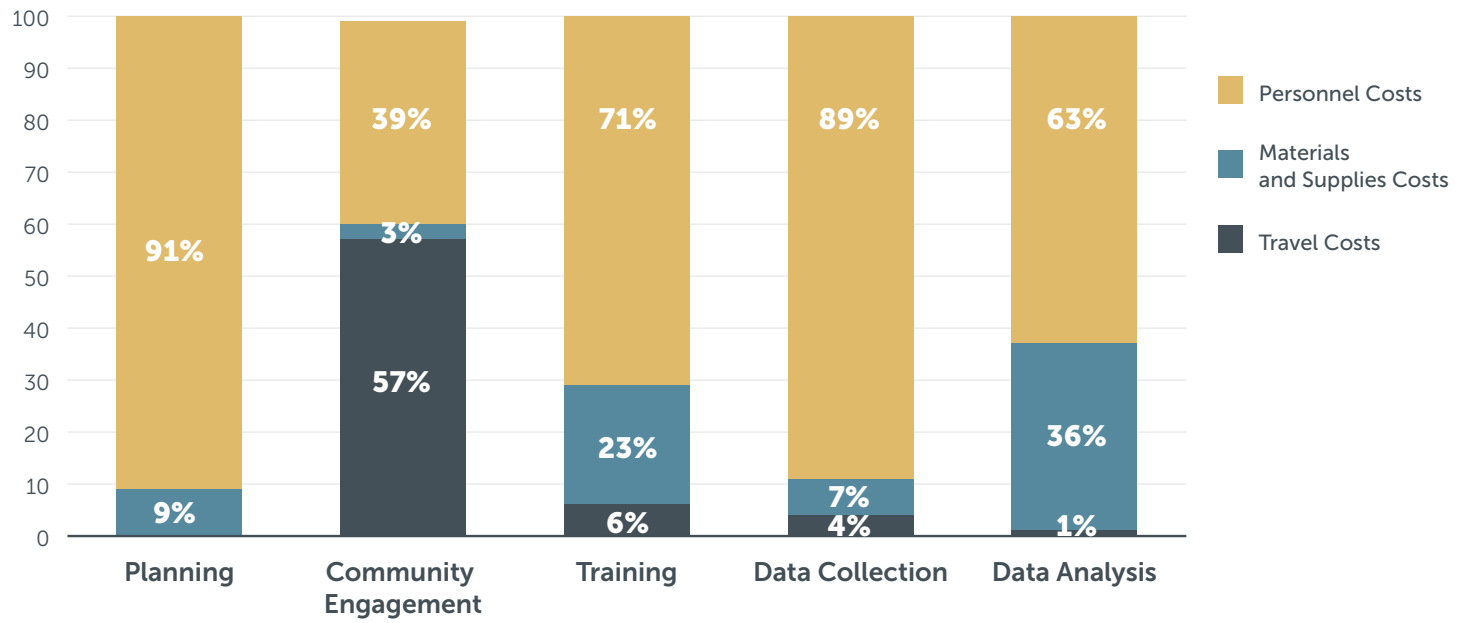
BUDGET CATEGORY	EXAMPLE BUDGET ITEMS	KEY CONSIDERATIONS
Ethics approval	• Institutional Review Board fees	In some countries, Institutional Review Board or Ethics Committee review may be required at the national and sub-national level
Wages for community researchers	• Hourly or daily rate of community researchers over course of project, including analysis, dissemination and publication of peer-reviewed articles	Community researchers should be paid local rates for their time and reimbursed for travel and communication expenses related to the project.
Equipment and supplies for community researchers	• Computers • Internet/phone credit • Phones • Cameras • Audio recorders	To be full team members, community researchers must regularly communicate with the team and have the tools needed for participatory methods. This includes equipping them with computers, phones (if needed) and phone/internet credit.
Data collection travel	• Multiple trips to a community, household or participant for recruitment and data collection	The number of trips to a participant's household or meeting place will vary by method, but multiple visits are often needed. For example, photovoice may require three visits: first to recruit, obtain consent and give instructions; second to review the photos and conduct the interview; and third to return the printed photos to the participant.
Translation and transcription	• Professional translation of engagement and data collection tools • Professional translation and transcription of data • Professional translation of any peer-review publications if done in a different language than spoken by community researchers	If professional translation/transcription is unavailable for local dialects, budget extra time for community researchers to handle these tasks, allowing for additional buffer time due to their lack of professional tools and training.
Trainings	• Training for community researchers on community-based research, ethics and data collection tools • Refresher trainings before implementation of each new phase	Budget enough for in-person training for community researchers and short refresher sessions before each project phase (e.g., HCD). Ensure enough time to allow for practice and community researchers to provide feedback.
Human-centered design workshops	• Multi-day ideation workshop • Multi-day prototyping workshop • Materials that can be used for creative brainstorming and prototyping (colored paper, stickers etc.)	Budget enough time for live translation during the workshops, as community participants, health workers and government officials may not speak the same languages or dialects.
Compensation for participation	• Compensation for participants' time	Ethics committees often require appropriate compensation, which you can inquire about for guidance.
Participatory analysis workshops	• 3–5 day in person workshops for participatory analysis, including community researchers	This can also be done remotely if there are budget constraints. If done remotely, budget for peer-researchers to have good access to internet and to leverage a collaborative online tool such as Miro.
Stakeholder and community engagement	Visits to national and sub-national government officials, target health facilities and target communities at: • Pre-study implementation • Mid-implementation visits • Visits to share results	Whether for methods requiring multiple trips to participants' homes (such as photovoice) or for gaining consent and sharing results, ensure ample budget for meaningful engagement at each project stage, particularly when sharing results. In some contexts, there is a need to rent separate space to host these meetings.
Prototyping	• Materials to create the rough prototypes • Time and travel to prototype and interview target users for feedback	After developing a prototype idea, budget for building a rough version, testing it and gathering feedback from your target users.
Dissemination materials	• Professional design of any collateral • Publication fees • Conference fees (including opportunities for peer participants)	Consider budgeting for dissemination of findings both globally, nationally and back to study sites. This may require producing a wide variety of collateral that meets different audiences' information needs and preferences. It is also important to give community researchers an opportunity to contribute to and provide feedback on peer-reviewed publications and other collateral, which may require translation services.

