In this module, we discuss a range of principles and models for community engagement and involvement (CEI). We describe how a ‘one-way’ form of communication used in the ‘public understanding of science’ evolved to become more a ‘two-way’ form of engagement. We explore the extent to which different CEI methods encourage different levels of participation and involvement in research and address a range of goals. We discuss how CEI often makes use of social science and participatory tools and how these have shaped different methods and approaches. Finally, we look at two specific models for CEI called Patient and Public Involvement (PPI) and Good Participatory Practice (GPP).

INTRODUCTION

CONTENT

- One-way communication and two-way engagement
- The spectrum of participation
The goals of CEI

Deep and wide CEI

CEI as an approach to find out about the community where the research is taking place

Using deliberative and participatory methods for engagement

Patient and Public Involvement (PPI)

Good Participatory Practice (GPP)

Summary
In this module, we discuss a range of principles and models for community engagement and involvement (CEI). We describe how a ‘one-way’ form of communication used in the ‘public understanding of science’ evolved to become more a ‘two-way’ form of engagement. We explore the extent to which different CEI methods encourage different levels of participation and involvement in research and address a range
of goals. We discuss how CEI often makes use of social science and participatory tools and how these have shaped different methods and approaches. Finally, we look at two specific models for CEI called Patient and Public Involvement (PPI) and Good Participatory Practice (GPP).

**Aim**

To have an understanding of a range of principles and models for CEI and how they can be used in practice.

**Learning Outcomes**

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

- Explain and be able to give examples of the difference between one-way communication and two-way engagement.

- Recognise how CEI can be explained in terms of how much community members are involved in research decision-making.

- Recognise that CEI allows researchers to better understand community perspectives, values, norms and traditions so that research is sensitive to these.
Identify and differentiate between forms of 'deep' and 'wide' engagement.

Identify a range of CEI goals.

Describe deliberative processes as activities in which researchers and community members can learn together about complicated aspects of research, towards improving research practice and policies.

Explain how participatory processes can enable co-production between researchers and community members.

Outline important guidelines and principles for CEI.

A note on terms

First, let’s understand the key terms used in this module.

*Select each of the tabs from left to right to learn more.*
**Principles** are the rules or assumptions which explain why and how something happens.

A **model** is used here to mean a theoretical description which can help you understand, in this case, how CEI works.
Theories, principles, concepts and models form the foundation of our approach to CEI and then in turn influence the methods we use to undertake CEI (see also Module 5: Approaches and Methods for 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.

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.*
Building on what was covered in Module 1: Understanding CEI in Health Research, we will look at the way in which engagement with the public about science and research has changed from attempting to increase public understanding of science through giving information, towards more of a two-way communication. Two-way communication involves both scientists learning from the public, and the public learning from scientists.

For a better understanding of the term ‘engagement’, it can be useful to look at how engagement with science has changed over the years, drawing examples from several places. As a first example, let’s look at how engagement evolved in the UK and East Africa.

**Public Understanding of Science (PUS) in the UK**
Before 1970

Before 1970 most UK policy-makers felt that public views about science were not very important.

1985

However, the UK government became concerned when interest in taking up school science subjects was decreasing through the 70s and early 80s. In response to this, in 1985, the UK’s Royal Society released the Bodmer Report which stated that the public should be made more aware of science in order to improve the country’s economy and give people a better understanding of risk regarding scientific developments.

What did the ‘Public Understanding of Science’ involve?
One way
The strategy of increasing the general public's scientific understanding would be achieved by encouraging “scientists to communicate more clearly and entertainingly in lay terms” (Wynne, 1992) through public statements and lectures.

This strategy became known as the 'Public Understanding of Science (PUS)'. A similar approach was used in the USA in the 1980s.

This approach could be described as a 'one-way' communication where scientists provided information to the public, and the public were given very little or no opportunities to respond.

Can you think of any problems with the Public Understanding of Science (PUS) approach?

Reflect on what you have read so far and decide whether you agree or disagree with the following statements.

