

Stakeholder Engagement in Global Health Research

A RESOURCE GUIDE





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FOREWORD

Progress toward sustainable development requires collaboration that encompasses a wide range of perspectives, knowledge, and resources. No single person, professional group or organisation can identify and execute solutions to major global health challenges. As a result, there is both a need and an opportunity for each individual actor, as well as for society as a whole, to work together to tackle these challenges. As a key part of this process, it is essential to recognise that individuals affected have the right to voice their experiences and play a significant role in decisions and actions.

For all of the above reasons we, at the NIHR Global Health Research Unit on Respiratory Health [RESPIRE], believe that practising stakeholder engagement in health research is vital for long-term sustainability and impact. We have spent the last five years learning and building standards and best practices for incorporating stakeholder perspectives into the research process and decision-making. We have produced this guide to share our learning and experiences with public health researchers and development practitioners. It provides insights into ways to involve and engage stakeholders in health research and to translate evidence and knowledge into practice, ultimately improving the health and lives of people. We hope you can use and adapt this resource guide in your own journey of research and sustainability.

We are grateful to the National Institute for Health and Care Research for funding support and encouragement in involving stakeholders in our research. This resource guide would not have been possible without the valuable inputs and time spent by RESPIRE researchers, stakeholder engagement champions and stakeholders from Bangladesh, India, Malaysia and Pakistan. We would like to thank all our colleagues from the University of Edinburgh and the International Primary Care Respiratory Group and our partners for their collaborative efforts in bringing this resource together.

ABOUT THE RESOURCE GUIDE

Breathing...something as simple and essential for life is a challenge for millions of people around the world. Acute and chronic respiratory diseases affect the lungs, causing breathlessness and resulting in infections, hospital admissions, high costs for individuals and families, strain on health systems, reduced productivity and quality of life, and even death. The number of people affected by respiratory diseases has only increased, particularly in low- and middle-income countries.

In 2017, the UK National Institute for Health and Care Research (NIHR) funded 'RESPIRE', a Global Health Research Unit that focuses on improving respiratory health in Asia. The RESPIRE collaboration spans across Asia with organisations in Bangladesh, India, Malaysia and Pakistan working in partnership with the University of Edinburgh and the International Primary Care Respiratory Group. Together, they mapped the burden of respiratory diseases in this region and tested interventions with the potential to reduce illness and deaths.



RESPIRE team members from Bangladesh, India, Malaysia and Pakistan attended the Annual Scientific Meeting in Kuala Lumpur, Malaysia in 2019

Over five years, the RESPIRE partnership conducted 52 research studies covering acute and chronic respiratory diseases and COVID-19 and including feasibility testing of diagnostic and management interventions with the potential for scale up within the local health systems. Across the four countries, RESPIRE partners facilitated skill development of 300+ primary healthcare staff and capacity building of local research teams through twelve doctoral, four postdoctoral fellowships, and several online courses and workshops. Every year, RESPIRE researchers convened at Annual Scientific Meetings across programme countries (see the image above from the meeting in Malaysia) to share their research findings, lessons learned, and actionable recommendations with relevant stakeholders.

WHAT IS THE PURPOSE OF THIS RESOURCE GUIDE?

At the outset, RESPIRE established a Stakeholder Engagement Platform, inviting country research teams to reflect on their stakeholders, consider who and how to engage in all the stages of the research studies. The goal was to ensure that the research reflected local priorities and needs, used local knowledge and experience, was disseminated widely, and, in some cases, translated into practice. Initially, some country teams found this process challenging, particularly while dealing with the initial stages of finalising research contracts, funding, recruitment and ethical approvals. However, the teams committed to the principle of stakeholder engagement, resulting in this resource guide after five years of learning.

RESPIRE researchers engaged with a wide range of stakeholders including patients, caregivers, community members and leaders, frontline health workers, healthcare providers, public health managers and policy-makers, media and other researchers and development partners. This resource guide narrates the journey of engaging stakeholders in a global health research programme and provides lessons and resources that can be adapted by public health researchers and development practitioners to enhance the relevance and impact of their work.

Additionally, this resource guide provides guidance for researchers and development professionals writing grant applications for global health research funding, offering them a roadmap to conceptualise, plan, and budget their stakeholder engagement approaches.

Lastly, the resource guide outlines the five essential steps of stakeholder engagement (see figure 1), constituting a continual process for developing and sustaining meaningful relationships with stakeholders.



Figure 1: Five steps of stakeholder engagement

WHAT DO WE HOPE TO ACHIEVE WITH THIS RESOURCE GUIDE?

1. Provide step-by-step guidance for engaging a diverse range of stakeholders in a timely, contextual, and transparent manner.
2. Offer simple tools and templates for developing and implementing stakeholder engagement plans tailored to local contexts and linked with planned outcomes.
3. Encourage readers from diverse settings to compare their stakeholder engagement strategies and identify best practices applicable to global health research programmes.

WHO CAN BENEFIT FROM THIS RESOURCE GUIDE?

- Researchers
- Stakeholder engagement coordinators and practitioners
- Research project managers
- Public health practitioners
- Development professionals
- Anyone interested in collaborative work with stakeholders in research studies or development projects

HOW DOES THE RESOURCE GUIDE WORK?

This resource guide is divided into six chapters. In each chapter, we:

- Outline the learning objectives.
- Define and explain key concepts and frameworks.
- Provide a reflective exercise.
- Offer practical case studies from our RESPIRE partners in Bangladesh, India, Malaysia, and Pakistan.
- Provide easy-to-use tools and activities.

Welcome to this journey of exploring and practising stakeholder engagement in global health research. We appreciate your use of this resource guide and hope it enhances your understanding of meaningful and impactful stakeholder engagement.



Diverse stakeholders discuss palliative care requirements and solutions for individuals with Chronic Obstructive Pulmonary Disease (COPD) at a workshop led by Universiti Malaya in Malaysia.

CHAPTER 1

WHAT IS STAKEHOLDER ENGAGEMENT AND WHY IS IT IMPORTANT IN HEALTH RESEARCH

LEARNING OBJECTIVES

By the end of this chapter, you will be able to:

- Identify stakeholders for your research study
- Define stakeholder engagement
- Outline the benefits of stakeholder engagement in health research

WHO ARE THE STAKEHOLDERS?

A stakeholder is any individual, group or organisation that has an interest in or is affected by your research study and its outcomes.

This wide definition can include anyone who is directly or indirectly impacted by your research study. It also encompasses those who may have an interest in the study or the power to influence its outcomes, either positively or adversely. A stakeholder does not have to be a direct user of the health intervention being tested in order to be influenced or affected by your research study or its outcomes. This means that you could have several stakeholders for your research study, such as those outlined in figure 1.1.

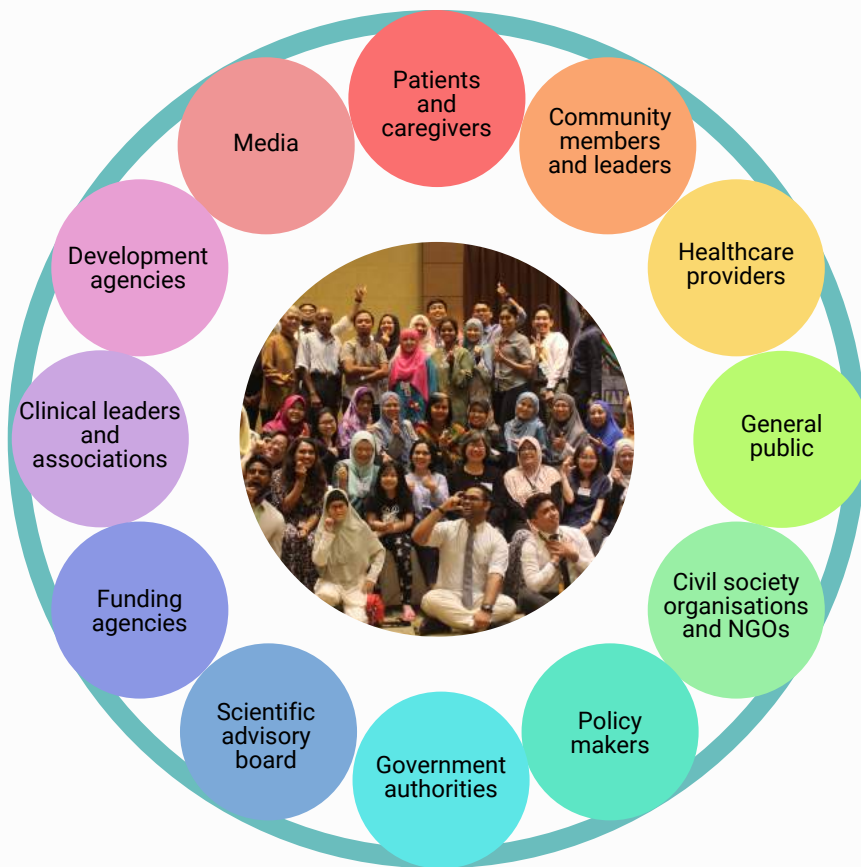


Figure 1.1: Potential stakeholders in a research project
(Malaysian RESPIRE team in the image)

WHAT IS STAKEHOLDER ENGAGEMENT?

Stakeholder engagement is an iterative process of working with relevant stakeholders with a clear purpose to achieve mutually agreed outcomes.

Stakeholder engagement aims for 'mutually agreed outcomes.' This means working on issues that are equally important to you and your stakeholders, involving them at an early stage, being transparent, and agreeing on an appropriate process and goals that add value to both parties.

Stakeholder engagement involves a bi-directional relationship. It ensures that relevant stakeholders are identified and included throughout the research process. They can contribute to prioritising a research topic and questions based on local needs, designing and implementing the study, and translating the findings into practice. Identifying stakeholders during the planning phase and understanding the reasons for engaging each stakeholder at every stage of your research study are crucial for meaningful and impactful engagement.

Stakeholders can play multiple roles in your research study. Explore and understand these possible roles so that you can identify the mutual benefits of involvement, persuade them to participate, get their buy-in and support, and develop lasting partnerships that can extend beyond your study. See table 1.1 for the list of potential stakeholders in a research study and the possible roles that each stakeholder could play.

Table 1.1: Possible roles of stakeholders in a research study and the benefits engaging them

STAKEHOLDERS	ROLES AND BENEFITS
Patients and caregivers	<ul style="list-style-type: none"> • Actively lead or participate in identifying research priorities and developing the research design. • Collaborate on grant applications as co-applicants. • Share lived experiences to influence what data are considered important, inform and guide all stages of the research study. • Share powerful testimonies for advocacy with policy-makers.
Community members and leaders	<ul style="list-style-type: none"> • Determine local priorities and support researchers in developing ideas for studies. • Facilitate community support and ownership for the study. • Support with recruitment and addressing barriers in study implementation. • Disseminate research evidence widely.
Healthcare providers	<ul style="list-style-type: none"> • Collaborate on research studies as co-investigators. • Facilitate permissions for conducting the study in health facilities. • Act as gatekeepers for gaining access to study participants. • Assist in training researchers, obtaining informed consent from study participants, and data collection. • Provide advice in data analysis and interpretation. • Promote the integration of findings into policy and practice.
General public	<ul style="list-style-type: none"> • Support in the dissemination of research evidence. • Adopt and practice research-based recommended actions. • Promote recommended actions.

STAKEHOLDERS	ROLES AND BENEFITS
Civil society organisations and Non-governmental organisations	<ul style="list-style-type: none"> • Establish local priorities and assist researchers in developing early ideas for the study. • Mobilise local communities to generate their support and ownership for the study. • Assist in overcoming any obstacles and gaining community support for study implementation and the use of research findings.
Policy makers	<ul style="list-style-type: none"> • Guide research prioritisation and study development. • Collaborate as co-investigators in the study. • Provide approvals to facilitate study implementation. • Influence and facilitate the integration of research evidence into health policy and practice.
Government authorities	<ul style="list-style-type: none"> • Contribute to the identification of research priorities. • Provide approvals and support in data collection. • Offer feedback on research findings and how they can be used to improve local health services. • Influence the adoption of findings into the local health system.
Scientific advisory board	<ul style="list-style-type: none"> • Review, revise, and approve the research study for participants and ensure they are treated ethically. • Ensure the participants and local communities' interests and beliefs are adequately considered. • Allow and promote ethical and responsible exchange of individual participant data.
Funding agencies	<ul style="list-style-type: none"> • Fund research studies. • Promote sharing of data and evidence and linking research with impact in local health systems. • Facilitate capacity strengthening for research and data sharing that will benefit local communities, researchers and health systems.
Clinical leaders and associations	<ul style="list-style-type: none"> • Endorse the research study and galvanise support from the clinical community. • Advise in research design, data collection and interpretation of findings. • Influence patients and decision-makers to adopt research-informed recommended actions.
Development agencies	<ul style="list-style-type: none"> • Facilitate introductions between researchers and influential stakeholders including government decision makers. • Support researchers with resources and networks for data collection. • Harmonise resources to implement research findings and recommended actions to scale.
Media	<ul style="list-style-type: none"> • Increase public awareness of the research study, findings and recommended actions. • Shape public discourse and influence policy-makers to adopt the recommended actions.



