Module 1: Understanding Community Engagement and Involvement (CEI) in Health Research

In this module, we introduce the key terms used in community engagement and involvement (CEI) and define what we mean by 'community', 'stakeholders', and 'the public' in this course. We discuss the history of CEI in research and how it has developed over time. We describe terms which have similar meanings and aspects to CEI, like community engagement, but practiced in different parts of the world, like patient and public involvement (PPI). We also look at why CEI is important in health research, its benefits and its impact. Finally, we identify the challenges of CEI and what is needed for CEI to be successful.

INTRODUCTION

Introduction

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Key terms used in CEI

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identify the challenges of CEI and what is needed for CEI to be successful.

Aim

To build understanding of community engagement and involvement (CEI), raise awareness of some of the terms used to describe it and to outline the value, benefits and challenges of CEI.

Learning Outcomes

By the end of this module, you should be able to:

- Describe the key terms used in CEI.

- Explain how CEI has been understood and applied in health research.

- Outline why CEI is important and what it can achieve.

- Highlight some benefits and impacts of CEI.

- Identify some of the main challenges of CEI.

A note on terms

In this course, CEI is understood to mean:

An active involvement of the community throughout the research process, using participatory approaches and working in partnership with all key stakeholders.

CEI includes a range of activities which involve interactions between researchers, community members and stakeholders, aimed at improving the relevance, value and conduct of health research.

Below is a glossary of common terms you can use to help guide your CEI journey. We have also hyperlinked some of the key terms as they appear throughout the module to this glossary.

Select the grey box to download the glossary.

PDF	**Glossary.pdf** 1 MB	↓

CONTINUE

Key terms used in CEI

In this section, we look at the range of different terms used to describe community engagement and involvement within health research.

In 2023, Dr. Tedros Adhanom Ghebreyesus, Director-General of the WHO described Community Engagement as the "heart and soul" of Global Health Research, ensuring "that our efforts are not only scientifically sound but also socially relevant and culturally sensitive." This really highlights that CEI contributes to scientific rigour, as well as contributing to ethical conduct in research (Davies *et al.*, 2023).

There are a range of terms and words that have similar meanings to community engagement and involvement (CEI) in research. They are used to describe engagement with a range of types of research, from large clinical trials to community surveys to observational studies on hospital wards. Terms include:

- Community outreach

- Community engagement

- Patient and Public Involvement (PPI)

- Public engagement

- Collaborative research

- Participatory action research

- Citizen science

- Science communication

- Knowledge exchange
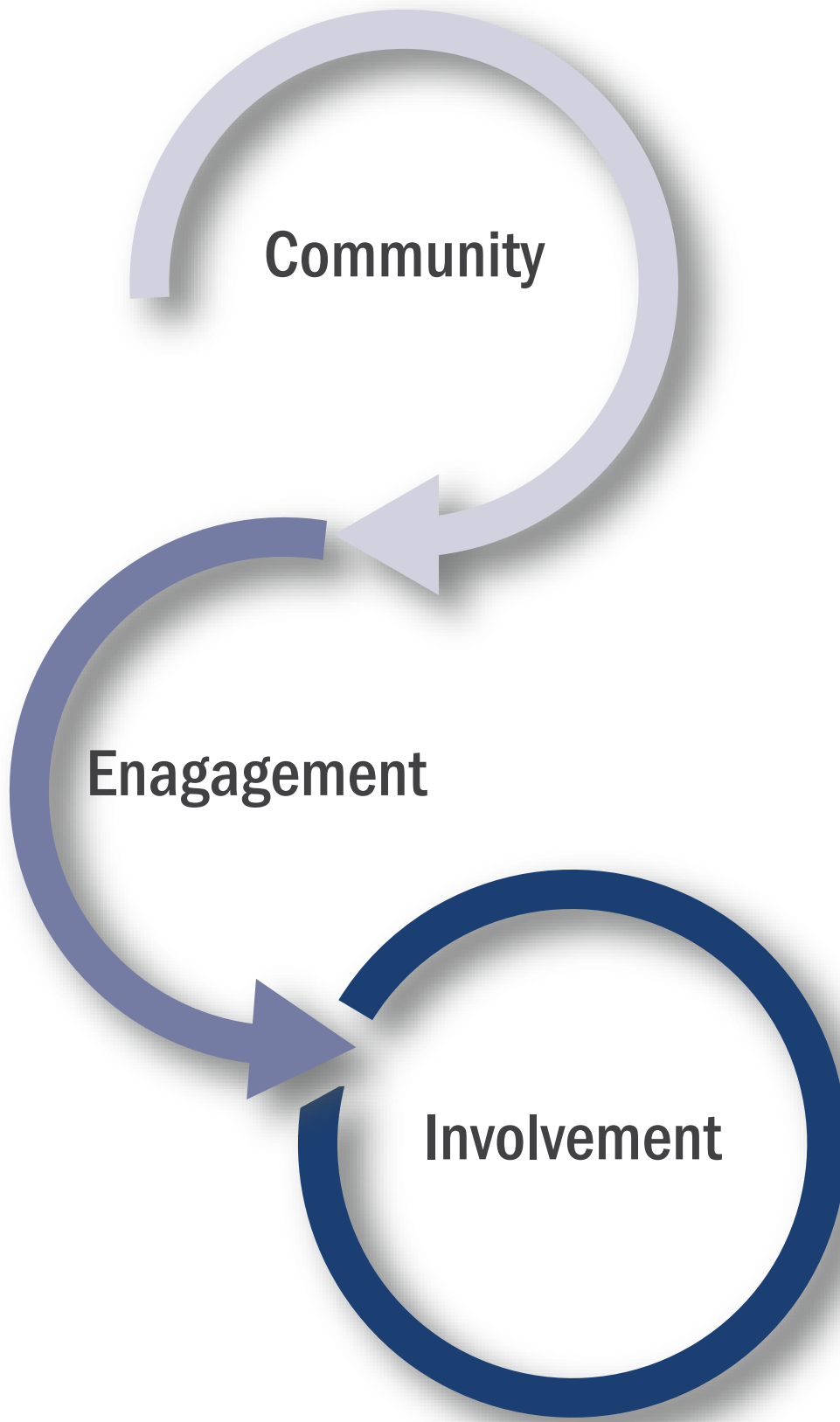
- Participatory arts

> (i) Some of these words, like community, public, engagement, communication and involvement mean different things to different people.