Cost Considerations of Implementing Participatory Research and Design in Mozambique

In Mozambique, VillageReach conducted bottom-up costing analysis to determine the cost of conducting the CBPR and HCD approach. This analysis identified and estimated the costs associated with each resource used throughout the project's phases. Data was gathered from project financial records, interviews with the project team and detailed reviews of expense reports. Key cost components included personnel costs for caregiver research assistants, government health staff and VillageReach core program staff. Only direct financial costs were considered, excluding indirect or overhead expenses.

The primary cost drivers for both CBPR and HCD were personnel costs (**Figure 6**). The CBPR approach, which relied heavily on caregiver researchers, significantly increased costs compared to traditional methods. Similarly, for HCD workshops, personnel costs were the largest expense, followed by travel/per diem for participant involvement.

Figure 6. Cost of conducting the CBPR and HCD approach in Mozambique



CONCLUSIONS

Participatory research and design are powerful methodologies for addressing complex challenges in global immunization. These approaches foster trust and collaboration between researchers and community members and lead to solutions that are impactful, relevant and sustainable. Beyond improving data collection and analysis, these methods promote sustainable, community-driven solutions that can be adapted across diverse contexts.

We encourage readers to adapt and tailor these methods to their unique environments, recognizing that the flexibility of participatory approaches is key to their success. As you implement these methods, documenting the process, lessons learned and recommendations will be critical for refining future efforts and contributing to a growing body of knowledge on how to effectively and ethically implement participatory methods to improve immunization programming.

By sharing your experiences and insights, you not only enhance your own research but also support peer learning and the continuous improvement of participatory practices across the global health community. Ultimately, these approaches aim to foster sustainable, community-driven solutions and strengthen the relationship between communities and institutions, resulting in more effective and scalable health interventions.

Photo credit: Januário Bila

REFERENCES

1. Shuro L, De Man J, Knight L, et al. The Bate-Papo Vacina! Project in Zambézia, Mozambique. VillageReach, University of the Western Cape, University of Cape Town 2024.