STOP AND REFLECT

- What does the word 'stakeholder' mean to you?
- Think of any three stakeholders that you would like to engage or are currently engaging with for your research study.

FUNDAMENTAL PRINCIPLES OF STAKEHOLDER ENGAGEMENT

We have outlined the key principles of stakeholder engagement based on our experiences on RESPIRE.

RESPECT



Being respectful is central to developing successful relationships among stakeholders and this involves active listening, empathy, noting and understanding what is said and how it is expressed, regardless of one's own views and values.

COMMITMENT



Shared commitment among researchers and stakeholders to continuous and sustained stakeholder engagement and relationship building is crucial.

CONSENSUS



Working towards a mutual understanding of priorities, views and motivations will help reach a consensus around decisions and build a strong partnership.

ETHICAL INTEGRITY



Striving for ethical integrity by promoting stakeholder well-being, preventing any harm or risks, and incorporating lessons learned to improve engagement and intended outcomes.

ACCOUNTABILITY



Ensuring accountability involves providing regular feedback to stakeholders on how their interests and views are being addressed, as well as how their contributions impact the research study. It also entails following up on commitments made to them and by them.

INSTITUTIONALISATION



Institutionalisation is essentially embedding stakeholder engagement into organisational practice. This means allocated financial resources, dedicated staff, plans for learning and rewards, all of which make it possible to practise stakeholder engagement across all research studies.



Research team works with local housing board representatives ahead of the community survey in Malaysia.

CASE STUDY 1

PARTNERING WITH LOCAL COMMUNITY STAKEHOLDERS FOR A MULTI-COUNTRY SURVEY IN MALAYSIA

The 4 Country Chronic Respiratory Disease (4CCORD) study was designed to estimate the burden of chronic respiratory diseases in adult populations in Bangladesh, India, Malaysia and Pakistan. As part of the Malaysian arm of this study, the Universiti Malaya planned a door-to-door community survey for determining appropriate and effective diagnostic screening for chronic respiratory diseases.

The research team anticipated several challenges, one of them being poor community participation in the survey. Local community members, including housing board representatives, were identified as important stakeholders for the successful implementation of the survey, and researchers engaged and consulted with this group for their advice. The research team had also set up a Patient and Public Involvement (PPI) group consisting of patients with chronic respiratory diseases and interested public members, and consulted this group across the stages of the research study.

Recommendations from the PPI group and the community stakeholders were considered and built into the study implementation plan. First, researchers were provided with an identification card and dressed in formal attire. Second, permissions from the government authority (police) and community leaders were obtained prior to conducting the survey. By considering local context and knowledge in the research process, the team was able to respond effectively to challenges. Well-managed stakeholder engagement built trust among local communities, ensuring a high level of participation in the survey.



Community members watch a puppet show on chronic respiratory health in a rural village in South India.

CASE STUDY 2

USING PUPPET SHOWS AND STORYTELLING TO PROMOTE HEALTH IN RURAL INDIA

The Rural Unit for Health and Social Affairs at the Christian Medical College, Vellore, designed and tested the feasibility of a community healthcare worker-delivered intervention. This intervention aimed to improve health behaviors in individuals with chronic respiratory disease in rural communities of South India. Given the low levels of health literacy and challenges in reaching rural areas, the research team consulted their community advisory group (consisting of farmers, teachers, leaders and other interested community members) and decided on an entertainment education approach of puppet shows for generating awareness about chronic respiratory disease and garnering support for the research study.

Puppets were created by a research team member using recycled materials. A story, script and dialogues were developed keeping in mind the local language, culture and important health messages. Both comedy and drama elements were included as well as songs to increase the appeal of the puppet show. All of the dialogues were pre-recorded in a local studio so that voice actors did not have to be present on-site for every performance. Local community leaders supported the research team by spreading the word about the puppet shows. For every show, the research team members served as the puppeteers performing the story as recorded dialogues and songs played in the background. Community members attended the puppet shows in large numbers and noticeably enjoyed the performances. Through this innovative approach, community members started talking about chronic respiratory health and became receptive to the intervention tested by the research team, thus demonstrating the mutual benefits of community engagement for the stakeholders and researchers.

ACTIVITY 1

Ideate and make a list of potential stakeholders for your research study. We have presented some potential stakeholders in the table below. Think of one benefit that each stakeholder might have if they get involved in the research study. Then, think of one benefit of engaging this stakeholder for you and your team. Consider these benefits and reflect on how you can use this information to learn more about your stakeholders and persuade them to get involved in your study.

Table 1.2: Determining the benefits of stakeholder engagement

NO.	STAKEHOLDER	BENEFIT FOR THEM	BENEFIT FOR YOU
1	Patient		
2	Caregiver		
3	Family member		
4	Community member		
5	Community leader		
6	Frontline health worker		
7	Patient advocacy groups		
8	Primary healthcare provider		
9	Secondary healthcare provider		
10	Tertiary healthcare provider		
11	Public health manager		
12	Community-based organisations		
13	Clinical leaders		
14	Policy makers		
15	Media		
16	Development partners		

ACTIVITY 2

Practise this activity with a small group of team members. Assign one team member the role of a researcher or a stakeholder engagement lead, while the rest of the team members can play the role of stakeholders such as a patient, a frontline healthcare worker, and a public health manager or a policy-maker.

Next, the researcher should introduce the research study to each stakeholder in one minute. Think of this activity as an elevator pitch. You have met a stakeholder at an event or in a community setting and have a short time to introduce your study and make a connection. Reflect on the language, words, and the tone that you would use when speaking with each stakeholder, and if these change depending on the stakeholder. Avoid any jargon or technical words and simplify your introduction as much as possible.

You can use the following questions to craft your introduction for each stakeholder:

- **INTRODUCE YOURSELF**
- **What** is the topic of study?
- **Who** will you be studying?
- **Where** will the study be conducted?
- **How** will you conduct the study?
- **Why** are you doing this study?
- **CALL TO ACTION**

A call to action is simply what you want your audience to do after listening to your message or something that you want them to remember.

After the introduction, have each role-playing stakeholder give the researcher feedback on what they understood about the study, what they did not understand, and how the introduction could be improved. You can flip the roles and restart this role-play activity so that every team member gets an opportunity to introduce the research study as well as step into the shoes of a stakeholder.

CHAPTER SUMMARY

- A stakeholder is anyone who has a 'stake' or interest in your research study or someone who can affect or be affected by your study and its outcomes.
- Stakeholder engagement is an iterative, two-way process of involving and working with relevant stakeholders to achieve mutually agreed outcomes around the research study and its translation into practice.
- Identifying stakeholders and determining mutual benefits and goals of working together right from the start of your study can yield several benefits and is vital for meaningful and impactful engagement.



NOTES

A series of horizontal dotted lines spanning the width of the page, providing a guide for writing notes.



Researchers from Projahnmo Research Foundation presenting their study on digital auscultation for childhood pneumonia diagnosis to key stakeholders from the Ministry of Health and Family Welfare in Bangladesh.

CHAPTER 2

HOW TO PLAN AND BUDGET FOR STAKEHOLDER ENGAGEMENT

LEARNING OBJECTIVES

By the end of this chapter, you will be able to:

- Assess your existing capacities and learning needs for stakeholder engagement
- Determine what resources you will need and identify opportunities
- Plan your budget for stakeholder engagement

WHY DO WE NEED TO PLAN AND BUDGET RIGHT AT THE START?

Developing a funding application for a research study can be a lengthy process and financial resources are necessary to involve stakeholders in this stage. If stakeholders are not engaged early on, there is a risk that local needs and priorities may not be adequately considered and reflected in the research questions. Importantly, there is no funding for unsuccessful research applications, making it difficult to compensate stakeholders for their time and input in the development stage. Even after you receive funding for your research study, if an adequate budget has not been allocated for stakeholder engagement, it becomes challenging to conduct any engagement activities.

This is why planning and having a realistic understanding of your existing capabilities, needs and resources for stakeholder engagement is essential, even before you involve stakeholders in your research study.

In this chapter, we will take you through four steps to plan and budget stakeholder engagement activities right at the start of your research study, ideally in the study development or funding application phase. Undertaking these steps will give your team a head start in your journey of meaningful stakeholder engagement.

STEP 1: ASSESS YOUR TEAM'S BASELINE CAPACITIES AND RESOURCES

Evaluate your team's baseline or existing capacities (abilities) and resources (e.g., people, infrastructure, finance, materials, guidelines, and networks) for conducting stakeholder engagement. An organisational self-assessment tool (see Table 2.1) can help you determine your team's baseline capacity and identify your strengths and gaps. Follow up this self-assessment with thinking about ways to address any gaps before planning your stakeholder engagement.



Table 2.1: Organisational self-assessment

No.	Please tick 'Yes' or 'No' for each statement	Yes	No
1	Does any staff member in your team have experience in stakeholder engagement? If yes, describe: _____		
2	Does your team have a protocol or process for planning and conducting stakeholder engagement? If yes, describe: _____		
3	Does your team follow a set of guiding principles for engaging stakeholders? If yes, describe: _____		
4	Has your team conducted any research on or is familiar with the local context where the study is taking place? If yes, describe: _____		
5	Does your team have the budget, staff and other resources to support stakeholder engagement throughout the research study and beyond? Describe existing resources and any limitations: _____		
6	Has your team ever mapped relevant stakeholders for a research study? If yes, describe: _____		
7	Has your team identified any relevant stakeholders for this research study? If yes, list the stakeholders: _____		
8	Does your team have any existing relationships or networks with any of these identified stakeholders? If yes, describe: _____		
9	Do you have any plans to monitor the stakeholder engagement activities and its effectiveness? If yes, describe: _____		

STEP 2: DRAW UP A BROAD PLAN

Use the planning tool (see Table 2.2) to explore which type of stakeholders you could possibly involve in each stage of your research study. This can be a long list for now and you might eventually choose to only involve a few of these stakeholders based on your needs and available time and resources.

In this tool, for each stakeholder, think about the objective or purpose of engaging them in each of the selected stages of the research study. Deciding on the objectives from the start of the study can give you clarity in planning your engagement. Additionally, clear objectives can help you track your stakeholder engagement and its impact.

Here are some example objectives for engaging with different stakeholders across the research study cycle:

- Patients could be invited to join a study advisory group which can be consulted across all the stages of the research study, especially in the prioritisation stage where you determine the research topic and questions. Patients could also be supported and trained as co-investigators and as advocates in the dissemination and translation stages.
- Community leaders can be engaged during the research prioritisation and proposal development (for endorsement and support letters), recruitment (for gaining access and entry to sites and participants in local communities) and dissemination stages (as agents of influence within communities).
- Frontline healthcare workers and healthcare providers can be engaged across the study through a study advisory group or in selected stages such as recruitment and data collection as well as translation (using research evidence to improve clinical practice).
- Policy makers (civil servants, bureaucrats, parliamentarians) could be involved as co-investigators or invited to a task force overseeing the study, thereby also influencing accountability for future use of the research findings.
- Clinical leaders or professional medical associations can be engaged during the research design and dissemination phase through in-person or online webinars for their inputs on study design, strategies to reach a wider audience and translation of findings into the local health system.

After setting objectives, develop a broad outline of the possible stakeholders, sample activities for each stakeholder group, resources required, and the desired outcomes (i.e. expected change/s as a result of your engagement) (see table 2.3). This exercise will help you visualise the kind of resources needed (such as people, spaces, money, and any equipment) to plan your budget in the initial stages of the study.

Detailed plans for stakeholder engagement can also be developed after securing the funding and allocating adequate budget for this component (refer to chapters 3-4).

Table 2.2: Exploring possible stakeholders and their engagement across the stages of the research study

Stakeholder	Prioritisation and proposal development	Research design	Ethical approvals	Recruitment	Data collection	Data analysis	Dissemination	Translation into practice
Patient								
Caregiver								
Community leaders								
Frontline health worker								
Healthcare providers								
Public health managers								
Policy makers								
Clinical leaders								
Industry								
Media								

Table 2.3: Broad action plan for stakeholder engagement

Stakeholder	Proposed engagement activity	Research stage	Resources needed	Desired outcome of this engagement activity	Team member responsible for this activity
Patient					
Caregiver					
Community members					
Community leaders					
Frontline health workers					
Healthcare providers					
Public health managers					
Policy makers					
Clinical leaders					
Industry					
Media					

STEP 3: DETERMINE YOUR TEAM AND THEIR NEEDS

With a broad plan in hand, establish which team member(s) will be responsible for stakeholder engagement. Do you have an existing team member with the required knowledge, skills and interest to take on this responsibility or would you need to find an external candidate for this role?

The designated lead should be experienced in or familiar with stakeholder engagement, community mobilisation, public relations and/or communications. They need to be familiar with the research study and the local context and, ideally, have organisational and project management skills.