Next, we will consider some of these terms and describe how we will use them in this course.

What does community engagement and involvement (CEI) mean to you?

Community

Enagagement

Involvement

Take a few moments to think about the following question and write down your answer.

What does community engagement and involvement with health research mean to you?

Who is the community in CEI?

The word 'community' is not as simple as you might initially think. It can mean a range of different things to different people. Here are some examples:

Select each of the circles to reveal the information

Who are 'the public' and who are 'stakeholders'?

There are similar challenges with the term 'public', which can mean the population of a whole city, country or continent, or the public who watch TV or listen to the radio or vote.

People also have different understandings of the term 'stakeholder'. Stakeholders could range from local politicians to school-teachers and doctors. We will explore these later.

Defining 'Community', 'Stakeholders' and 'the Public' for use in this course

Let's make things easy and set out what we mean by 'Stakeholders', 'Community' and 'the Public' for health research in this course:

Stakeholders	'Stakeholders' are people who have an interest in, or influence over, what research is done and how it is done.
Community	The 'community' comprises the people who are affected by the research, whether they take part in the research or not. They may also be stakeholders.

The Public

'The public' are a broader group of people, which the community and stakeholders are part of, who may have a general interest in research and its role in society.

These terms will have different meanings for different research projects. For example, the 'community' to be engaged with for research involving sex workers will be very different from the community engaged with in research exploring different treatments for childhood malaria.

For this reason, it is very important that we explicitly describe who we mean by 'the public' or 'the community' or 'stakeholders' for each project and activity.

CONTINUE

So, with whom should you engage?

For any research plan you need to:

- Understand about **all the groups of people who are, or could be, affected** by the research in the community.

- When planning the CEI, think carefully about which groups you are **prioritising.**

- Consider which people are **included or excluded**, and why.

  - Explore the groups, regular meetings and venues which already exist in the community, and how your plans for CEI could connect with them.

  - Identify important individuals and groups. You and your team might want to **'map' important stakeholders** early, to prioritise and plan the research (Lesson 3: Whom to engage and involve in Module 2, provides more information on stakeholder mapping).

Your community groups and stakeholders

Thinking about an example of research you have been involved with, are planning, or have heard about:

- Can you think of community groups and stakeholders that the research may affect, and whom the researchers should talk with?

- Why should you communicate with these community groups and stakeholders?

Make a note of some of those community groups and stakeholders and why you think interacting with them is important.

> ⓘ Remember, 'stakeholders' are people who influence what research is done and how it may be done. The 'community' or 'community groups' refer to the people who are affected by the research, whether they take part in it or not.

Your list of potential research stakeholders may include:

Select each of the individuals below to reveal their titles.

Your list of potential community members may include:

Select each of the community groups below to reveal their titles.

You may want to engage with all stakeholders and affected community members.

However, who is engaged with, and how, will depend on:

- the type of research and research topic;

- the context in which research is being conducted;

- the aims of the CEI;

- the resources available for CEI.

> (i) It is important that CEI practitioners are clear about who they mean by 'stakeholders', 'the community' and 'the public' from the beginning of research and CEI planning.

CONTINUE

Understanding CEI

In this section, we look at what is understood by the term community engagement and involvement, how it has changed over time and what we mean by CEI in health research in this course. We also define some of the key terms used to understand CEI.

Understanding CEI in research

When you start to read and learn about community engagement and involvement in research, as well as noticing the different terms outlined in Lesson 2: Key terms used in CEI, you will also see that people have a range of ways in which they understand what it means. Here are some views from the Mesh 'connectors' online workshop (Mesh 2021).

Select the play symbol to start. Closed captions are available by selecting 'CC'.

We will explore the terms in more detail as we proceed, but first, let's consider how CEI has developed over time.

IAP2 Spectrum of Public Participation

IAP2's Spectrum of Public Participation was designed to assist with the selection of the level of participation that defines the public's role in any public participation process. The Spectrum is used internationally, and it is found in public participation plans around the world.

INCREASING IMPACT ON THE DECISION →

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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The history of CEI

CEI has **developed alongside clinical research in global settings, with a range of goals.** The goals of CEI are discussed further in Module 4: Principles and Models.

Here are some of the key points in history which have shaped CEI.

1978

The Alma Ata declaration

Community participation and involvement have a long history in global public health. The Alma Ata declaration (1978) stated that community engagement and involvement in the planning and implementation of health care was a crucial part of promoting people's health and wellbeing.

1980s

Advocacy

From the 1980s onwards, social movements of people living with HIV & AIDS advocated relevant and appropriate involvement of people affected, both in health initiatives and research (Karris *et al.* 2020).

Today

Meaningful engagement

Researchers, research funders and bio-ethicists have argued that CEI has the potential to strengthen meaningful involvement of local people and the ethical conduct, relevance and value of research. International research ethics guidelines recommend **meaningful engagement of research participants at all stages** of the research process (CIOMS 2016).

CEI has also been influenced by (and has influenced) other areas of development and research, as the examples below illustrate:

While a large proportion of health research focuses mainly on particular diseases and medical interventions, there is a significant element of **global development work that promotes 'participation'** and engagement of communities to understand and address health and the social causes of illness (NIHR 2019).

Participatory Action Research (PAR) carried out by community-based organisations (CBOs) and non-governmental organisations (NGOs) as part of development programmes, seeks to ensure that the people most affected by health and development challenges are involved: in defining the priorities for research, the kind of knowledge that counts as evidence and the actual conduct of research (Loewenson 2014).