2. International Collaboration for Participatory Health Research (ICPHR). Position Paper 1: What is Participatory Health Research? Berlin: International Collaboration for Participatory Health Research 2013.

3. Hall R, Brent Z, Franco J, *et al*. A Toolkit for Participatory Action Research. Published Online First: 2017.

4. Tudor G, Hickler B. Demand for Health Services Field Guide: A human-centred approach. UNICEF 2020.

5. IDEO.org. The Field Guide to Human-Centered Design. 2015.

6. Dhaliwal BK, Seth R, Thankachen B, *et al*. Leading from the frontlines: community-oriented approaches for strengthening vaccine delivery and acceptance. *BMC Proc*. 2023;17:5. doi: 10.1186/s12919-023-00259-w

7. Sabin Vaccine Institute. Structural Inequities in Vaccine Acceptance, Demand, Delivery, & Decision-Making. Sabin Vaccine Institute 2023.

8. Qasim R, Farooqui WA, Rahman A, *et al*. Community centred co-design methodology for designing and implementing socio-behavioural interventions to counter COVID-19 related misinformation among marginalized population living in the squatter settlements of Karachi, Pakistan: a methodology paper. *BMC Proc*. 2023;17:15. doi: 10.1186/s12919-023-00265-y

9. Enria L, Bangura JS, Kanu HM, *et al*. Bringing the social into vaccination research: Community-led ethnography and trust-building in immunization programs in Sierra Leone. *PloS One*. 2021;16:e0258252. doi: 10.1371/journal.pone.0258252

10. Powelson J, Magadzire BP, Draiva A, *et al*. Determinants of immunisation dropout among children under the age of 2 in Zambézia province, Mozambique: a community-based participatory research study using Photovoice. *BMJ Open*. 2022;12:e057245. doi: 10.1136/bmjopen-2021-057245

11. Powelson J, Kalepa J, Kachule H, *et al*. Using community-based, participatory qualitative research to identify determinants of routine vaccination drop-out for children under 2 in Lilongwe and Mzimba North Districts, Malawi. *BMJ Open*. 2024;14:e080797. doi: 10.1136/bmjopen-2023-080797

12. Sabin Vaccine Institute. Grant Partner Coalition. Vaccin. Accept. Res. Netw. https://www.vaccineacceptance.org/social-and-behavioral-research-grants-program/coalition/ (accessed 9 September 2024)

13. VillageReach. Integrating Community Insights to Build Responsive Primary Health Care Systems. 2023.

14. International Collaboration for Participatory Health Research (ICPHR). Position Paper 2: Participatory Health Research A Guide to Ethical Principles and Practice. Baltimore, USA: International Collaboration for Participatory Health Research 2022.

15. Behavioural and social drivers of vaccination: tools and practical guidance for achieving high uptake. World Health Organization 2022.

16. Behavioural and social drivers of vaccination. TechNet-21. https://www.technet-21.org/en/topics/programme-management/behavioural-and-social-drivers (accessed 9 September 2024)

17. Leung MW, Yen IH, Minkler M. Community based participatory research: a promising approach for increasing epidemiology's relevance in the 21st century. *Int J Epidemiol*. 2004;33:499–506. doi: 10.1093/ije/dyh010

18 . Vogel AL, Stipelman BA, Hall KL, *et al*. Pioneering the Transdisciplinary Team Science Approach: Lessons Learned from National Cancer Institute Grantees. *J Transl Med Epidemiol.* 2014;2:1027.

19. Sabin Vaccine Institute, UNICEF. Vaccination Acceptance Research Network 2023 Conference: When Communities Lead, Global Immunization Succeeds. Conference Report. 2024.

20. John Snow, Inc., Kathmandu University School of Medical Sciences, UNICEF. Understanding the Behavioural and Social Drivers for Under-vaccination of Children in Nepal. 2023.

21. Lauren Landry. What Is Human-Centered Design? Harv. Bus. Sch. Online Bus. Insights Blog. 2020. https://online.hbs.edu/blog/post/what-is-human-centered-design (accessed 22 August 2024)

22. World Health Organization, United Nations Children's Fund. Human-centred design for tailoring immunization programmes. Geneva 2022.