Determine if you will need other people on your stakeholder engagement team such as a coordinator or administrative assistant or community liaison. Your team should also include a researcher so that the stakeholder engagement activities are closely linked with the research study objectives and outcomes. Most importantly, if stakeholder engagement is to be taken seriously, it needs support and commitment from the senior research leaders and members of the project management team.

Once you have your team in place, think about any potential capacity building or training that your team members might need. Your team members need to have an understanding of the research study protocol and ethical practices and be provided with tools and reporting templates; some members might need training in advocacy and communication skills.

STEP 4: PLAN YOUR BUDGET

Stakeholder engagement is possible only if you have designated people and resources and this will need a dedicated budget. Develop a broad budget for stakeholder engagement and build this into your overall research study budget right at the development and funding application stage.

Use the planning tool (see table 2.4) to discuss possible budget areas with your research team. Identify which areas are 'needs' and which are 'wants;' prioritise the needs or nonnegotiable areas in your final budget. Build in flexibility, if possible, so that after the funding is secured you are still able to reallocate the resources based on your specific plans for stakeholder engagement.

Researchers may not always have the luxury of sufficient or allocated financial resources for stakeholder engagement from the overall research study budget. In some cases, funding comes in much later or is reallocated from the overhead budget or other study components, and in many cases, financial resources are limited. Such challenges are common and should not discourage you and your team.

Try and find creative ways to harmonise existing resources and networks to ensure an adequate level of stakeholder engagement.

Table 2.4: Sample template for planning your budget for stakeholder engagement

Budget categories	Amount	Budget categories	Amount
SALARIES		MEETINGS/WORKSHOPS	
Stakeholder engagement lead		Venue	
Administrative support		Facilitator	
Community liaison		Sound/projector	
Other staff member		Refreshments	
		Softwares	
TRAINING		AWARENESS, DISSEMINATION	
Facilitator		Design and printing materials	
Venue		Audio-visual materials	
Sound/projector		Translation	
Printing		Promotional items	
Refreshments		Web design, software subscription	
PATIENT INVOLVEMENT		OPERATIONAL COSTS	
Honorarium		Communications (phone, internet)	
Transport		Laptop, hard-drive	
Mobile data		Printing	
Venue		Travel	
Refreshments		Accommodation	
Informational materials		Camera, voice-recorder	
SUBTOTAL		SUBTOTAL	
		TOTAL	



STOP AND REFLECT

HOW TO CONDUCT STAKEHOLDER ENGAGEMENT ON A LIMITED BUDGET

LOOK WITHIN:

- If you do not have the budget to hire a full-time professional to plan and coordinate stakeholder engagement for your study, look inside your team for researchers or programme staff who have the skills and experience or even the enthusiasm to take on this role.
- If they are interested, ensure a balanced allocation of job responsibilities, including stakeholder engagement-related tasks. Provide the necessary training and incentives, such as supportive supervision, mentoring, and recognition.

IDENTIFY EVENTS AND SPACES:

- Identify common events where you can meet the local community, healthcare providers or policy stakeholders.
- Invite healthcare providers or public health managers to an event of another relevant study or visit stakeholders at their workplaces with appointments.
- Partner with community leaders who can allow access and entry to local spaces for meetings (e.g., community halls, schools).

MOBILISE COMMUNITY MEMBERS:

- Through community gatekeepers (e.g. frontline health workers or local elected leaders), identify and mobilise community members who are interested in the health problem being studied and want to contribute their skills and time.
- Collaborate with existing community groups, such as self-help or youth groups. These community members can become champions in local communities, assisting in the organisation of stakeholder meetings and dissemination events.
- Within the healthcare system, identify champions who are passionate about change and also influential; these champions can be your allies in gaining the buy-in from other stakeholders in the system.
- Provide incentives to interested community members and champions. These incentives could include accredited training courses and honorariums (subject to local regulations and precedent).

SEEK EXTERNAL FUNDING:

- Apply for any engagement grants offered by research funders.
- Partner with local community businesses, charitable organisations or other interested stakeholders (e.g. private sector or industry) to fund community meetings or dissemination events.
- However, it is important to clarify and ensure that there are no conflicts of interest or undue influence when partnering with external funders for your stakeholder engagement.

VIRTUAL TRAINING WORKSHOPS:

- Conduct virtual meetings, workshops, training programmes, and dissemination events using platforms like Zoom, Microsoft Teams, and Skype for stakeholders with access and comfort using these tools, such as healthcare providers or policymakers.



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RESPIRE Malaysia's Facebook page is used to engage with public stakeholders.

CASE STUDY

MAXIMISING THE IMPACT OF STAKEHOLDER ENGAGEMENT WITH LIMITED RESOURCES IN MALAYSIA

Faced with the challenge of a limited budget for stakeholder engagement across multiple research studies, the team at the Universiti Malaya implemented the following strategies to identify additional resources and ensure meaningful engagement.

Prioritisation of Stakeholders:

The team conducted an extensive stakeholder analysis, identifying key individuals and organisations crucial to the successful implementation of the research studies. This strategic approach optimised resource allocation and forged partnerships with influential stakeholders.

Leveraging Existing Platforms:

The team capitalised on existing forums, national conferences, and local community events to engage stakeholders. This approach proved to be cost-effective, enabling them to reach a broader audience while minimising expenses associated with organising standalone events.

Digital Outreach:

The team used virtual meeting platforms, such as Zoom, to provide regular study updates to stakeholders and gather their input and feedback. Social media forums like Facebook and Instagram were employed to share updates about upcoming events and key research findings, fostering interactive discussions among stakeholders with access to digital media. To ensure accessibility, the team covered nominal mobile data costs, ensuring that certain stakeholders did not have to incur out-of-pocket expenses to participate in online events.

ACTIVITY 1

This activity is best done with a team. Identify a room for this activity and set up three large poster papers on a wall or table. Think of three stakeholder engagement activities that you want to conduct in the immediate future. Divide your team into three groups and assign one stakeholder engagement activity to each group. If you have a small team, then assign each member one activity.

Provide each group or team member with sticky notes and marker pens to ideate and plan the activity, covering aspects including (1) Objectives, (2) Target audience, (3) Agenda, (4) Venue, (5) Facilitator / Resource person, (6) Advertising, (7) Equipment, (8) Refreshments, (9) Logistics, (10) Honorarium, (11) Potential challenges, and (12) Documentation methods (e.g., photography, report).

Each group or team member should write planning points on sticky notes and place them under the relevant stakeholder engagement activity poster paper. Allocate a specific budget to each group or team member that they can use to "purchase" the aspects they have listed on the poster. Groups or team members can negotiate, trade, and collaborate with each other to acquire the necessary aspects within their budget constraints.

Allow time for each group or team member to present their final activity plan, explaining their chosen aspects and budget allocations, and how they plan to effectively engage stakeholders.

Facilitate a group discussion to review the different strategies used by each group and encourage team members to share insights and lessons learned.

CHAPTER SUMMARY

- Identify a designated lead or coordinator, and if possible, assemble a team for stakeholder engagement. Evaluate your team's existing skills and resources for stakeholder engagement right at the start of the research study and organise the necessary capacity building for them.
- Create a broad plan that outlines which stakeholders you might want to involve and in which stages of the research study. This will assist you and your team in planning potential stakeholder engagement activities and allocating an appropriate budget accordingly.
- Ensure flexibility in your budget. Utilise existing resources, platforms, events, and networks to conduct meaningful stakeholder engagement activities, even when facing budget constraints.



NOTES

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Dr. Rutuja Patil presents during the inauguration of a telehealth service at a rural health center in Pune district in India with community and health system stakeholders in attendance.

CHAPTER 3

HOW TO IDENTIFY AND PRIORITISE STAKEHOLDERS

LEARNING OBJECTIVES

By the end of this chapter, you will be able to:

- Identify possible stakeholders for your research study
- Analyse the level of power and impact of your stakeholders
- Prioritise the most relevant stakeholders for your study
- Determine the level of engagement for each stakeholder group

HOW TO MAP STAKEHOLDERS?

Mapping stakeholders and bringing on board the most relevant actors at the start of the research study is the first step in the engagement process. This will ensure that your research questions are developed based on local priorities, context, and the needs of the study beneficiaries. Even if it might not always be possible to involve stakeholders at the start, look for chances to do so as soon as you have the available resources. Stakeholder mapping has three stages: (i) Identify, (ii) Analyse and (iii) Prioritise.

STAGE 1: IDENTIFY POTENTIAL STAKEHOLDERS

Consider any stakeholders - individuals or groups - that are affected by your research study or may be interested in it and its outcomes. Make a list of these stakeholders; this can be a long list! You can use the templates provided in chapter 2 to do so. During this stage, adopt an inclusive approach and consider all potential stakeholders for the study.

Here are some questions that you could use to prepare this list of potential stakeholders:

- Who will benefit from the research study?
- Who holds the most power within your healthcare system?
- Who does not have as much power but would still be affected by the study?
- Who can contribute to the different stages of the study?
- Who could block your study?
- Who can be affected by the outcomes of your study?
- Who could use the findings from the study?

Where can you find potential stakeholders?

- Primary healthcare clinics
- Patient support and advocacy groups
- Community-based groups
- Public health department and agencies
- Non-governmental organisations
- Conferences and events
- Social media
- Other ongoing research studies

What methods can you use for mapping stakeholders?

- Consultations with your team and experts
- Meetings with patients, community leaders and gatekeepers
- Review of published and grey literature
- Personal networks
- Snowballing or asking existing stakeholders to recommend potential stakeholders

Additionally, you can also use the various frameworks or models presented in Table 3.1. You will notice similarities and differences in the types of stakeholders identified across these frameworks but this is largely a matter of classification. You could use one or more of these frameworks to start thinking about the possible stakeholders for your research study. Their value is to ensure you think comprehensively about stakeholders.

While most of the frameworks list stakeholders that are easy to understand, the 9C Stakeholder Model developed by the UK National Health Service (NHS) offers broader categories, each of which can comprise multiple stakeholders. For instance, a 'customer' can be anyone who could use the evidence and knowledge generated by your research study such as a clinician or a policy maker or community health worker. This model also encourages you to think of a 'competitor,' who is a stakeholder that you could collaborate with, or someone with the potential to block your work.

In all your interactions when mapping potential stakeholders, make sure to provide a clear explanation of your research study and its implications. Additionally, emphasise the role of stakeholder engagement in achieving the broader objectives of the research study, such as incorporating patient voices and lived experiences, enhancing clinical practice, improving health service delivery, influencing community-level knowledge and behaviors, and contributing to health policy reform. Discuss the benefits and potential risks (if any) of becoming involved as a stakeholder, and ensure agreement for participation in the study.



STOP AND REFLECT

- What do you think is the difference between research and stakeholder engagement?
- Is it necessary to obtain informed consent from stakeholders, even if they are not research participants?



Table 3.1: Frameworks for mapping stakeholders

9 C Stakeholder Model	Patient-Centred Outcomes Research Institute (PCORI) Model	Center for Medical Technology Policy (CMTF) Model	Tufts-RAND 7Ps Model	Ottawa CGH 6Cs Model	Cochrane Model
COMMISSIONER (those who pay you to conduct research, e.g., funders)	PATIENTS	PATIENTS AND CONSUMERS	PATIENTS AND THE PUBLIC	PATIENT	CONSUMERS AND THE PUBLIC
CUSTOMERS (those you will use your research, e.g., clinicians, managers, policy makers)	CLINICIANS	CLINICIANS	PROVIDERS	PUBLIC	PRACTITIONERS
COLLABORATORS (those who will work with you to develop or deliver research)	RESEARCHERS	HEALTHCARE PROVIDERS	PURCHASERS	PRACTITIONER	POLICY MAKERS AND HEALTHCARE MANAGERS
CONTRIBUTORS (those who provide content for your research study)	PURCHASERS	PAYERS AND PURCHASERS	PAYERS	PRIVATE SECTOR	RESEARCHERS AND RESEARCH FUNDERS
CHANNELS (those who provide a route to your customers)	PAYORS	POLICY MAKERS AND REGULATORS	POLICY MAKERS	POLICY MAKER	
COMMENTATORS (those whose opinions are influential for your customers)	INDUSTRY	INDUSTRY	PRODUCT MAKERS	PRESS	
CONSUMERS (those served by the customers, e.g. patients)	HOSPITALS AND HEALTH SYSTEMS	RESEARCHERS	PRINCIPAL INVESTIGATORS		
CHAMPIONS (those who will promote your research)	POLICY MAKERS	RESEARCH FUNDERS			
COMPETITORS (those doing the same work as you)	TRAINING INSTITUTIONS				

STAGE 2: ANALYSE THE NEEDS AND CONCERNS OF STAKEHOLDERS

Now that you have your list of possible stakeholders, the next step is to analyse their needs and concerns. This analysis will give you insights on how to first approach potential stakeholders, influence them to get involved, and later, to tailor your engagement based on their priorities.