Community Based Participatory Research (CBPR) seeks to involve community members as partners in the design, conduct, data collection, analysis and dissemination of findings or research in issues they have helped to identify, including around health (Wallerstein and Minkler 2018).

It should be noted that debates continue about how much community engagement and involvement (or similar terms and approaches such as patient and public involvement) truly enable communities to have their views included in the way in which research is done. There is a risk that community engagement and involvement, when badly done, could be tokenistic, enabling researchers to conduct their work without properly considering local views and concerns. This concern has continued to drive

practitioners to evaluate and reflect on engagement practice and strive to make it as inclusive as possible (Beresford 2021).

CEI in contemporary global health research

Following international guidelines, **major funders of global health research increasingly require engagement and involvement** as a core part of research strategy, design, planning, implementation and dissemination.

Examples of these funding institutions include the following.

Select the purple button to open the webpage.

The Wellcome Trust

WELLCOME TRUST

National Institute for Health and Care Research (NIHR)

NIHR

National Institutes of Health (NIH)

NIH

Grand Challenges Canada

GRAND CHALLENGES

UNICEF

UNICEF

CEI in global health research continues to evolve and develop and there are various sources which collate learning around CEI.

Select the purple button to open the webpage.

Mesh Community Engagement Network

MESH

NIHR Learning for Involvement

NIHR LFI

CONTINUE

Key terms used to understand CEI

Because of the different 'traditions' of CEI, it is important to recognise that it is understood and applied differently in different settings.

As we saw before, there are various terms and labels used to describe aspects of CEI, many with the same or similar meanings.

- Community engagement

- Citizen science

- Patient and Public Involvement (PPI)

- Community outreach

- Science communication

- Participatory arts

- Collaborative research

- Knowledge exchange

- Participatory Action Research (PAR)

Let's look at these terms.

Select each of the tabs from left to right to learn more.

COMMUNITY ENGAGEMENT	CITIZEN SCIENCE	PATIENT AND PUBLIC INVOLVEMENT (PPI)

Across sub-Saharan Africa, the term 'community engagement' has been used to describe a range of meetings and interactions between researchers, stakeholders and members of the community who are likely to be affected by, or participate in, research.

The World Health Organization (WHO) has defined community engagement as:
"a process of developing relationships that enable stakeholders to work together to address health-related issues and promote well-being to achieve positive health impact and outcomes" (WHO, 2020).

COMMUNITY ENGAGEMENT	CITIZEN SCIENCE	PATIENT AND PUBLIC INVOLVEMENT (PPI)

Citizen science projects have enabled citizens to collect research data in pre-designed research projects, and sometimes shape research design itself (The Citizen Science Manual, 2019 and Wiggins & Wilbanks, 2019).

COMMUNITY ENGAGEMENT	CITIZEN SCIENCE	PATIENT AND PUBLIC INVOLVEMENT (PPI)

In the UK and other European countries, patient and public involvement (PPI) is a commonly used term. Find out more about CEI models and approaches in Module 4: Principles and Models and Module 5: Approaches and Methods.
PPI aims to actively work in partnership with patients and members of the public to plan, manage, design and carry out research.

PPI is defined as "Research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them" (NIHR, 2023).

COMMUNITY OUTREACH	SCIENCE COMMUNICATION	PARTICIPATORY ARTS

An effort to bring services or information to people where they live or spend time.

SCIENCE COMMUNICATION

The use of media, activities and dialogue to describe and explain aspects of science, and produce the "AEIOU" personal responses to science: Awareness, Enjoyment, Interest, Opinion-forming and Understanding.

COMMUNITY OUTREACH	SCIENCE COMMUNICATION	PARTICIPATORY ARTS

A collaborative effort which can involve researchers, community members, artists, poets, musicians and actors etc. to co-create artistic pieces or performances aimed at stimulating discussion about research.

COLLABORATIVE RESEARCH	KNOWLEDGE EXCHANGE	PARTICIPATORY ACTION RESEARCH (PAR)

Research which involves researchers, institutions, organisations and/or communities working towards the same research goal(s).

COLLABORATIVE RESEARCH	**KNOWLEDGE EXCHANGE**	**PARTICIPATORY ACTION RESEARCH (PAR)**

Bringing together academic staff, users of research and wider groups and communities to share ideas, data, experience and expertise, to increase the research impact.

COLLABORATIVE RESEARCH	**KNOWLEDGE EXCHANGE**	**PARTICIPATORY ACTION RESEARCH (PAR)**

A collaborative process where researchers and community members reflect on problems, co-plan solutions, implement and reflect on outcomes. Cycles of these processes can be repeated.

Which term?

Match the term which applies to each scenario.

Drag and drop the term (left) onto the scenario (right), then select 'submit'.

☰   Participatory arts

			Co-creation of a community drama script to promote road safety
☰	Science communication		A slot on a radio show to talk about malaria prevention
☰	Community outreach		A film shown in rural schools to share information on dental health
☰	Collaborative research		A workshop with researchers and community leaders to produce a burns awareness programme
☰	Knowledge exchange		Researchers sharing findings of a tuberculosis treatment trial to gather community insight
☰	Participatory Action Research		Community-led activities to explore barriers to good hygiene practices

SUBMIT

CONTINUE

How CEI in health research is understood in this course

Because of the range of interpretations of CEI, in this course CEI is understood to mean:

An active involvement of the community throughout the research process, using participatory approaches and working in partnership with all key stakeholders.

And includes:

A range of activities which involve interactions between researchers, community members and stakeholders, **aimed at improving the relevance,**

CEI in practice

As we near the end of this lesson, reflect on what you have learnt so far. Which of the following activities do you think could be described as CEI in health research?

Select all that apply and then select 'submit'.

☐ Consulting communities who are most likely to be affected by the research outcomes about the research.

☐ Publishing an article in a peer reviewed journal.

☐ Submitting a research design for ethical review.

☐ Ensuring marginalised groups of communities have a meaningful voice, in the research funding process as well as in the design, delivery and dissemination of research.

☐ Providing an HIV test.