23. Scope Impact. HCD Toolbox & Glossary. Kaleidoscope. https://kaleidoscope.scopeimpact.fi/toolbox (accessed 10 September 2024)

24. McDavitt B. Dissemination as Dialogue: Building Trust and Sharing Research Findings Through Community Engagement. *Prev Chronic Dis*. 2016;13. doi: 10.5888/pcd13.150473

25. Sabin Vaccine Institute. Boost. Boost Community. https://boostcommunity.org/ (accessed 20 September 2024)

26. Sabin Vaccine Institute. Boost Community Bright Spots. Boost Community. https://brightspots.boostcommunity.org/ (accessed 20 September 2024)

27. Sabin Vaccine Institute. Behavioral Science for Immunization Network. Boost Community. https://boostcommunity.org/topics/13897 (accessed 20 September 2024)

28. Sabin Vaccine Institute. The Vaccination Acceptance Research Network (VARN). Vaccin. Accept. Res. Netw. https://www.vaccineacceptance.org/vaccination-acceptance-research-network/ (accessed 10 September 2024)

29. The Global HPV Consortium. Sabin Vaccine Inst. https://www.sabin.org/communities/the-global-hpv-consortium/the-global-hpv-consortium-mission-and-values/ (accessed 10 September 2024)

30. Rutgers International. Photovoice: Facilitators Guide. 2021.

APPENDIX

APPENDIX A: PARTICIPATORY DATA COLLECTION METHODS

Photovoice

Overview: Photovoice is a participatory data collection methodology that empowers participants to capture and discuss photographs representing their perspectives and experiences, facilitating deeper insights and community-driven dialogue on specific issues. Generally, participants capture photos in response to a specific prompt, such as: "For the next two weeks, please take photos of anything that you feel relates to your experience immunizing your child from when they were a newborn up until they were 2 years old."

Pros: Photovoice empowers participants by giving them a tool to visually capture and share their own stories and perspectives, resulting in rich and contextualized data.

Cons: This methodology requires special ethical considerations (described below) and can be time and resource intensive. It may be less suitable for populations with low digital literacy or comfort with technology.

Ethical issues: Potential ethical issues relate to consent and confidentiality of photographed individuals, especially anyone depicted in the photos who is not enrolled in the study and did not sign an informed consent form. Ethics committees may also require additional ethical considerations to comply with different countries' or institutions' policies.

Logistics:

- **Practical issues:** Requires at least 2 visits to each participant, typically about 1-2 weeks apart
- **Tools/materials:** Cameras (plus chargers, batteries, memory cards, etc.); camera instruction sheet for participants; laptops (for researchers and participants to view photos at the start of the IDI); interview guides, consent forms, etc.

Example process:

- **Camera orientation and photo brainstorming (1st visit):** Researchers recruit participants for the study and obtain informed consent from enrolled participants. Researchers instruct participants on how to use the provided cameras and discuss the Photovoice prompt. At this stage, it can be helpful for the researcher to have a "photo brainstorming" session with the participant by asking them to think about the prompt and talk about what kinds of photos they might take. The researcher can ask for more details or ask probing questions to help the participant brainstorm how to visually depict their perspectives and experiences. The researcher and participant should agree on a date when the researcher will return for the follow-up interview.

- **Taking photos:** Participants take photos with the provided cameras. The time required for this step of the process is variable depending on the Photovoice prompt, but typically requires at least one week so that participants have enough time to fit the Photovoice activity into their schedules.
- **Photo discussion and interview (2nd visit):** Researchers return on the agreed-on date to collect the photos and cameras and to conduct the main interview. Researchers begin the interview by loading the photos onto a laptop and asking the participant to select roughly 4–5 photos that they feel best represent their experiences or perspectives in response to the Photovoice prompt. Researchers discuss each photo with the participant to better understand what the photo depicts, how it represents their experience, why it is important to them, etc. After discussing each photo, researchers continue with any other semi-structured interview questions.
- **Photo distribution (3rd visit):** To thank the participant for taking the time to engage in the Photovoice activity, we recommend printing and delivering copies of the participant's selected photos.