You can use the tool in Table 3.2 to discuss with your team and identify the needs and concerns of your potential stakeholders. You can also consult with experts or even stakeholders themselves by using appropriate channels (e.g., in-person, telephone, email) and methods (individual or group meeting, online form). Table 3.2 contains a suggested list of stakeholders. You can revise and update this based on the most relevant stakeholders for your research study.

Table 3.2: Needs and concerns of potential stakeholders for your research study

NO.	STAKEHOLDER	NEEDS	CONCERNS
1.	Patients	E.g., Need information and skill building in management of the disease.	E.g., Health service being tested is far away from home and results in costly travel fare and loss of wages.
2.	Caregivers		
3.	Family members		
4.	Public members		
5.	Community leaders		
6.	Frontline health workers		
7.	Healthcare providers		
8.	Public health managers		
9.	Policy makers		
10.	Researchers		
11.	Clinical leaders		
12.	Development agencies		
13.	Media agencies		

STAGE 3: PRIORITISE STAKEHOLDERS

Prioritising which stakeholders to engage with and to what extent is crucial, as we often have limited financial and technical resources at our disposal. Now that you have identified stakeholders and explored their needs and concerns, you can use the 'Power-Impact' matrix in Figure 3.1 to categorise your stakeholders into one of the four quadrants and determine the most pragmatic approach for each group.

Understanding the concepts of power and impact is essential for using this matrix. Power refers to a stakeholder's influence over the implementation and translation of your research study. In his 1957 book titled 'The Concept of Power,' the US political scientist Robert Dahl famously defined power as: "A having power over B to the extent that he can get B to do something that B would not otherwise do." Impact is the study's effect on a stakeholder; essentially, how much of a difference your study will make to this stakeholder's life or work.

<p>HIGH POWER High power to block or create change, might be due to position or to the individual</p>	<p>INVOLVE AND KEEP SATISFIED</p>	<p>ENGAGE CLOSELY</p>
<p>LOW POWER Low power to block or create change, might be due to position or to the individual</p>	<p>INFORM AND MONITOR</p>	<p>CONSULT</p>
	<p>LOW IMPACT How much impact it will have on them</p>	<p>HIGH IMPACT How much impact it will have on them</p>

Figure 3.1: Power-Impact matrix for prioritising stakeholders

High power-Low impact: These stakeholders are opinion formers who need to be satisfied with what is happening but may not wish to be actively engaged in your study.

High power-High impact: These are key stakeholders who are interested in your study and have the power to change things, so this group needs to be fully engaged throughout the planning and implementation of your study.

Low power-Low impact: These stakeholders need to be monitored for their reactions but are a low priority if resources and time are stretched.

Low power-High impact: While these stakeholders may have limited or no power, they are affected by your study and should be consulted as they can provide important insights.

Review the Power-Impact matrix regularly and update it as new stakeholders enter the landscape or existing stakeholders move between quadrants as their level of power or impact changes. For example, if a stakeholder who was previously in the Low Power-High Impact quadrant moves to the High Power-High Impact quadrant, you would need to change your engagement approach accordingly. If you do not identify a stakeholder with High Power-High Impact, this should probably revise your plan to actively find and influence such a stakeholder.

While the Power-Impact matrix is one recommended way for prioritising a wide range of stakeholders and determining an appropriate engagement approach for each group, the International Association for Public Participation (IAP2) offers another useful spectrum of approaches to identify the different levels of participation and engagement of public members, including patients, caregivers, family members, and the general public. This spectrum moves from a low level of engagement by informing and consulting members of the public to a medium level by involving them, and a high level of engagement through collaborating with them and ultimately empowering them (see Figure 3.2).

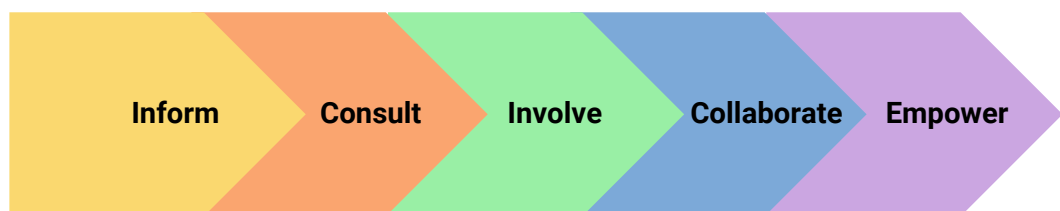


Figure 3.2: (c) International Association for Public Participation www.iap2.org

What do we mean by each of these levels of engagement?

INFORM: Provide objective and balanced information to help stakeholders understand the problem, alternatives, opportunities, and solutions.

CONSULT: Obtain feedback from stakeholders, especially during the initial research prioritisation and development phases of your study.

INVOLVE: Work directly with stakeholders to ensure that their experiences and concerns are understood and considered in your study.

COLLABORATE: Partner with stakeholders in decision-making across the stages of your study.

EMPOWER: Place the final decision-making in the hands of the stakeholders.

As you move forward in this spectrum from involving to consulting and so on, decision-making is shared between researchers and stakeholders, and ultimately when you aim to empower your public stakeholders, decisions are led by them.



Stakeholder prioritisation meetings organised by icddr,b in Bangladesh.

CASE STUDY

PRIORITISING STAKEHOLDERS FOR IMPROVING CHILD HEALTH IN BANGLADESH

icddr,b (formerly known as the International Centre for Diarrhoeal Disease Research, Bangladesh) designed a research study to test the feasibility and acceptability of using pulse oximeters in routine child health services for timely detection of pneumonia and averting preventable child deaths in Bangladesh. A pulse oximeter is a low-cost, non-invasive device used to detect hypoxaemia (low oxygen level in blood), which is common in children with pneumonia and a strong predictor of mortality.

Through a desk review of published and grey literature and key informant interviews, the icddr,b team mapped 15 potential stakeholders at the national level and 16 at the district level. These stakeholders included officials from the Ministry of Health and Family Welfare, UN agencies, medical associations, local and international non-governmental organisations, and municipality. The team organised a workshop to consult with key managers from the national newborn health programme in the Ministry of Health, and together, they ranked all the identified national and district-level stakeholders on a 10-point scale for power and impact where one was regarded as the lowest and ten was considered the highest. Stakeholders were then plotted on the Power-Impact Matrix based on their average scores allotted by the workshop participants.

Using this matrix, the team prioritised High Power-High Impact stakeholders and focused their engagement and communication efforts on this group throughout the research study. As a result of this collaborative engagement, research evidence has been integrated into the national child health policy and guidelines and pulse oximeters have been procured for 200 primary healthcare centres across the country with scale-up being planned for the remaining centres.

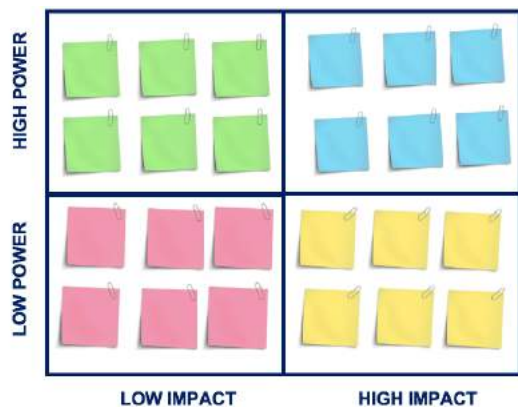
ACTIVITY 1

This activity is best carried out with your team at the start of your research study and after you have mapped a list of potential stakeholders.

Place a poster paper on the wall or a large table. Divide the poster paper into four boxes representing the four quadrants of the Power-Impact Matrix. Create a deck of up to 30 cards. List a stakeholder on each card. These should include potential stakeholders that can be relevant for your study. You could just note down the role of the stakeholder instead of their actual name (e.g., district public health manager).

Shuffle the stakeholder cards and distribute equally among the team members. In each round, a team member places or tags a stakeholder card into one of the four quadrants of the Power-Impact matrix and briefly explains their reasons for doing so.

Encourage team members to have an open discussion and to challenge or support each other's perspectives. Think about which stakeholders could potentially move across quadrants owing to a change in power or impact. Repeat the rounds until the team has exhausted all the stakeholder cards and they have been divided across the four quadrants. By the end of this activity, you will have prioritised stakeholders and identified which groups to focus on as well as the overall engagement strategy for each stakeholder group.



CHAPTER SUMMARY

- Mapping stakeholders is the initial step in the engagement process and consists of three stages: (i) Identifying potential stakeholders, (ii) Analysing their needs and concerns while considering mutual benefits for engagement, and (iii) Prioritising relevant stakeholders and determining the appropriate approach for engagement.
- Stakeholders can be identified through a review of relevant published and grey literature, consultations with your team and external experts, and informal discussions or meetings with patients, caregivers, community members, or the beneficiaries of your study.
- Prioritise stakeholders using the Power-Impact matrix. Closely engage and manage stakeholders with high power and high impact as this group is most likely to influence study implementation and translation of evidence into policy and practice. If there are no stakeholders in this quadrant, prioritise engagement efforts to gain interest from those with power.



NOTES

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Researchers from the Bangladesh Primary Care Respiratory Society conducting a sensitisation workshop with policy and health system stakeholders in Rangpur, Bangladesh.

CHAPTER 4

HOW TO ENGAGE STAKEHOLDERS

LEARNING OBJECTIVES

By the end of this chapter, you will:

- Learn about the various types of methods to engage stakeholders
- Identify the methods most appropriate for your stakeholders
- Explore the role of framing in your engagement

WHAT METHODS CAN BE USED TO ENGAGE STAKEHOLDERS?

We have listed a range of methods or activities for engaging stakeholders in a research study based on our experiences on the RESPIRE programme (see table 4.1). These methods have been categorised by the level or extent of engagement and four types of channels, which are mediums for communicating messages with intended stakeholders.

The level of engagement (Inform, Consult, Involve, Collaborate and Empower) should be based on the Power-Impact of the stakeholder as well as your objective or goal of working with them. The choice of the communication channel will depend upon your stakeholder needs and skills as well as the available resources. Some questions to consider when selecting a communication channel:

- Are stakeholders able to access this channel?
- Is it easy for them to navigate this channel and understand your messages?
- Can they interact with you and give feedback?
- Will this channel help you achieve your objective of engaging the stakeholder?
- Do you have the required budget for using this channel?

You can combine channels and methods to engage stakeholders throughout your study. If you plan to inform your stakeholders at the mass media level, you could work with the local or national newspaper to publish articles introducing your study. Harnessing existing folklore or community-based activities, such as street plays or mobile health vans with announcements can be considered for outreach, especially in rural or remote areas. Setting up a research study website or social media account may be more suitable for stakeholders with smartphones, internet access, and higher health literacy levels. Meetings and telephone calls are the most commonly used methods for informing stakeholders using the interpersonal channel.

Consulting with stakeholders can be achieved through informal interviews, working groups, consultations in public meetings, surveys, and interactive voice response polls on mobile phones. Four important interpersonal methods for consulting stakeholders, particularly at the start of the study, are as follows:

- Conducting home visits: Visiting stakeholders, especially those who are unable to travel or who live with advanced health conditions.
- Conducting research prioritisation exercises: Have stakeholders identify and rank local priorities that will inform the research questions.
- Using the Delphi technique: Administer a series of consecutive questionnaires moderated by a facilitator to allow stakeholders to prioritise research topics and reach a consensus.
- Organising roundtable discussions: Encourage stakeholders to discuss and debate a topic, either in-person or online, and reach an agreement on key insights or lessons.

Table 4.1: Methods for stakeholder engagement

CHANNEL	LEVELS OF ENGAGEMENT				
	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
Mass media	<ul style="list-style-type: none"> Interviews or programmes on television and/or radio News articles or editorials in newspapers and other print media. Print Posters 	<ul style="list-style-type: none"> Audience feedback calls on television and/or radio programmes 	<ul style="list-style-type: none"> Stakeholder quotes in newspaper articles Audio-visual material or resources featuring stakeholders, for mass media dissemination 	<ul style="list-style-type: none"> Co-producing audio-visual materials and/or resources, for mass media dissemination 	<ul style="list-style-type: none"> Stakeholder interviews on television and/or radio Audio-visual material or resources developed by stakeholders, for mass media dissemination Community radio or podcast developed by a stakeholder
Mid-media	<ul style="list-style-type: none"> Street plays Puppet shows Film screening Mobile vans Photo exhibitions Posters and community notice boards Health camps School competitions Rallies 	<ul style="list-style-type: none"> Consultations during town meetings or local elected council meetings 	<ul style="list-style-type: none"> Inviting stakeholders to local council meetings 	<ul style="list-style-type: none"> Community-based events jointly designed and led by researchers and stakeholders 	<ul style="list-style-type: none"> Community-based events designed and led by stakeholders
Social and digital media	<ul style="list-style-type: none"> Text or audio-visual posts on Facebook, Twitter, Instagram, WhatsApp Websites and blogs Newsletters Virtual competitions Webinars Podcasts 	<ul style="list-style-type: none"> Survey or poll on social media platforms Interactive voice response poll on mobile phone Meetings on video-conferencing platforms 	<ul style="list-style-type: none"> Support groups on Facebook, WhatsApp and other such platforms 	<ul style="list-style-type: none"> Online intervention design workshop Online communities 	<ul style="list-style-type: none"> Social media texts and/or audio-visual posts led by stakeholders (e.g. posts by a patient advocate)
Interpersonal	<ul style="list-style-type: none"> Telephone calls Individual or group meetings Lectures Workshops Conferences 	<ul style="list-style-type: none"> Home visits Research prioritisation exercise Interviews Focus groups Delphi method, Roundtables Individual or group meetings 	<ul style="list-style-type: none"> Mapping or scoping workshop Sensitisation meetings Training programmes Individual or group meetings 	<ul style="list-style-type: none"> Project advisory group Steering committee Patient advocacy group Taskforce Consensus meetings Partnership agreement Co-applicant on study proposal Co-investigator 	<ul style="list-style-type: none"> Patient support network Patient advocacy group Lead applicant on study proposal Lead investigator PhotoVoice Citizens juries

Stakeholders can be involved through in-person or online meetings and support groups, sensitisation and training workshops. Continuing medical education programmes can be an effective method for involving healthcare providers in your study.