☐ Giving leaflets about research to community members at local open-air markets around areas where participant recruitment for research will happen.

☐ Consulting community leaders, non-governmental and civil society organisations, about planned health research.

☐ Ensuring equal distribution of access to health services.
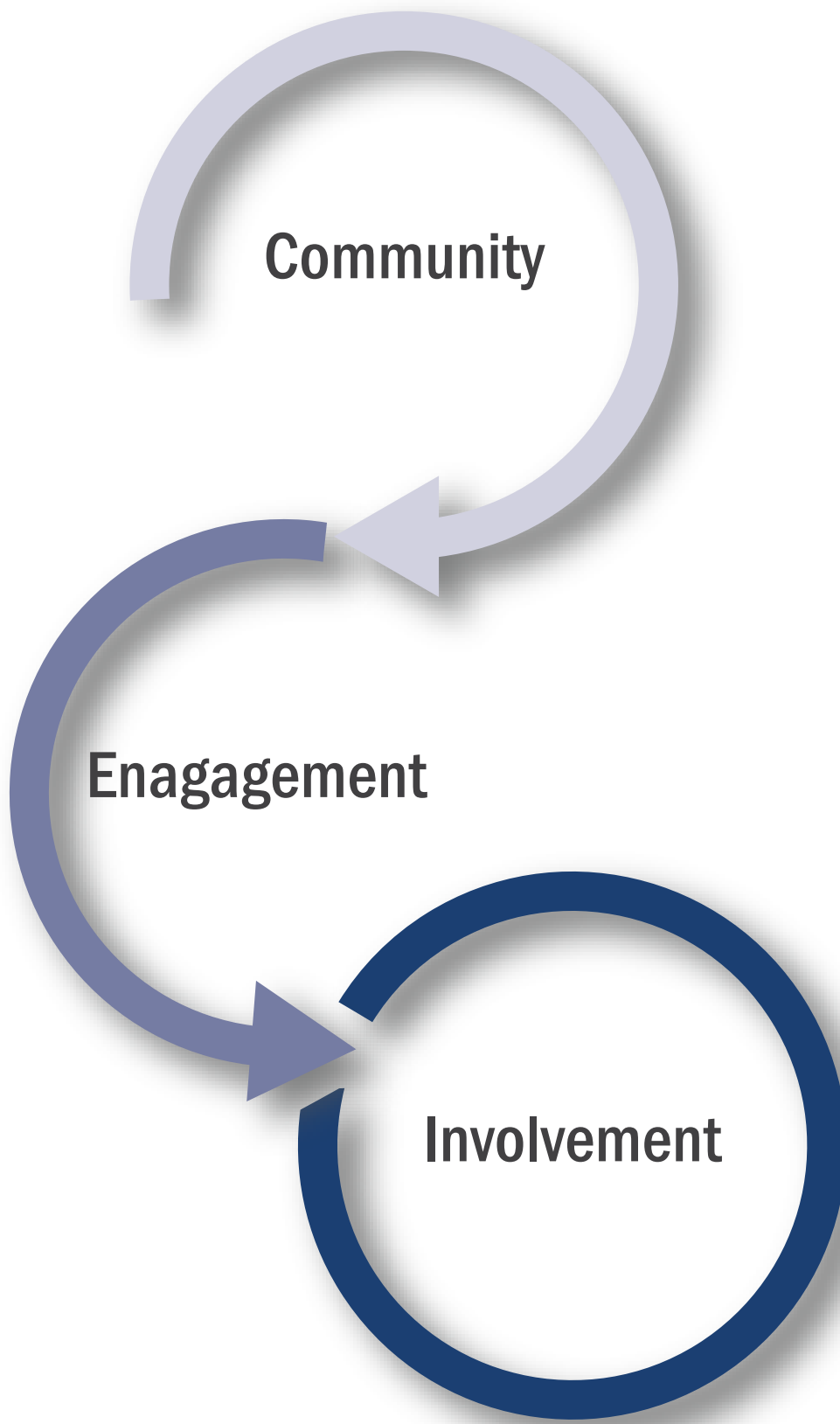
submit

CONTINUE

Why is CEI important?

In this section, we discover why CEI in health research is important. We look at how CEI can build relationships with communities and include the views of those most affected by the research topic. We also look at why CEI is ethically important and how CEI can support study implementation.

Community

Enagagement

Involvement

Take a few moments to think about the following question and write down your answer.

Why do you think community engagement and involvement within health research is important?

There are several reasons why CEI is needed and important.

Consider the following scenarios. What might CEI contribute? Why is CEI important?

Scenario A

Researchers in Malawi want to recruit volunteers for a research project which explores the feasibility of HIV self-testing.