Challenges and mitigation strategies:

- Challenges ensuring privacy and consent of photographs depicting people apart from the participant. → Develop robust ethical guidelines for how to obtain informed consent from any people depicted in photos or for how to securely anonymize photographs. Exact procedures may vary depending on your own institution's photograph policies as well as on different ethics committees' standards for photographs.
- Populations with lower digital literacy may not feel comfortable using cameras. → During the first visit, researchers should spend time showing the participant how to use the camera and then giving the participant time to practice until they feel comfortable. Researchers can also leave participants with an instructions sheet that visually depicts how to use the camera.

Additional resources and examples:

- **Photovoice Training Facilitator's Guide:** This tool can be used by research teams to help train community researchers to conduct photovoice research.[30]
- **Mozambique Example:** Determinants of immunisation dropout among children under the age of 2 in Zambézia province, Mozambique: a community-based participatory research study using Photovoice.[10]

Photo-Elicitation/Photonarratives

Overview: Photo-elicitation or Photonarrative is a data collection method in which an existing set of photos or images is used as a tool to help participants' visually craft a narrative and talk about their experiences and perspectives on the research topic. Researchers can show participants a set of photos and ask them to reflect on each of the photos individually and talk about how their own experience compared to what is depicted

in each photo or can ask participants to select photos that they feel relate to their own experiences or perspectives.

Pros: Photo-elicitation is logistically much easier than photovoice and requires fewer resources to implement. The use of photos still enables participants to engage visually and can help prompt them to remember their experiences in more detail.

Cons: Participants are generally limited to selecting only photos from the provided photo set. This can limit their ability to craft their own stories and can result in certain nuances being missed. Developing the initial photo set requires researchers to already have a hypothesis and to make assumptions about which photos will be most relevant to the participants' experiences.

Logistics:

- **Practical issues:** This method only requires one data collection visit to each participant.
- **Tools/materials:** A printed set of photos or other kinds of images — the research team can take these photos during early phases of the study such as site selection or while piloting tools.

Example process:

- Generate a set of photos or images: Drawing from existing literature related to the research topic, the study team (including community researchers) brainstorm a list of types of photos or images to include in the photo-elicitation photo set. Researchers then visit the study sites and take photos aligning to the planned list. The study team reviews photos and narrows down the final set of photos to include in the tool. These photos should be printed prior to data collection.
- **Conduct photo-elicitation interviews:** After introducing the study and obtaining informed consent, researchers begin the interview by asking the participant to look at the set of printed photos and to select the 5 photos that they feel most closely relate to their own immunization experience (or adapt this prompt based on your specific study objective). After the participant selects 5 photos, the researchers go through each photo individually and ask the participant to describe what they see in the photo, how it relates to their experience and why it's important. Researchers can ask additional probing questions about the photos in line with the study questions. After discussing the photos, researchers conduct semi-structured interviews to also collect data on topics that may not have arisen during photo discussion. (*Note: there are many ways to incorporate photos into an interview — this is just one example of a simple way to use photos to enhance an interview*).

Challenges and mitigation strategies:

- Initial photo sets may not capture the full range of images needed to represent all participants' experiences → Involving community researchers in taking or selecting the photos as well as piloting the tools multiple times can help ensure that photo sets are complete.

Additional resources and examples:

- Malawi Example: Using community-based, participatory qualitative research to identify determinants of routine vaccination drop-out for children under 2 in Lilongwe and Mzimba North Districts, Malawi.[11]

SMS Exchange Interviews

Overview: SMS exchanges are a data collection method that allow researchers to dig into a participant's repeated experiences of an activity or event, such as a health worker's experiences during immunization sessions. Participants are prompted to regularly send the researchers SMS messages in response to a prompt relating to the research question. Researchers then reply to the SMS messages to probe into more detail. Researchers can also ask for additional details about observations or experiences that arose during the SMS exchanges when they conduct follow-up interviews.

Pros: This method allows for real-time data collection on a participant's experiences and day-to-day activities relating to the prompt. Back-and-forth exchange allows researchers to respond to participants' messages to probe for additional detail. Researchers can send regular reminders to participants to encourage them to send messages.