Collaborative methods necessitate a partnership between researchers and stakeholders, involving equal participation in decision-making (e.g., Intervention design workshops, Advisory groups, or Task forces) during the research study.

Finally, you can employ methods that have the potential to transform stakeholders' experiences, abilities, and influence through capacity building and empowering them to take the lead in decision-making. In these approaches, stakeholders are in control, making decisions and leading activities. Such methods can include citizens' juries, patient advocacy groups, and stakeholders serving as lead investigators on a study.

As you progress along the spectrum of engagement levels and methods, researcher-led involvement gradually shifts towards greater stakeholder autonomy. Stakeholders evolve from simply being informed, providing opinions, and participating in decision-making to having full autonomy in achieving specific outcomes that they prioritise and need.

HOW TO DETERMINE THE MOST APPROPRIATE METHOD FOR ENGAGING WITH YOUR STAKEHOLDERS?

We have provided a simple tool to help you plan the most effective method for engaging different stakeholders (see table 4.2).

- First, prioritise the stakeholder you want to engage.
- Second, determine the stage/s of the research study where you intend to engage with the stakeholder; this will depend on your objective or purpose for working with that particular stakeholder.
- Third, based on the Power and Impact of this stakeholder, select the level at which you want to engage this stakeholder (e.g., Inform, Consult, Involve, Collaborate, or Empower).
- Fourth, choose an appropriate channel and select a method or activity accordingly.
- Finally, consider the timing of this activity as well as its frequency or number of occurrences.

You can plan two different approaches for the same group of stakeholders, as shown in the table 4.2 below.

For example, patients with asthma can be engaged throughout the study through a patient and public advisory group that is consulted periodically for their inputs and feedback. These insights can then be integrated into the study tools or processes. To reach and inform a larger group of people with asthma within the general public, you can use various channels and methods (e.g., TV appearances, street plays, WhatsApp messages, and meetings) toward the end of the study.

Table 4.2: Tool for planning the methods for engaging different stakeholders

STAKEHOLDER	STAGE OF RESEARCH	LEVEL OF ENGAGEMENT	CHANNEL	METHOD	TIMING	FREQUENCY
Patients with asthma	Research prioritisation, design, data collection and analysis, translation	Consult	Interpersonal	Patient and public advisory group meetings	Throughout the study	Six meetings
	Dissemination	Inform	Mass media	Appearance on a TV programme	End of the study	One appearance
Patients with asthma			Mid-media	Street play	End of the study	One play
			Social media	WhatsApp messages to a Patient Network	End of the study	Five messages
			Interpersonal	Group meetings with patient groups and associations	End of the study	One meeting with five groups

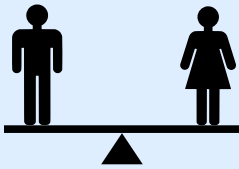
HOW TO PRACTISE ETHICAL STAKEHOLDER ENGAGEMENT?

AGREEMENT



Stakeholder engagement is not research, but you still need to secure stakeholders' agreement for their involvement. Engage in an open conversation with potential stakeholders to ensure their complete understanding of the research study, their role in it, and any mutual benefits or risks associated with their involvement. Gaining stakeholders' agreement helps build trust, enhances mutual respect, and fosters a shared understanding between researchers and stakeholders

POWER



Some stakeholders wield more power than others, either through their ability or resources to influence decision-makers or make decisions themselves. Others may possess the potential to affect decision-makers due to their knowledge or experience but may not realise it. Identifying power dynamics early on can aid in the strategic and ethical distribution of your efforts. It is crucial to include, involve, and support those with limited or no power.

VOICE



Who is your most important beneficiary? While you may have various individuals or groups to answer to (such as funders, organisational leaders, ethics committees, local health officials, and community gatekeepers), your ultimate responsibility lies with the patients or the specific population group you are studying, testing, delivering interventions to, or evaluating. Always ensure that their voices and needs are considered in your approach and decisions.

OPEN TO CHANGE



Stakeholder engagement is often an iterative and time-consuming process that may not yield immediate tangible results. During the course of your study, you might encounter potential stakeholders who were not initially considered relevant but could now play essential roles. It is important to recognise that not everyone will necessarily agree with you, and you may also need to manage emerging tensions or conflicts with stakeholders. Therefore, it is crucial to remain flexible and open to change, adapting as needed. Ultimately, your focus should be on building trust and cultivating sustainable relationships.

FRAMING YOUR MESSAGES



Framing a message is all about what we say, how we say it, and what we choose not to say. The choices we make in our messaging affect how a stakeholder will think, feel, and respond to us.

Take a look at the figure above. Different audiences may interpret a message differently based on their own prior experiences and what matters most to them. Similarly, each of your stakeholders will interpret your research-based messages differently, depending on their experiences and priorities.

Therefore, understanding each stakeholder audience, their needs, and concerns will help you frame your messaging appropriately. This will ensure that they respond positively and take action based on the research-based recommendations. You can frame your messages by either highlighting the benefits of the recommended action for a stakeholder or illustrating the potential losses if they do not adopt that action. You can also vary the tone to convey your message effectively.

If you are presenting an evidence-based health intervention to a policymaker, should you discuss all its benefits, costs, and potential challenges? Should you share a patient's story, detailing their lived experiences and how this intervention could enhance their health and quality of life? Should you present substantial data to demonstrate how many lives could be saved and the cost-effectiveness of this intervention? These are all questions to ponder when crafting your messages for various stakeholder groups.

Framing plays a vital role in stakeholder engagement, allowing you to tailor both your communication and channels to the different stakeholders you are engaging with while discussing your study and/or health issue in a cohesive manner.

Image source: VicHealth, <https://www.vichealth.vic.gov.au/media-and-resources/hpcomms>



STOP AND REFLECT

Think of any one relevant stakeholder, and depending on the stage of your research study, frame a brief message that you can present to this group in a meeting.

USING PHOTOGRAPHY AS A TOOL FOR EFFECTIVE STAKEHOLDER ENGAGEMENT

Photographs can tell a story, they can convey messages, raise awareness, mobilise support, and even influence powerful stakeholders. Here is some guidance on how to use photography as a powerful tool for stakeholder engagement in health research.



Determine your Objectives: Think about what you want to convey through your photographs. Who is your target stakeholder audience? What are their interests and concerns? This understanding will help you capture photographs that resonate with your audience and hopefully achieve your objective.



Identify Key Themes: Based on the overall objectives of your study, identify key themes that reflect the issues you want to address (e.g., prevention, treatment, patient experiences, healthcare facilities, research, and community engagement). Each theme will require different types of images, so plan your photography accordingly.



Engage with Stakeholders: Interact with individuals and communities impacted by the health challenges you are studying. Listen to their stories and understand their experiences and challenges. Establish trust and ensure their dignity and privacy are respected.



Tell a Story: Capture authentic photographs that can tell a story about an individual or a community, their lived experiences, successes and resilience associated with a health challenge.



Showcase Impact: Use photographs to monitor progress and illustrate positive changes that have occurred during and after your study.



Use Visual Composition: Pay attention to elements such as lighting, perspective, framing, and colours. Consider the rule of thirds (i.e. placing your subject in the left or right third of an image, leaving the other two thirds more open) to create a balanced composition.



Include Diversity: Ensure your photographs reflect diversity in terms of age, gender, ethnicity, socioeconomic background, and geographic locations. Including diverse perspectives will enhance the representation and relevance of your images to a broader range of stakeholders.



Maintain Ethical Standards: Obtain consent from individuals before capturing their images. Ensure sensitive information is not disclosed inadvertently. Use the photographs responsibly, ensuring they do not perpetuate stereotypes or exploit vulnerable individuals.



Caption and Context: Accompany your photographs with informative and concise captions. Use captions to highlight key messages, statistics, or personal stories that deepen the viewer's understanding.



**LET'S SPREAD
ASTHMA
AWARENESS!**



T-shirt for first 500 finishers & e-certificate for all participants

Register now at ticket2u.com.my/event/25059

**5th May 2021 -
4th June 2021**

Record using any running app & upload your result to Ticket2U by

4th June 2021

Runners eligible for free T-shirt will be contacted by

11th June 2021

'5k Virtual Run for Asthma' advertising poster shared on social media.

CASE STUDY 1

USING DIGITAL MEDIA TO RAISE ASTHMA AWARENESS DURING THE COVID-19 PANDEMIC IN MALAYSIA

With the COVID-19 pandemic continuing and government-mandated lockdowns still in place, the team at the Universiti Malaya in Malaysia had to rethink their in-person stakeholder engagement activities planned for May 2021 to coincide with World Asthma Day. In response to this challenge, the team designed a completely virtual event aptly called the '5km Virtual Run for Asthma.'

This event was aimed at raising awareness about asthma; and more importantly, addressing misconceptions that can often delay or disrupt healthcare and also add to the existing stigma around this health condition. One such myth is that people with asthma should avoid exercise or any physical activities. This virtual marathon was geared to challenge this myth and instead promote the message that people with asthma can continue to live an active lifestyle and be healthy.

Over a month, the team advertised this 'Virtual Run' on their social media platforms (such as Facebook and Instagram) and encouraged people with or without asthma to register on the Ticket2U online platform for free and to run 5kms in their own outdoor or indoor (treadmill) settings to raise awareness around asthma. Incentives such as a T-shirt for the first 500 finishers and e-certificates for all participants helped the team reach a total of 760 participants. Participants were encouraged to complete their 5km run in a month and upload their results on Ticket2U.

The team received positive feedback from participants, especially those with asthma, on how they felt empowered and motivated to participate and also share their lived experiences.



Stakeholders attending and observing a Photovoice Study Exhibition in Kuala Lumpur, Malaysia.

CASE STUDY 2

UTILISING PHOTOVOICE TO ENGAGE STAKEHOLDERS IN EXPLORING THE LIVED EXPERIENCES OF PEOPLE WITH ASTHMA IN MALAYSIA

Researchers from Universiti Putra Malaysia employed the Photovoice methodology to explore and understand the lived experiences and challenges faced by individuals with asthma. In the context of policy influence, the team organised a photography exhibition during an annual RESPIRE scientific meeting held in 2019 in Kuala Lumpur, which was attended by researchers from four countries in Asia and also by influential government personnel from Malaysia, including the Deputy Minister of Health and the Deputy Director General of Health.

With the support of a researcher, a study participant interacted with the stakeholders, representing the voices of people with asthma. An accompanying booklet was created to explain the exhibited photographs, enabling the participant to respond to questions about images that did not directly belong to them. Despite the patient-participant's initial concerns about participating and with support, the exhibition was a success, emphasising the importance of supporting participants and providing the formal training for future public exhibitions.

Recognising the global reach of the internet and collaboration, the photographs from this study have also been shared with the global community, though not in a traditional local exhibition. They were featured in abstract publications, on the RESPIRE website, and in an online photo-exhibition as part of the UK Being Human Festival's Visualising Bodies programme. Notably, the work was featured on the NIHR Global Health network to commemorate World Asthma Day 2021, and it caught the attention of the British High Commission in Kuala Lumpur.



Dr. GM Monsur Habib (right) being interviewed about Pulmonary Rehabilitation on a television programme in Bangladesh.

CASE STUDY 3

UTILISING A MULTILEVELED APPROACH TO ENHANCE LUNG HEALTH IN BANGLADESH THROUGH STAKEHOLDER ENGAGEMENT

Chronic obstructive pulmonary disease (COPD) is a highly prevalent and underdiagnosed public health problem among Bangladeshi adults aged 40 years or older. It is a leading cause of illness, hospitalisations, and deaths, significantly affecting productivity and quality of life. Pulmonary rehabilitation (PR) is an effective, evidence-based therapy routinely used in the management of COPD patients in developed countries. However, in Bangladesh, this therapy is scarcely known, with limited availability in a few healthcare facilities across the country.