Scenario B

Researchers in Kilifi, Kenya want to ensure they compensate research volunteers across a range of projects appropriately and equitably.
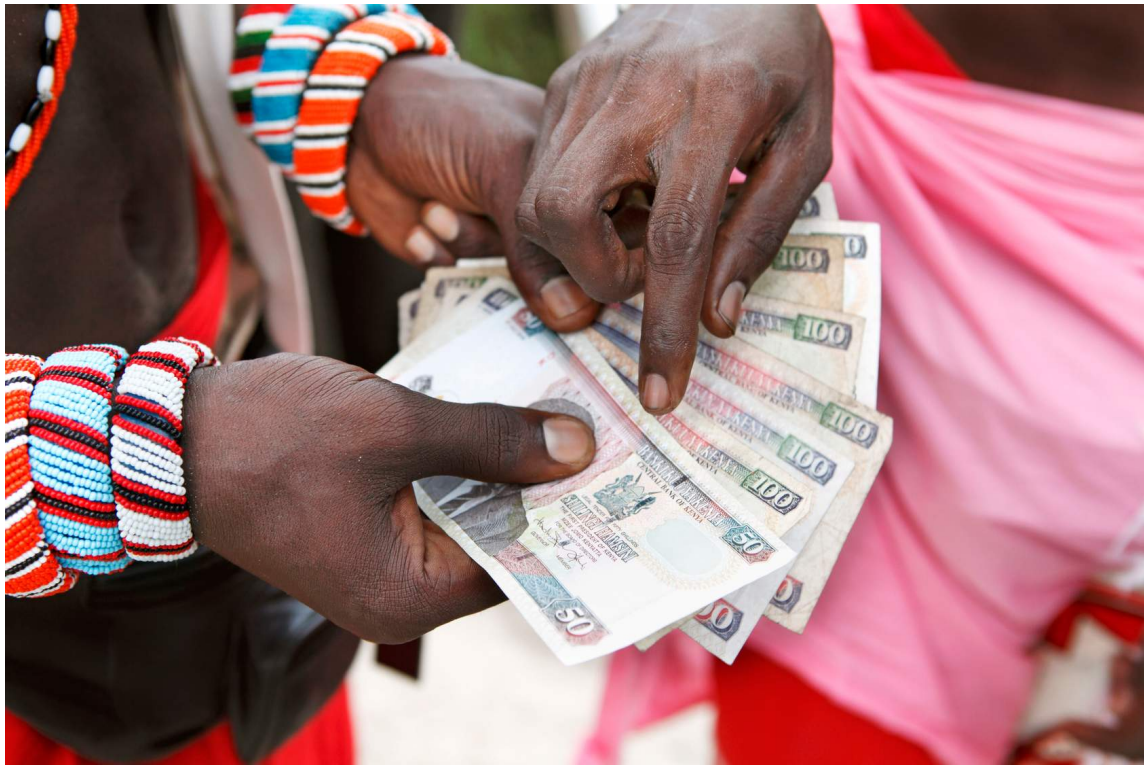
Compare your answers with the key benefits of CEI outlined next.

Select the 'next' button to move to the next slide.

CEI can build relationships:

Interacting with communities helps to better understand their culture, societal norms, and perceptions about health and research.

We will now look at each of these in turn.

CONTINUE

CEI can build relationships

Building relationships through CEI can:

- Provide ways to encourage critical reflection that can challenge researcher views.

- Enable researchers to **identify existing community and stakeholder groups**. These might be groups or organisations that are already established and have regular meetings. Researchers might be able to work with them to help address wealth and [power dynamics](#) between researchers and communities and to build local [capacity](#).

- Promote local **interest** in science and careers that could lead to more locally based scientists and researchers.

- Promote **sustainable relationships** between researchers and community stakeholders that go beyond the life of a single research project.

- Nurture **trust** between communities and researchers, through such sustainable relationships, and break down communication barriers to enable people to freely share their views.

CEI can include the views of those most affected by the research topic

It is important to listen to the thoughts and views of community members who host research, from the planning stages of research projects through to sharing the research findings.

Select each card below to flip and reveal the information.

listening, learning, and responding

Meaningful CEI in health research is responsive. It enables listening to, learning about and responding to community expectations and concerns/issues arising from the conduct of research, and can address misinformation and rumours about research projects.

feedback and action

CEI supports interaction with communities and stakeholders over time, allowing opportunities for continuous feedback and action, thus promoting an open, ongoing relationship between scientists/researchers and communities.

Including those directly affected by the research topic can influence the success of the project.

Select the 'start' button followed by the right arrow to navigate through the slides.

Let's revisit Scenario A introduced earlier

Researchers in Malawi want to recruit volunteers for a research project which explores the feasibility of HIV self-testing.

In Malawi, a [community advisory board](#) (CAB) was created as part of an HIV self-testing project. The CAB included people who used HIV testing services.

They suggested that instead of the study recruiters working from 08:00 to 17:00 Monday to Friday, they should, instead, work until 18:00 and include Saturday as well, to accommodate individuals in full time work, especially men.

Having people who used HIV testing services as members of the CAB ensured that the views of the most relevant people informed the HIV self-testing project.

It is ethically important

- CEI aims at making researchers aware of the **health priorities** of all those affected by the research (communities, stakeholders, patients).

This can help researchers to assess whether the research is useful and relevant locally.

- CEI helps ensure appropriate **methods of engagement** and [informed consent](#) in research are used.

- Community discussions aim at improving individuals' **understanding** of research so they can make informed choices about whether they want to participate in research or not.

- Community views can be included in the **development of institutional policies**.

- When done well, CEI has the potential to strengthen the protection of research participants, including reducing their risk of **[stigmatisation](#)**.

Let's revisit Scenario B introduced earlier.

Deciding on appropriate benefits and payments made to participants for their participation in research can be challenging. Giving too little might mean that participants face costs to participate in research, whilst giving too much might make it hard for community members to refuse taking part.

To address this challenge, community representatives in Kilifi, Kenya, participated in consultative meetings to discuss appropriate benefits and payments for research volunteers.

These consultations resulted in the creation of a Study Benefits and Payments guideline document, that research teams use to determine compensation for all research participants in Kilifi.

Having community representatives participating in the decision-making ensured community views could be included in the development of institutional policies and the benefits and payment amounts were ethical.

It supports the study implementation

- CEI is important for the success of a research project as it can enhance participant **recruitment and retention** into studies.

- Through CEI activities, any rumours and **misconceptions** circulating in the community, which can be damaging to the research, can be detected, discussed and acted upon where necessary.

- CEI can help with ways to share important **research findings** with participating communities and stakeholders.

- Conducted meaningfully and over time, CEI can **strengthen community relationships** and promote a supportive environment, where other research studies can be implemented.

> ⓘ CEI, done well, will also foster an environment where the results of research are more likely to **influence change** longer term, for example, policy decisions at local, national, and global level.

Test your knowledge about the importance of CEI in health

research

Read the question below and select your chosen answer. Then select 'submit'. The next question will then load.

1. Thinking about why it is important to involve community members in institutional policies, such as how money should be given to participants as compensation for taking part in research, **are the following statements true or false?**

CONTINUE

Benefits and impact of CEI

In this section, we learn about the benefits and impact of CEI in health research from the points of view of researchers and communities. We also look at the structural benefits and impact of CEI for communities, and the benefits of CEI for community research partnerships.