Cons: This method is reliant on both researchers and participants having at least somewhat reliable phone network and phone charging. This method may not work as well for participants with lower literacy levels, though depending on the platform being used, this challenge can be mitigated by allowing participants to exchange voice messages instead of texts.

Logistics:

- **Practical issues:** This method requires at least two trips to each participant. Using a platform such as WhatsApp or Telegram may make it easier to export and download the message exchanges after the data collection is complete.
- **Tools and materials:** Participants who do not have their own phones need to be provided with phones to use for the data collection period. All participants should be provided with a data or texting bundle.

Example Process:

- **Orient participants and set up phones and chats**: After recruiting participants and obtaining informed consent, researchers explain the purpose and process for the SMS exchange data collection. Researchers provide phones to any participants who do not have their own or whose own phones do not have the right capabilities. They then help participants set up accounts on the messaging app that the research team decided to use and orient them on how to send both text messages and voice messages. The researchers then initiate a chat exchange or chat group with the participant. Researchers instruct participants to send messages in response to the prompt and leave participants with a print-out of the prompt as a reminder to send messages.
- **Message exchange period:** Over a defined time period (e.g. 2 weeks or 1 month), participants send messages to the researchers in response to the prompt. Researchers respond to the messages with probing questions to ask for more details. If participants don't send any messages for

more than 3-5 days, researchers send the participants a reminder of the prompt and encourage them to send messages.

- **Preparation for follow-up interview:** Prior to the follow-up interview, researchers review the message exchanges and note any specific exchanges they want to follow up on during the interview.
- **Follow-up interview:** Researchers return to conduct a follow-up semi-structured interview. They begin the interview by asking for more details about important topics or observations that arose during the message exchange. Then, the researchers continue with the remainder of the interview questions.

Challenges and Mitigation Strategies:

- Participants of lower literacy levels may not be comfortable writing and reading messages → researchers can provide the option of exchanging voice messages over the platform instead of texts.
- Poor network or charging may hinder message exchanges → alternative methods, such as Voice Diaries (described below), may be more appropriate in those contexts.

Voice Diaries

Overview: Voice Diaries is a data collection method in which participants use simple voice recording devices to record a 'diary entry' in response to a prompt. This method is similar to the SMS exchanges in that it tends to work well when a participant has a repeated experience of an activity or event and uses the diary to reflect on each iteration of the experience.

Pros: This method can work effectively for users with a wide range of literacy levels. The voice recorders are not dependent on the phone network and participants can use them to record their diaries at a time convenient to them.

Cons: Because this data collection is not 'live', it does not allow researchers to react to or probe for more information until after they collect the recorders and researchers have no way to track progress or quality of data until after the method is complete.

Logistics:

- **Practical issues:** This method requires at least 2 visits to each participant.
- **Tools and materials:** Simple voice recording devices.

Example Process:

- **Orient participants to voice recorders and diary prompt**: After recruiting participants and obtaining informed consent, researchers explain the purpose and process of the Voice Diaries, including the diary prompt. They orient the participant on how to use the voice recorder devices and ask the participant to practice making a voice recording to ensure that they are comfortable using the devices. Researchers leave the participants with a print-out of the diary prompt and a print-out with basic, visual instructions on how to use the voice recorders.

- **Participants record Voice Diaries:** For the duration of the data collection period (e.g. two weeks), participants use the voice recorders to respond to the diary prompt after their experiences with the event or activity of interest. For example, health workers might record voice diaries after each immunization session.
- **Follow-up interviews:** Researchers return to collect the voice recorders and conduct a follow-up semi-structured interview. In this case, researchers will not have time to listen to or reflect on the content of the Voice Diaries prior to the interview but can ask the participant to describe what they talked about in their diaries and then probe for more details.

Challenges and mitigation strategies:

- Researchers have no way to monitor the quality or frequency of the Voice Diaries during the data collection period → researchers can collect contact information from participants and try to contact them after the first week of the Voice Diaries to check on progress and make sure the participant isn't experiencing any technical challenges.

VillageReach is happy to share data collection tools and other participatory research materials upon request.

Photo credit: Greg Bodwell