The Bangladesh Primary Care Respiratory Society conducted a feasibility study on implementing PR, yielding positive results for its integration into the local health system. Led by Dr. GM Monsur Habib, the research team identified and engaged key stakeholders to enhance the visibility and acceptability of PR. A patient group was actively consulted throughout the study, while the general public was engaged through community events, television appearances, and public rallies featuring celebrities who advocated for lung health. Medical students, primary healthcare providers, and medical representatives from across the country were trained in PR based on the evidence generated from the study through a series of seminars and workshops. The team also engaged policymakers from the National Ministry of Health and Family Welfare through regular meetings and an invitation to an international RESPIRE conference.

Thanks to this multilevel approach, PR is now being offered in two new centers in Bangladesh. Hundreds of primary healthcare providers have been trained in this therapy, and policymakers are showing interest in including PR services in public health programmes.



Oxygen cylinders are locked up in a hospital facility.

CASE STUDY 4

TRANSITIONING FROM LOCAL RESEARCH STUDIES TOWARDS GLOBAL IMPACT: THE LANCET GLOBAL HEALTH COMMISSION ON MEDICAL OXYGEN SECURITY

Medical oxygen is a critical treatment for newborns in respiratory distress, children with pneumonia, adults with chronic obstructive pulmonary disease (COPD) and many more life-threatening conditions. However, it is still unavailable in low-resource settings and when available it is unaffordable for the most vulnerable populations. The COVID-19 pandemic amplified the wide disparities in access to medical oxygen affecting millions of healthcare workers and families who struggled to obtain oxygen for critically ill patients.

In response to this major public health crisis, the Lancet Global Health Commission on Medical Oxygen Security was announced in September 2022. The Commission plans to report in 2024 on the need for oxygen, measuring its access, solutions, and financing, and to ultimately advocate to global health leaders for improving access and delivery to medical oxygen.

RESPIRE researchers from icddr,b are leading a multi-country study to assess the readiness of oxygen delivery systems for promoting oxygen security in Asia. Owing to their previous and ongoing research in this area, they have been invited to serve key roles in the Lancet Global Health Commission. icddr,b is one of the key LMIC co-hosting organisations for the Commission; RESPIRE researchers from icddr,b and the University of Edinburgh play key roles as an Executive Committee member and Commissioner. Through their continuous research on medical oxygen security over past few the years, RESPIRE researchers have thus built national, regional and global networks and are currently well placed to strategically use the research evidence to advocate directly with influential stakeholders at a global level for ensuring oxygen security and that no patient ever dies again for lack of access to oxygen.

ACTIVITY 1

Identify three pertinent stakeholders for your research study. Utilise the following template to facilitate discussions with your team and devise suitable methods for engaging each of these stakeholders.

Stakeholder	Stage of Research	Level of Engagement	Method	Timing	Frequency

ACTIVITY 2

Reflect on and respond to the following scenarios:

- You need to engage two relevant stakeholders for your study. However, one stakeholder is powerful, and the other has less influence. Convening a meeting with both stakeholders might be challenging because there is a risk of the powerful stakeholder dominating the discussion, while the less powerful one might feel intimidated to express their experiences and opinions. How will you address this situation to ensure both voices are heard and considered?
- You have been engaging with the local frontline health worker, community leader, and district public health manager for your study. Consider non-financial incentives, rewards, or methods to recognise their efforts and strengthen these relationships.
- You are in the midst of a public health emergency, yet you must maintain engagement with communities in rural areas, vital stakeholders for your study. Consider innovative ways to reach out to and sustain meaningful engagement with these stakeholders.

CHAPTER SUMMARY

- Determining the power and impact of your stakeholders will assist you in choosing the appropriate level of engagement (Inform, Consult, Involve, Collaborate, or Empower). This, in turn, will guide your selection of the engagement method.
- Create a comprehensive plan outlining which stakeholders you may involve and at which stages of the research study. This will aid you and your team in planning potential engagement activities and allocating an appropriate budget accordingly.
- Practise ethical engagement by ensuring stakeholders' agreement to participate in your study and by amplifying the voices of the most vulnerable and marginalised individuals.



ASAD ZULQARNAIN

POLLEN ALLERGY PATIENT

but after that I started
having flu.

▶ ▶▶ 🔊 1:12 / 8:00



Mr. Asad Zulqarnain, a patient advocate, featured in a documentary film created by the Allergy and Asthma Institute. The film explores the lived experiences and challenges encountered by patients with pollen allergies in Pakistan.

CHAPTER 5

HOW TO ADDRESS BARRIERS TO STAKEHOLDER ENGAGEMENT

LEARNING OBJECTIVES

By the end of this chapter, you will be able to:

- Explore and identify potential barriers to stakeholder engagement
- Identify strategies for overcoming these barriers
- Establish a supportive team system for addressing the barriers

WHAT ARE SOME BARRIERS TO STAKEHOLDER ENGAGEMENT?

Stakeholder engagement demands skilled individuals, time, financial resources, and other assets; it can be time-consuming and challenging. Even with the necessary resources and plans in place, unexpected barriers may arise, posing a threat to your engagement efforts. It is crucial to anticipate potential obstacles and establish a support system to address challenges when they occur.

A key lesson learned from RESPIRE is that challenges are inevitable, but with an open mindset that accepts setbacks and seeks to learn from them, it is possible to enhance stakeholder engagement and achieve impactful outcomes.

Here are ten potential barriers that may arise when engaging with stakeholders, along with suggested ways to address them. Ultimately, finding an appropriate solution will depend on your research team, available resources, local knowledge, and the specific context.



Figure 5.1: Potential barriers to stakeholder engagement

ENGAGING WITHOUT A CLEAR PURPOSE:

Organising multiple meetings or workshops with a key stakeholder without a clear goal or shared vision may not yield any results; instead, it could lead to disinterest and disappointment among the stakeholder and your research team, impacting future engagement.

RESPONSE:

- Establish objectives for engaging each stakeholder group from the beginning.
- Discuss with stakeholders and reach mutual agreement on objectives.
- Recognise that objectives may change during the study, so remain flexible and adapt.

ORGANISATIONAL LIMITATIONS:

Without designated skilled staff, ongoing capacity building, and a dedicated budget, it becomes incredibly challenging to engage meaningfully with stakeholders and move beyond tokenistic activities. During periods of budget cuts, stakeholder engagement can often be sacrificed when competing with other equally vital research costs. The absence of support from senior leadership, reduced motivation within your research team, and a limited understanding of the policy environment and government systems can compound these challenges.

RESPONSE:

- Allocate an adequate budget for stakeholder engagement.
- Senior leadership commitment is critical to ensure the above response.
- Enlist a senior team member who believes in the value of engagement to champion this cause among other senior decision-makers in your organisation.
- Appoint a dedicated person on your research team to lead stakeholder engagement. Provide stakeholder engagement training to your research team so that everyone can contribute to the process in case the designated person leaves or is absent for an extended period.

CONTEXTUAL BARRIERS:

Communication can be challenging in communities with low literacy levels or when languages or dialects unfamiliar to your research team are spoken. Geographically remote rural or indigenous communities can be hard to access, and transportation to these areas can be difficult due to poor infrastructure. Stakeholders may lack access to mobile phones, smartphones, and the internet, coupled with low digital literacy. In certain areas, despite owning mobile phones, cultural norms may restrict women's access and use.

RESPONSE:

- Explore and comprehend the local setting, including its history, cultural norms, languages, and challenges.
- Desk reviews and meetings with community and health system gatekeepers can offer a deeper understanding of the context.
- Establish and maintain relationships with local gatekeepers.
- Ensure compensation or support for local travel expenses for stakeholder meetings and cover internet costs for digital engagement.

LACK OF TRUST:

Patients or communities that have previously faced challenges in receiving attention and support from public health authorities when accessing healthcare may approach your research team with caution. Trust issues could also arise from past negative experiences with the public health system or government agencies. Moreover, during public health emergencies, communities may be hesitant to engage due to the very real risk of infection.

RESPONSE:

- Early, clear, and frequent communication from influential research team members is crucial for establishing trust with stakeholders.
- Consult stakeholders informally to explore and understand any challenges and precedents that could impact your relationship with them.
- Collaborate with community and health system leaders, as well as gatekeepers, as they can play a key role in fostering trust within communities.

UNEXPECTED EVENTS:

If your stakeholder engagement lead or coordinator leaves their position, finding a suitable replacement might prove challenging, resulting in a gap in your engagement plans. Frequent changes in political power can necessitate restarting conversations with new policy stakeholders, wasting the time invested in previous negotiations for action. Unforeseen crises, such as conflicts, natural disasters, and public health emergencies, can disrupt and indefinitely postpone planned stakeholder engagement activities.

RESPONSE:

- Develop your research team's stakeholder engagement skills.
- Incorporate flexibility into your budgets for unforeseen events.
- Consider safe and feasible ways to stay in touch with stakeholders during a crisis, such as telephone calls, WhatsApp texts, or communication through frontline health workers and community leaders.
- Identify champions within the public health system who can provide support, even when there are changes among policy stakeholders.

ETHICAL CHALLENGES:

Patients or community members may anticipate financial support or guidance on healthcare matters from the researchers. During engagement, you may witness unjust practices or impacts on stakeholders but have limited experience or resources to address these situations. For clinician-researchers, recruiting their own patients for a study and subsequently involving some of these patients in an advisory capacity can be challenging, as they must strike a balance between sensitivity and maintaining the patient-provider relationship.

RESPONSE:

- Clearly explain the engagement objectives and the resources and support available.
- Exercise awareness and sensitivity in your language and practices.
- Establish an ethical issue response system within your team.
- Utilise your networks to offer support to stakeholders when both feasible and ethical.

SOCIO-ECONOMIC AND CULTURAL CHALLENGES:

In places where stakeholder engagement is still a new concept, stakeholders might not feel comfortable getting involved. Community stakeholders may find it difficult to attend meetings during daytime hours due to work shifts, caregiving responsibilities, potential loss of wages, and travel costs. In some areas, involvement can be difficult without the approval of family or community elders. Existing social hierarchies, such as caste differences, class structures, or religious groups, could also pose barriers when organising dialogues with heterogeneous groups of stakeholders. In certain settings, bringing together patients, healthcare providers, and public health managers could result in a power imbalance, with patients potentially feeling intimidated to share their honest opinions.

RESPONSE:

- Consider socio-economic challenges within stakeholder groups and plan engagement accordingly, such as scheduling evening or weekend meetings for working stakeholders.
- Virtual meetings or phone calls can save time with healthcare providers and policymakers.
- Respect social, cultural, and gender norms in your study site and involve influential leaders to gain acceptance within the stakeholder group.
- Strive for power sharing among stakeholders, which involves listening to all parties, encouraging their input, and involving them in decision-making.
- Organise tailored engagement activities to address power imbalances, like separate meetings for patients and policymakers. If joint meetings are necessary, support the stakeholder with less power to share their voice and participate in decision-making.

HEALTH SYSTEM CONSTRAINTS:

Frontline health workers and primary healthcare providers may encounter difficulties in engaging with your research team or implementing your research recommendations, particularly amidst budget cuts, heavy workloads, and workforce shortages. In certain settings, primary care teams may have limited influence compared to their secondary or tertiary-level counterparts, adding complexity when attempting to bring these diverse stakeholders together. Navigating these tensions, especially when uniting different stakeholders, can be challenging. Public health managers often face competing priorities, coupled with limited access to financial resources and decision-making authority. Your research area may not be a part of the national health agenda, and policy makers might lack interest.

RESPONSE:

- Comprehend the health system landscape, including key actors, decision-makers, priorities, and challenges, and establish realistic expectations for engagement with health system stakeholders.
- Seek synergies between your research priorities and stakeholders' key concerns.
- Provide stakeholders with incentives, such as capacity-building, collaborative projects, or partnerships.

STIGMA

Stigma in the health system, within the community, and even self-stigma regarding a particular topic can pose significant barriers to stakeholder engagement. In one of our research studies, we observed stigma directed at young students with asthma by school teachers. Similarly, in another study we observed that the stigma associated with the symptoms of pollen-induced allergies made daily life and social activities challenging for patients.

RESPONSE:

- Be aware of, acknowledge, and respond to existing stigma.
- Addressing stigma will require time, so please be patient.
- Ensure that all your team members use appropriate language and responses.
- Disseminate facts to address misconceptions.
- Engage community influencers and champions within the health system.
- Amplify the voices of stigmatised individuals and offer support wherever possible.

ENGAGEMENT FATIGUE:

Excessive engagement activities without a clear purpose can result in fatigue for both stakeholders and the research team. Furthermore, when stakeholders cannot discern if or how their inputs are being utilised, they may disengage or become hesitant to collaborate with you in the future.