> (i) The benefits and impacts of CEI in health research can be experienced by community members, by researchers, in research practice and in the strengthening of partnerships between the community and researchers.
>
> 'Beneficence' and 'Social Value' are important principles in research ethics.

Select each card below to flip and reveal the information.

Beneficence

Meaning research should not harm participating individuals or communities and should aim to benefit those communities who host research.

Social Value

Meaning research should be relevant and important to the communities in which it is being carried out.

In this lesson we consider how CEI can provide benefits from the perspectives or researchers, community members and the partnership between them.

Module 3: Ethical CEI, explores ethical CEI in more detail and Module 7: Evaluation of CEI, helps us understand how to assess the different impacts and benefits of CEI.

Benefits of CEI to research practice

CEI in health research aspires to democratic goals through enabling communities to define research priorities, decide on what research processes are appropriate and acceptable and support implementation through sharing their views on design. CEI can support research design that is driven by community values. Some of these values include:

- equity in research processes; for example, who bears the burden of risks and who receives benefits

- transparency of research

- accountability of research

- relevance of research

- improved research policy

- better research guidelines

Structural impacts in research practice require engagement with policymakers and decision-makers. This is discussed further in Lesson 4: Policy engagement in Module 2: Justifying CEI, Considering Stakeholders and Engaging Policymakers.

Benefits of CEI to researchers

Watch the video below which gives examples of the benefits of CEI from the point of view of researchers.

Select the play symbol below. Closed captions are available by selecting 'CC'. The transcript can be viewed underneath be selecting the '+' symbol.

Video Transcript ⎯

Undertaking CEI has led to me publishing CEI methods, evaluation and outcomes in academic journals.

I now know more about the characteristics (for example, symptoms) of the health challenge I am exploring.

As a result of participating in CEI, I can design my research in ways that are more relevant to the needs of the community by generating ideas for interventions that are practical and effective in community settings.

I now know more about the lived experience of the health challenge I am exploring and its implications for a family.

By including CEI, I am better informed about what benefits or impacts my research may have.

Through participating in CEI, I am better informed about the risks and challenges that are associated with my research.

CEI helped me learn how to boost the dissemination of my research findings in the communities where I am working and in other communities.

By engaging with members of the communities where I am working, I have a better understanding of where my research priorities should lie.

I have developed my skills and confidence in designing CEI activities and programmes.

Having practical experience of designing and undertaking CEI has really helped my career development.
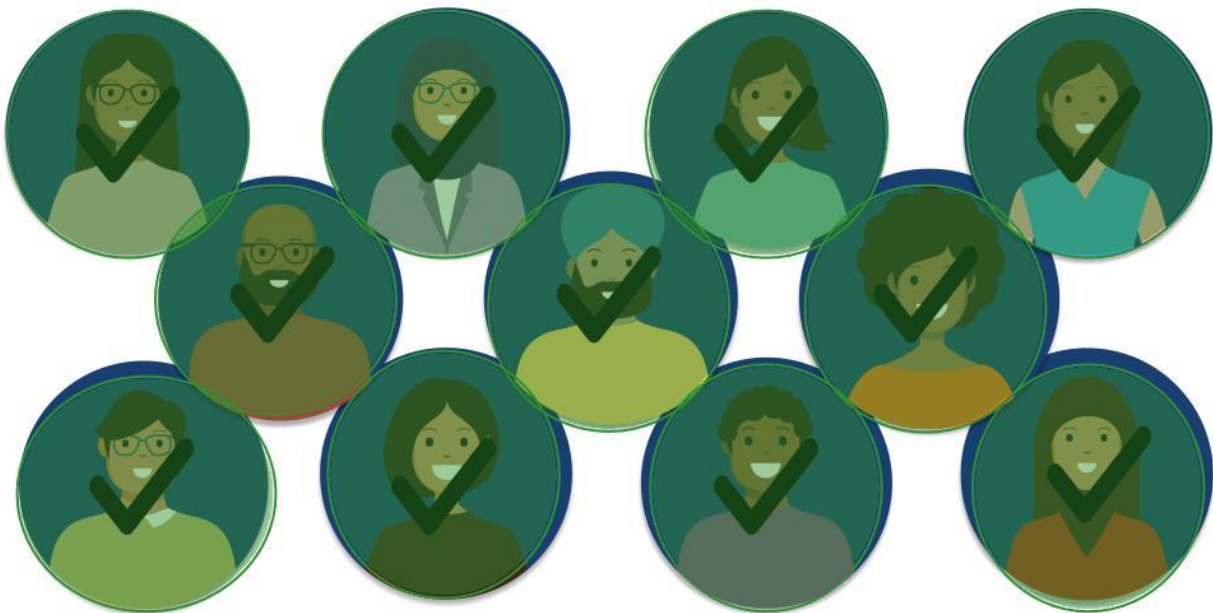
Benefits of CEI for communities

In community settings, CEI in health research benefits communities through:

- enabling community members to prioritise, guide and influence research through partnership with researchers,

- demonstrating respect to communities through the recognition of local expertise and experience, and incorporating their ideas in a research process,

- providing a stronger sense of ownership over personal health and the health of family and community,

- enabling marginalised groups to gain greater control over their lives and their community,

- strengthening community members' skills and competencies.

Let's look at examples of some of the ways that CEI in health research can have an impact on **community members.**

Select each of the faces below to hear examples. To select a different person, select 'x' to return to the main screen.

CONTINUE

Structural benefits and impact of CEI for communities

In communities, the impact of CEI in health research can also be **structural**. For example:

Building research institutions can improve local [healthcare infrastructure](#).

Research that includes CEI can enable community members and stakeholders to share their views on which aspects of healthcare should be prioritised, resulting in the provision of health services that are better targeted to address community needs.

This is discussed further in Lesson 4: Policy engagement in Module 2: Justifying CEI, Considering Stakeholders and Engaging Policymakers.