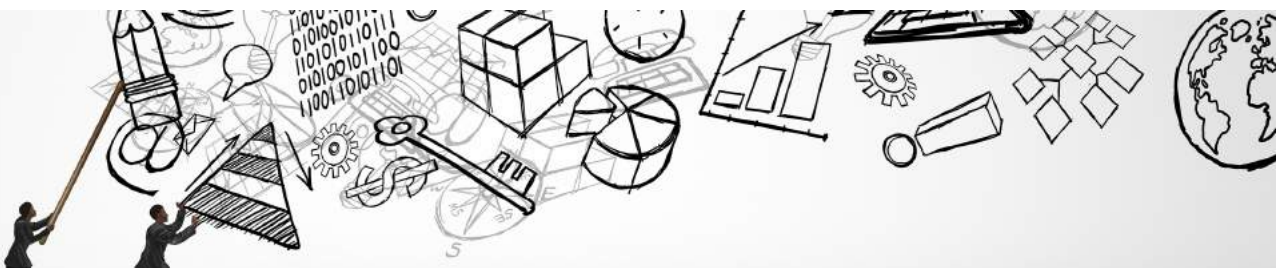
RESPONSE:

- Establish clear and realistic objectives for engaging with each stakeholder group.
- Listen to stakeholders through regular and brief meetings.
- Monitor for signs of engagement fatigue (e.g., disinterest, meeting cancellations).
- Investigate their reasons for disengagement and respond proactively.



STOP AND REFLECT

- Identify three potential barriers you may encounter when engaging with stakeholders for your research study.
- Outline the steps you would take to address the above barriers.



5 STEPS FOR BUILDING A RESPONSIVE SYSTEM TO ADDRESS BARRIERS IN STAKEHOLDER ENGAGEMENT

1

START EARLY

Dedicate team meetings right at the start of the project to think about potential barriers that you might face when engaging with different stakeholders, as well as possible solutions.

2

DESIGNATE A CHAMPION

Identify an experienced team member as a dedicated champion whom team members can turn to when they face challenges during their stakeholder engagement.

3

CREATE A SAFE AND SUPPORTIVE SPACE

Identify a physical space or virtual platform where team members can drop in, share, and discuss the barriers and failures around the research study and stakeholder engagement. This space should also encourage the exploration of creative and innovative solutions for moving forward.

4

TAKE STOCK

Regularly check whether your applied solutions have worked or if you need to consider alternative approaches for addressing any barriers. Involve your stakeholders in the process of identifying feasible solutions by listening to their input.

5

DOCUMENT LESSONS

Curate the knowledge of the various barriers you have faced, along with feasible solutions, including any failed attempts. Ensure that team members, especially new staff, can access and utilise this information. Additionally, disseminate these lessons among peers and relevant networks.



Community stakeholder meeting in Ambegaon Taluka of Pune district in India.

CASE STUDY 1

SUSTAINING COMMUNITY ENGAGEMENT DURING THE COVID-19 PANDEMIC IN RURAL INDIA

In early 2021, KEM Hospital Research Centre (KEMHRC), Pune, initiated fieldwork on COVID-19 seropositivity in rural communities within the western Indian state of Maharashtra. Around the same time, the country experienced a surge in COVID-19 cases and deaths, leading to lockdowns and strong resistance among communities toward participating in the research study.

Initially, the research team collaborated closely with district-level government officials, negotiating the continuation of travel and fieldwork after conducting risk assessments and establishing safety guidelines. Subsequently, they held meetings with influential community stakeholders from 120 villages, including locally elected village heads (Sarpanch), administrative heads (Gram Sevak), public health nurses, frontline health workers, and local government members. These meetings took place in well-ventilated open spaces, such as temples, schools, and libraries. During these sessions, the team explained the significance of the research study, addressed queries and doubts raised by stakeholders, provided examples of similar studies conducted in other parts of the country, and assured safety.

These interactions helped the team earn the trust of community leaders and fostered a sense of ownership, as these stakeholders were consulted and involved throughout the study. Community stakeholders, in turn, encouraged villagers to participate and facilitated the team's access to their communities. Frontline health workers organised open-air and well-ventilated spaces for data collection. Over six months, the KEMHRC team successfully recruited 14,500 participants and completed data collection.



Dr. Hana Mahmood, Principal Investigator at Neoventive Solutions, meeting with the Parliamentary Secretary of Health in Pakistan.

CASE STUDY 2

MANAGING STAKEHOLDER ENGAGEMENT IN THE MIDST OF CHANGES IN THE POLITICAL REGIME

Pneumonia continues to be the leading cause of illness and death in children under five in Pakistan. Neoventive Solutions conducted research studies to understand care-seeking behaviors and the management of childhood pneumonia in Pakistan. Tasked with the goal of raising awareness and generating political priority for childhood pneumonia, the research team identified and began engaging with a wide range of stakeholders. This included caregivers of young children, community health workers, healthcare providers, public health managers, and policymakers from the National Ministry of Health.

However, frequent changes in government due to political instability meant that policymakers, including civil servants and parliamentarians, kept changing as well. This situation brought the team back to square one, requiring them to repeat the entire process of identifying and meeting with newly appointed policymakers. They had to explain the research study and its findings, as well as persuade new policymakers to support proposed recommendations for change. Despite these challenges, the team persisted. They had built rapport with influential civil servants in other government departments, and they used these networks to arrange meetings with newly appointed health policymakers and initiate a dialogue to gain support for initiatives related to pneumonia prevention and care in Pakistan. The team attributed the effectiveness of their policy engagement in the face of changing governments to three key factors: first, conducting a comprehensive mapping of the public policy landscape at the outset of the study; second, maintaining regular communication with government stakeholders and remaining flexible; and third, building strong relationships.

ACTIVITY 1

Using the following template, consider potential barriers to stakeholder engagement at each stage of your research study. For each barrier, outline feasible responses, which can include more than one option. Identify individuals, both internal and external, responsible for implementing these responses.

Table 5.1: Identifying barriers in stakeholder engagement and responses

NO	RESEARCH STAGE	BARRIER	RESPONSE	RESPONSIBLE PERSON
1	Prioritisation			
2	Proposal development			
3	Research Design			
4	Ethics approvals			
5	Sensitisation			
6	Recruitment			
7	Data collection			
8	Data analysis and interpretation			
9	Dissemination			
10	Translation of evidence into practice			

ACTIVITY 2

Barrier Buster Challenge

- Divide your team into small groups.
- Provide each group with a set of index cards.
- Instruct each group or team member to write down different barriers to stakeholder engagement on the index cards. For example, lack of communication, distrust, conflicting interests, limited resources, time constraints, or language barriers. Write each barrier on a separate index card.
- Once the index cards are ready, shuffle them and place them face down in a pile.
- Explain that each group will take turns drawing an index card and engaging in a quick problem-solving activity to address the barrier written on the card.
- Set a time limit for each problem-solving activity (e.g., 5 minutes).
- When a group draws an index card, they should discuss how each barrier will affect the team and the stakeholders and outline potential solutions or strategies to overcome the identified barrier. Encourage creativity and active participation from all group members.
- Start the timer as the first the group engages in the problem-solving activity. Other groups can observe and provide additional ideas afterward.
- After each problem-solving activity, allocate a few minutes for the observing groups to provide feedback, share their own suggestions, or discuss potential variations of the proposed solutions.
- Rotate turns among the groups until all the index cards have been used.
- Conclude the activity by facilitating a group discussion where all the participants share their experiences, insights, and lessons learned.

CHAPTER SUMMARY

- Despite all your planning, you can still encounter barriers in your stakeholder engagement activities that can impact your efforts and, worse, affect your relationship with stakeholders. Therefore, it is crucial to stay ahead by discussing potential barriers and appropriate solutions with your team at the start and at regular intervals.
- Build a supportive system to respond to any challenges that may arise. This involves:
 1. Starting early
 2. Designating a champion
 3. Creating a safe and supportive space for discussing challenges
 4. Taking stock
 5. Documenting lessons
- Stakeholder engagement is a dynamic process, and things may not always go as planned. Therefore, remain flexible and open to change.



Team members from RUHSA, Christian Medical College, Vellore presenting their puppet show model for community engagement around chronic respiratory diseases at a national nursing conference in South India.

CHAPTER 6

HOW TO MONITOR AND EVALUATE STAKEHOLDER ENGAGEMENT

LEARNING OBJECTIVES

By the end of this chapter, you will be able to:

- Understand the difference between monitoring and evaluation
- Identify the benefits of monitoring and evaluating your stakeholder engagement
- Develop a monitoring and evaluation plan

WHAT IS MONITORING AND EVALUATION?

Monitoring is essentially tracking your activities to check if they are progressing as planned; it is something you do continuously throughout the life of your research study. Evaluation, on the other hand, is done occasionally, either before the study, midway, or after the study ends, mainly to assess the final results and impact and to also understand what worked and what did not work and why.



Figure 6.1: Monitoring and evaluation

WHY DO WE NEED TO MONITOR AND EVALUATE STAKEHOLDER ENGAGEMENT?

Monitoring engagement activities helps you track if things are going to plan. You can easily identify any challenges or concerns that stakeholders might have and proactively address these issues. A timely response from your end will keep the stakeholders satisfied and strengthen your relationship. You are accountable to your beneficiaries – patients, study participants, local communities, healthcare providers, and policy makers. Monitoring engagement activities will give you information that you can share with your stakeholders and keep them updated. It also helps you track progress and achievements, which can help in motivating your research team and also influence certain stakeholders. Finally, monitoring provides you with information and insights for evaluation.

Evaluation tells you if your stakeholder engagement has achieved the planned objectives and whether it has been effective. It also gives you richer insights into what aspects or activities worked well and the reasons for this. It informs you about the activities that were not effective as well as the challenges you and your team faced. Ultimately, all of this information and lessons learned from evaluation improve your skills and experience in stakeholder engagement and help in planning for the next research study.

KEY CONCEPTS IN MONITORING AND EVALUATION

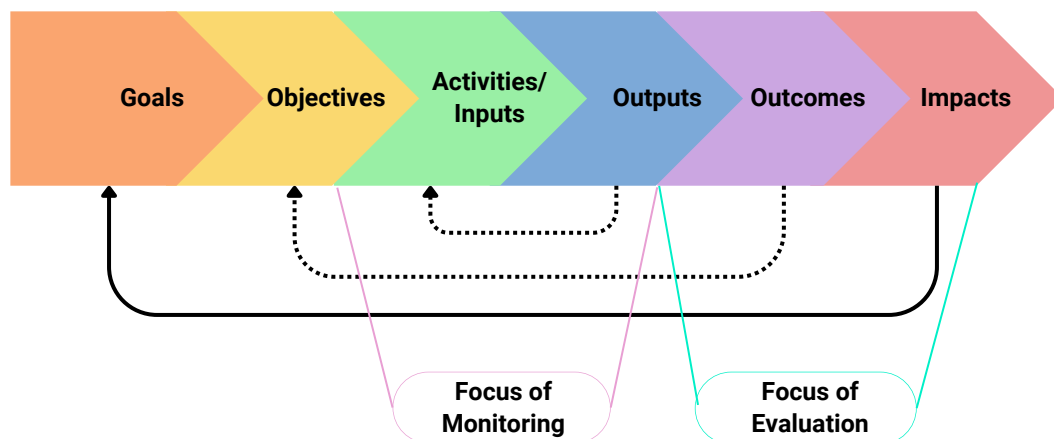


Figure 6.2: Monitoring and evaluation logical framework

- **Goals** and objectives are important concepts for monitoring and evaluation. A goal is the larger purpose of your stakeholder engagement (e.g., integrating evidence into local health system to improve screening of chronic respiratory diseases). Objectives are specific actions that will help you achieve the goal (e.g., training healthcare providers in using a spirometer to diagnose chronic respiratory diseases).
- **Inputs** refer to any human, financial, or technical resources required to conduct a stakeholder engagement activity. This can include people (staff or volunteers), money, equipment and materials, knowledge, and skills. A clear understanding of inputs for every engagement activity helps in budgeting and monitoring.
- **Activities** are the actions or events conducted using the above inputs or resources to meet your planned objectives. So, a training workshop for healthcare providers on using spirometry is an activity that can help you meet your objective of increasing the knowledge level of this stakeholder group. Similarly, demonstration and practice sessions are other activities that can help improve skills in using a spirometer.
- **Outputs** are the immediate results of an activity and are usually quantifiable. The output of a workshop or a meeting can be the number of people who attended, the number of materials distributed, or the participants' scores on a post-workshop survey.
- **Outcomes** are the short-term or long-term effects of the outputs. If you have conducted workshops to train healthcare providers in using a spirometer, an outcome could be the actual use of spirometry in health clinics or the increase in screening of patients with chronic respiratory diseases.
- **Impact** is the final goal you want to achieve through your stakeholder engagement. Using the above example of healthcare providers and spirometers, an impact indicator would be the reduction in the number of cases of hospitalisations due to chronic respiratory diseases, as the use of spirometry would have helped catch cases early and prevent advanced illness.

HOW TO MONITOR A STAKEHOLDER ENGAGEMENT ACTIVITY?

You can use the template below to monitor every stakeholder engagement activity, including meetings, workshops, training programmes, street plays, community-based events, television appearances, and newspaper articles.

Several of the questions or indicators on this template are quantitative in nature and can be completed using numbers or lists. The questions that require qualitative inputs can also be briefly completed using bullet points while ensuring that all the essential information has been captured.

Table 6.1: Template for monitoring an activity

NO	QUESTION	RESPONSE
1	Brief description of the activity	
2	Objective of the activity	
3	Number of stakeholders involved / attended the activity	
4	Names of stakeholders that attended the activity	
5	Number of materials distributed at the activity	
6	List of topics covered in the activity	
7	Key points or decisions discussed by stakeholders	
8	Any feedback from stakeholders	
9	Lessons learned including successes and areas for improvement	
10	Photographs from the activity or quotes shared by stakeholders	

The above template is one possible source of information for monitoring one stakeholder engagement activity. Other sources can include photographs or videos, stakeholder feedback forms, pre and post activity surveys, observations and team discussions.

We have provided another template below for collating all the monitoring information of all your stakeholder engagement activities in one place. This allows you to obtain a snapshot or an overall picture of the progress of your stakeholder engagement activities. Ideally, this template should be completed on a quarterly or periodic basis with your entire team. This way, you can gauge how the engagement is being implemented, the outputs achieved, and whether there are any emerging follow-on actions or areas for improvement. This information will also contribute to your overall evaluation.

Table 6.2: Template for snapshot of monitoring information

Stakeholder	Activity	Frequency	Inputs	Outputs	Sources of information	Lessons	Actions



STOP AND REFLECT

- Think of an engagement activity that you have planned with a relevant stakeholder. List up to three inputs that you will require to conduct this activity, and at least three outputs that you can achieve by the end of the activity.
- Which sources of information will you use to monitor the above activity?

HOW TO EVALUATE YOUR OVERALL STAKEHOLDER ENGAGEMENT?

We have provided a framework below (with suggested examples) to plan the evaluation of your stakeholder engagement activities.

Evaluation, similar to research, begins with questions. What do you want to find out, why do you want to evaluate your work, and who will use this information? Consider these points when crafting your evaluation questions, and ensure they are clear, simple, and easy to understand. Next, for each question, think of indicators or metrics that provide quantitative or qualitative information to answer them. Select appropriate methods or sources of data for evaluation. Reflect on how you will collate and analyse all this information, especially if you are using multiple methods. Finally, create a plan for translating, using, or sharing this rich information and lessons from your evaluation.

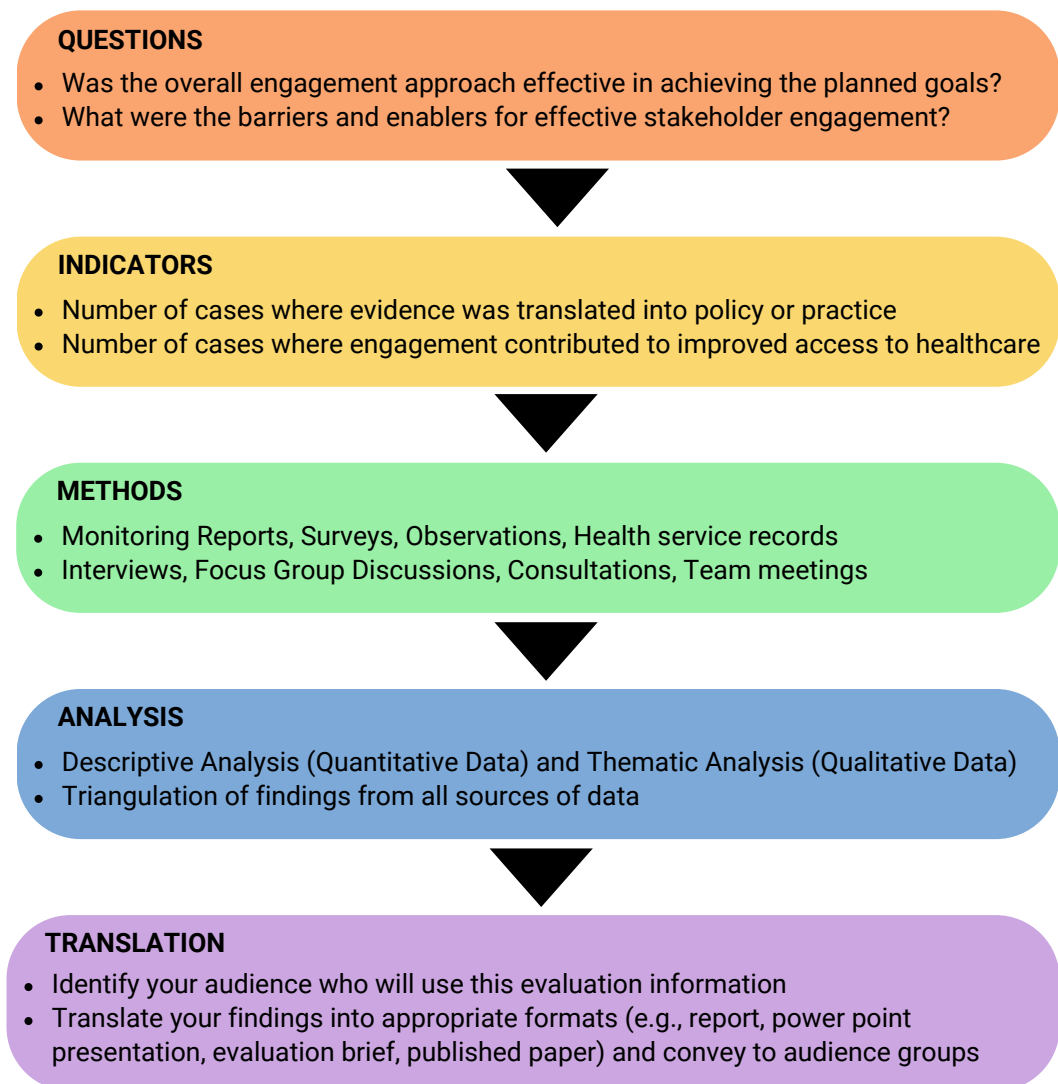


Figure 6.3: Framework for evaluating stakeholder engagement

KEY CONSIDERATIONS FOR MONITORING AND EVALUATION

- Monitoring should be conducted at regular points in the study, while evaluation can be conducted towards the end of the study. However, planning for both of these aspects should be done right at the start of the study.
- Designate a skilled and experienced team member who will lead or coordinate the monitoring and evaluation of your stakeholder engagement. Identify senior experts within your organisation, who you can reach out to in case of questions or support. Build in training initiatives for team members based on their learning needs.
- Allocate a reasonable and flexible budget for monitoring and evaluation activities and build these into your overall study timelines and deliverables, thereby assigning dedicated time for staff for this component.
- If you go back to figure 6.2, you will see that 'Outcomes' and 'Impact' are the focus of evaluations. Through your evaluation, you are therefore trying to assess what has been the result of your stakeholder engagement over the course of the research study. Did it contribute to any intended as well as unintended changes? Were there any engagement strategies or methods that were effective and some others that did not go as planned?
- Three components are important in evaluation - Context, Process, People - and there are interconnections between these. Context can include any organisational features, socio-economic, political and cultural factors in the study settings that might have affected your stakeholder engagement. Process refers to the mechanisms or ways in which engagement was planned and conducted. Two groups of people that your evaluation should focus on: Stakeholders and Team members. Select appropriate methods for monitoring and evaluation based stakeholders' needs (e.g., literacy, access to internet, time).
- While it is easy to gather information on inputs and outputs, and possibly outcomes as well, measuring impact takes time. For example, a reduction in cases of hospitalisation due to chronic respiratory diseases in a city might happen over a period of time even after your research team has trained healthcare providers in using spirometry for diagnosis and your evidence has influenced a policy change mandating spirometry in primary health care clinics. Further, even with your positive contributions, the desired impact might not occur due to various factors.
- Your evaluation may not always give you the positive results you hope for, so have an open mind, discuss existing biases with your team, and conduct this process in an objective manner. All your findings, regardless if they are positive or not so positive, will improve your understanding about stakeholder engagement and ultimately strengthen your skills for the future.



Ms. Ramsha Tariq Baig (Stakeholder Engagement Champion) in consultation with a patient advocate in Pakistan.

CASE STUDY

EVALUATING STAKEHOLDER ENGAGEMENT IN A GLOBAL HEALTH RESEARCH PROGRAMME

RESPIRE partners completed 52 research studies on the prevention, diagnosis, and management of acute and chronic respiratory diseases. Throughout these studies, partners engaged a wide range of stakeholders at local community, district, provincial, and federal levels. RESPIRE had a dedicated platform for stakeholder engagement based at the University of Edinburgh, which provided technical advice and training to all the partners and supported a dedicated stakeholder engagement lead (champion) within each partner organisation.

The scale of this partnership and the number of stakeholders engaged, coupled with a limited budget, made evaluation challenging. Nevertheless, the RESPIRE team initiated the evaluation process six months before the end of the first phase of the programme. They focused on three broad evaluation questions: (i) Did the stakeholder engagement activities achieve the planned objectives? (ii) How did the engagement contribute to change? (iii) What were the barriers and facilitators for effective stakeholder engagement?

In each of the four countries, the team consulted various sources of data, including quarterly monitoring reports, an online roundtable with the champions, and an online evaluation form completed by each partner team. These forms consisted of information and evidence on inputs, outputs, outcomes, and impacts. All of this data was analysed thematically and documented in a report and a manuscript. Key findings and lessons from this evaluation have been presented to all the partners and integrated into the stakeholder engagement plans for the second phase of the RESPIRE programme.

ACTIVITY 1

The table below lists five stakeholders and corresponding engagement activities. Discuss with your team and jot down the relevant inputs or resources that you would need to implement these activities. List possible outputs or the immediate results of each activity.

STAKEHOLDER	ACTIVITY	INPUTS	OUTPUTS
Patients	Advisory Group Meetings		
Frontline Health Workers	Training Workshop		
General Public	Interview on Television Programme		
Medical Association	Seminar		
Public Health Managers	Taskforce Meeting		

ACTIVITY 2

You have engaged three key stakeholders during your research study - Patients, Healthcare Providers and Decision-Makers. At the end of your study, you want to evaluate these stakeholders' experiences and feedback on the engagement activities and related outcomes. Which evaluation methods will you use for each of the three stakeholder groups?

CHAPTER SUMMARY

- Monitoring involves tracking your stakeholder engagement activities in real time throughout the course of your research study. While evaluation is usually conducted towards the end of the study to assess the results and impact of your stakeholder engagement and to also understand what worked and what did not work and why.
- Ensure a designated team member and allocate dedicated budget, time, materials and required training and support for monitoring and evaluation of stakeholder engagement.
- Monitoring and evaluation can provide evidence of the effectiveness of your stakeholder engagement approach and its impact or contributions to the overall goals of the research study.



NOTES

A series of 25 horizontal dotted lines spanning the width of the page, providing a guide for writing notes.

A NOTE FROM THE EDITORS

Stakeholder engagement is a significant component of health research and it works. Engaging relevant stakeholders improves the relevance of the research, increases trust and mutual learning, builds partnerships and ultimately improves the adoption of research evidence and knowledge into practice. Stakeholder engagement is vital for closing the gap between research production and use. However, it is not a simple or linear process.

Engaging stakeholders meaningfully in health research studies requires knowledge, people, resources, commitment, and more importantly, a system or process. This resource guide has tried to fill this gap by offering a process of five steps along with insights and user-friendly tools for anyone interested in conducting impactful health research, regardless of their background or expertise.

Each chapter covers a crucial step or phase of stakeholder engagement in health research. Whether you are just beginning to understand the importance of involving stakeholders in research, looking for guidance on identifying, prioritising, and engaging different stakeholders, or seeking ways to make research more impactful, this guide has you covered. Each chapter includes straightforward explanations, reflective exercises, real-life cases, and practical tools aimed at helping individuals effectively engage with stakeholders in the field of health research. The resource guide is designed to be accessible to everyone interested in improving the relevance and impact of their work in the health research field.

You may find yourself going back and forth as stakeholder engagement is a dynamic and iterative process, but an open and a learning mindset will help you and your team improve your confidence in this area and develop a process that works best for your organisation.

RESPIRE's story is one of success and challenges that spans across organisations and countries in Asia. It serves as a testament to the incredible power of involving stakeholders in a meaningful way. Whether you are a seasoned researcher with years of experience or new to the field, this guide encourages you to build meaningful partnerships, make informed decisions, and contribute to research that addresses the pressing health challenges of our time.

We hope that this resource guide can serve as a helpful resource for you and your team to create a space where all stakeholders voices are not only heard but also highly valued and acted upon within health research, ultimately leading towards a healthier and a more equitable world.

This resource guide was produced by the NIHR Global Health Research Unit on Respiratory Health (RESPIRE).

For more information on RESPIRE and our research, please visit the website www.ed.ac.uk/usher/respire

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