Benefits of CEI for community research partnerships

There can be multiple benefits of building and maintaining sustainable community research partnerships through CEI. Here are just some:

Select the '+' symbols to view more information.

Improve communication —

Creating valuable opportunities for two-way communication including sharing critical feedback

Build trust —

Building trust between community members and researchers through ongoing conversations.

Strengthen research —

Strengthening research funding proposals to continue, or build on, a programme of work.

Generate enthusiasm —

Generating enthusiasm to explore new research questions or topics.

Identify challenges —

Helping to identify differences in values and concerns early, which can be discussed before challenges become too big or get out of control.

Support new research —

Fostering community links that can help to support new research proposals and projects.

Reduce potential conflict —

Developing a mutual understanding of what researchers, research institutions, community members and community groups or organisations can and cannot do may reduce potential conflict and misunderstanding.
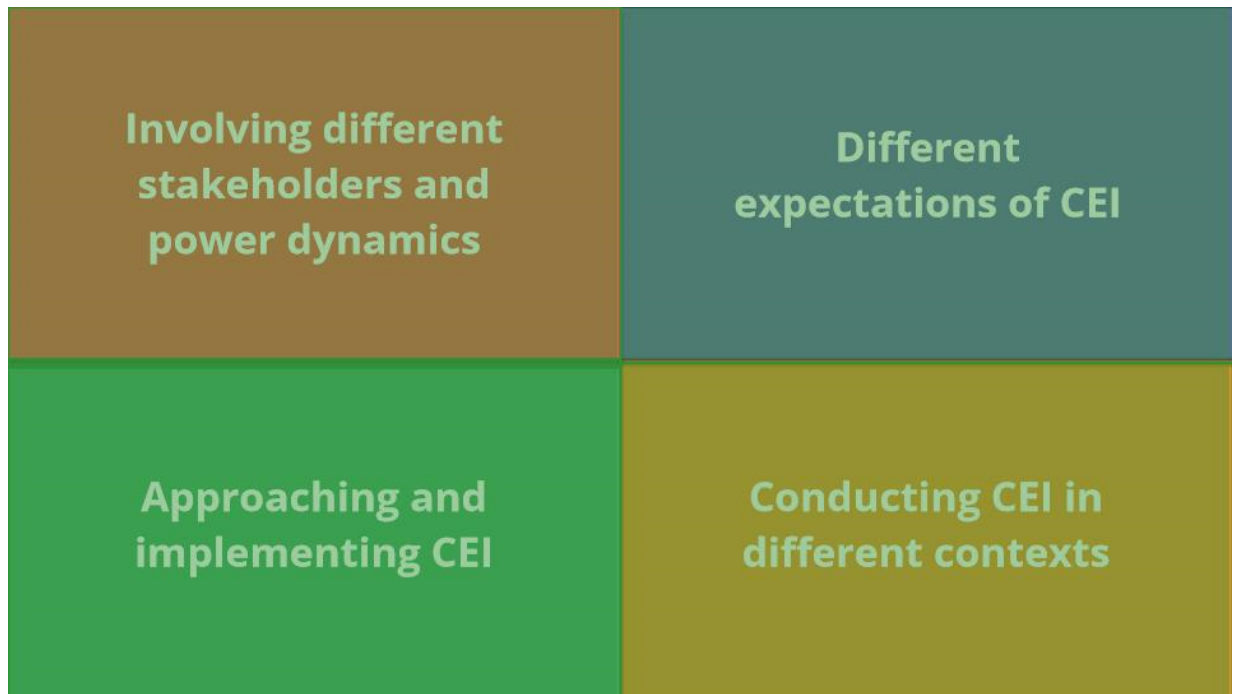
CONTINUE

Challenges when undertaking CEI

In this section, we discuss the challenges when undertaking CEI in health research and give examples using case studies.

When planning and undertaking CEI in health research there can be challenges.

Select each rectangle below and follow the on-screen instructions to progress.

Involving different stakeholders and power dynamics	Different expectations of CEI
Approaching and implementing CEI	Conducting CEI in different contexts

Identifying the possible challenges

Read through the next two short CEI case studies about recruiting study volunteers. Consider what issues might need addressing, reflecting on the points raised in the module so far.

Case study 1 – Antimicrobial resistance in Malawi

A recent research project in Malawi explored the impact of increasing awareness and knowledge in rural populations about the effects of antibiotic overuse and antimicrobial resistance.
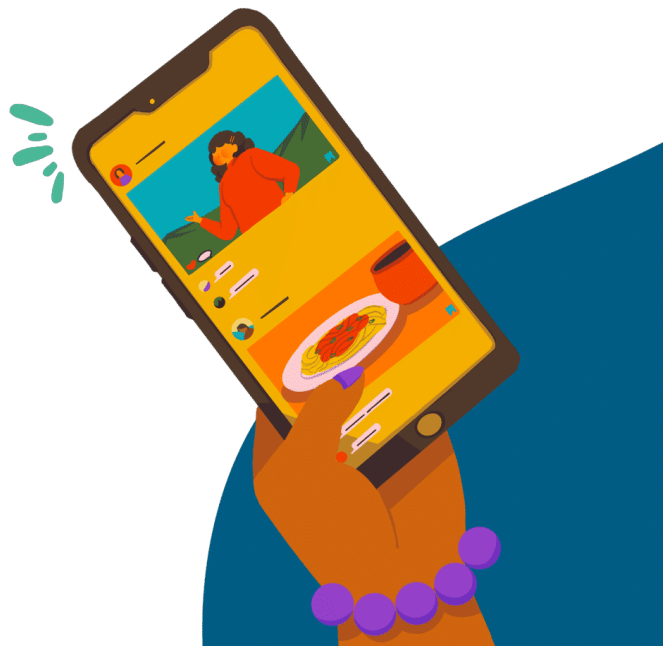
Researchers set up a community advisory board (CAB) to help plan their CEI. Members included an outspoken local politician, a head of a local secondary school, the owner of a restaurant chain and three small business leaders from Lilongwe, the capital city. The initial aim of the CAB was to establish the best way of recruiting volunteers to the proposed study.

They made plans to recruit potential volunteers by holding a research launch event with a free meal at a luxurious hotel in the city. Unfortunately, although a huge number of people came to the meeting, hardly any were eligible to take part in the study.

Case study 2 – Type 2 diabetes in India

Researchers from the United Kingdom and India are launching a study in Kerala, India. They want to investigate whether interacting with an educational phone app will improve the health of people identified as being at risk of developing type 2 diabetes.

They have set up a community advisory board (CAB) to help plan their CEI. Members included an outspoken local politician, a head of a local secondary school, the owner of a clothing factory, three small business leaders and a hotel waiter. The aim of the CAB was to establish the best way of recruiting volunteers to the proposed study.

At the first research information meeting they hoped to recruit a wide range of community representatives by providing a free meal, but there was very low turn-out.

ⓘ   For both of the case studies, what issues might need addressing? Write down your ideas.

Select the 'start' button, followed by the right arrow to navigate through the slides.

Here are some of the reasons why the two case studies were unsuccessful.

Bias

The researchers have made decisions based on their agenda, rather than consulting the community first.

Community

Are the researchers clear about whose input they need and why? Where are the individual community members? They all seem to be types of professional stakeholders or from less relevant localities.

Multiple Agendas

The power dynamics of the committee could be challenging. For example, the politician and restaurant chain owner may have their own agendas (or priorities).

Power Dynamics

It may be that those who have the most relevant contribution are the least heard or are even absent from this mix of stakeholders.

Managing Different Expectations

Community representatives or potential research volunteers coming to the first meeting may have had different expectations about what would be involved – it wasn't made very clear.

CONTINUE

The key ingredients of CEI

In this section, we summarise the key ingredients for successful CEI in health research.

Just like a tasty soup, CEI has some key ingredients. It needs:

- **A commitment to the social value of health research**, ensuring that research is relevant locally and that its conduct strengthens rather than undermines local health infrastructure, community relationships and inclusion

- **Creativity to design appropriate ways of engaging communities** with different types of research, from the most complex scientific studies for unfamiliar health challenges, to simple studies on well-understood diseases.

- **People who have an understanding of local structures and systems**, like local government, schools and hospitals, and who are able to form working relationships with key individuals within them.

- **People who have an understanding of the local culture** and ideally come from the area where the research is conducted.

- **Trained and experienced professionals** who understand the goals of CEI and whose job description is to facilitate engagement between researchers and communities.

- **Funding** to pay CEI staff salaries, compensate participants, and pay for equipment, materials and meeting costs.

CONTINUE

Summary

We hope you enjoyed exploring our understanding of CEI, its challenges and, most importantly, its value in health research.

We have learnt that:

- The term 'Community' has been used differently over the years based on the context, such as

geographical location, special interests and area of focus.

- CEI can be described using different terms. It can also have different meanings and associated practices. Historically, some CEI has used terminology that sounds inclusive but has been tokenistic in practice. There is growing consensus on the need to make health research as participatory and inclusive as possible, and to ensure that the reality matches the aspiration.

- CEI is a continuous and changeable process which is critical for the inclusion of those most affected by research and provides opportunities to address health research challenges.

- When done well, CEI also helps to break down power imbalances between scientists, researchers, communities and stakeholders, allowing true partnerships and shared decision-making for mutual benefit.

CONTINUE

Further Resources

Principles document

Clinical and Translation Science Awards Consortium (CTSA) (2015) *Principles of Community Engagement (Second Edition)*. NIH Publication Number 11-7782.

CTSA 2015

Journal article

Mitchell, J. *et al.* (2019) The values and principles underpinning community engagement approaches to tackling antimicrobial resistance (AMR), *Global Health Action*, 12(sup1), 1837484.

MITCHELL ET AL. 2...

Report

UNICEF (2020) *Minimum quality standards and indicators in community engagement*. UNICEF.

UNICEF 2020

Report

World Health Organization (WHO) (2017) *WHO community engagement framework for quality, people-centred and resilient health services*. WHO/HIS/SDS/2017.15. WHO.

WHO 2017

Report

World Health Organisation (WHO) (2023) *WHO framework for meaningful engagement of people living with noncommunicable diseases, and mental health and neurological conditions.* Geneva: World Health Organization; 2023. Licence: CC BY-NC-SA 3.0 IGO.

CEI resources and toolkits

Web page

Division of AIDS (DAIDS) at the National Institute of Allergy and Infectious Diseases (2020) *DAIDS Community Engagement.*

DAIDS 2020

Web page

HIV/AIDS network Coordination (HANC) (2020) *Community Engagement: Resources for Inclusive Community Involvement.*

HANC 2020

Toolkit

The International Federation of Red Cross and Red Crescent Societies (IFRC) (2021) *Community Engagement and Accountability (CEA) Toolkit.*

IFRC 2021

Web page

Mesh (2024) *Find collaborators.*

MESH 2024

Resource guide

Nelson, E. (2019) A Resource Guide for Community Engagement and Involvement in Global Health Research. NIHR.

NELSON 2019

Website

NIHR Learning for Involvement (2024) *Resources and training for public involvement in research.*

NIHR 2024

Resource guide

Nathan, J.J.N *et al.* (2023) *Stakeholder Engagement in Global Health Research: A Resource Guide.* RESPIRE; University of Edinburgh and Universiti Malaya.

RESPIRE 2023

References

All references for the module are available to download below.

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PDF **Reference list_Module 1.pdf**
953.6 KB

CONTINUE

Acknowledgements

Thank you to all who have been involved in creating the module content, its design and its testing. Thank you also to those who have kindly supplied images for use in this module and throughout the course.

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PDF **Image credits - Module 1.pdf**
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CONTINUE

Congratulations!

You have now completed this module. Please select the link below to be taken to the end of module quiz.

Module 1 Quiz: Understanding Community Engagement and Involvement (CEI) in Health Research