*Select all the statements you agree with, then select 'submit'.*
Critique of the Public Understanding of Science (PUS) Strategy

Watch the animation below to learn why the PUS Strategy has been criticised.
MAD COW DISEASE IS HERE
The example of 'Mad Cow Disease'

Public views about science in the UK and Europe continued to deteriorate in the 1990s and this was not helped by the so-called 'mad cow crisis'. The mad cow crisis was caused by scientists repeatedly and falsely claiming that bovine spongiform encephalopathy (BSE), or mad cow disease, could not pass from cows to humans. After these claims were made, several people in the UK became infected with Creutzfeldt-Jakob disease and this was linked to eating meat products from cattle infected with BSE. This series of events lowered public trust in science in the UK.

The **PUS** (deficit model) of one-way communication was seen by many as unsuccessful.

In the 2000s, a consultation with social scientists led to a new approach in the UK called ‘**Science in Society**’ with a shift from ‘understanding’ to ‘engagement’.

It was felt that a more **two-way engagement** approach between scientists and members of the public would be more likely to build public trust in science. Through engagement, scientists and the public could share their views.
**Similar changes in public engagement with health research**

- At the same time as the shift from PUS to engagement, there was a similar shift towards *involvement* in health research. In 1996, this shift was marked by the establishment of INVOLVE, which was part of, and funded by, the National Institute for Health and Care Research (NIHR), to support active patient and public involvement (PPI) in health research (Boaz *et al.*, 2016).

- PPI aimed to enable researchers, and patients and carers, to share power in the research process (Beresford and Russo, 2020).

- We will discuss PPI in more detail later in this module.
The development of engagement in East Africa
During colonial rule in east Africa (1940-1960), a considerable amount of research was done for a range of reasons; for example, to stop people getting sick with Lymphatic Filariasis and to find treatments for Bilharzia.
According to the anthropologist Graboyes, while colonial research was often described as deceptive, forceful and exploitative, east African community members frequently involved themselves in the research and influenced the way in which it was conducted. Sometimes, however, if communities disagreed with the research plans they would refuse to take part completely.
Also during this time, in east Africa, engagement often involved using chiefs to translate and explain research. In this way chiefs would demonstrate their support to the colonial government by promoting the research within communities.
Today, engagement in east Africa has evolved into a wide range of activities with a broad range of goals. Many of these activities can be described as “two-way” engagement between researchers and communities (Graboyes 2015, Tindana et al., 2015).

One-way communication or engagement?
Below you will find different types of public activities. You will need to decide if they are methods of one-way communication or the two-way ‘engagement’ model.

Sort the following means of communication into either ‘Public Understanding' or 'Engagement' by dragging and dropping them into the correct box.

- Clearly, some forms of engagement are more likely to be a form of two-way communication than others. For example, although a radio programme may be mostly one-way
communication, sometimes programmes enable listeners to contact the show by phone or through social media.

• It is also important to bear in mind that some forms of one-way communication have been useful to raise awareness; for example, wildlife documentaries have been very effective at raising public awareness of climate change.
In this section, we investigate various forms of CEI ranging from information giving to community led engagement and research.

**The spectrum of participation**

To what extent do engagement activities enable the public, or community members to contribute to research design, planning and implementation? The Spectrum of Public Participation was developed by the International Association of Public Participation (2018). It provides a good way to think about the degree to which we engage with people and communities. As we move from ‘informing’, on the left of the table, towards ‘empowering’ on the right, members of the public become more involved in the decision making and have more influence on the project.
Frameworks like 'The Spectrum of Public Participation' continuously change as engagement practitioners and researchers gain more experience in the field. For example, 'empower', is a debated term. We might instead use the term 'community led', here, to show that some engagement initiatives may be designed and implemented by communities, sometimes with very little input from researchers.
You may have heard the term 'co-production' where community members work together with researchers, for example to design a study, produce a document or film (see later), or develop a policy. Co-produce might be included within the 'collaborate' column of the spectrum, or even on its own between 'collaborate' and 'empower'.

Amount of involvement?

Community members can be involved in CEI activities to different extents. Read each example of a CEI activity below and decide how much involvement community members have in the activity.

Drag and drop the activity onto the level of involvement.
A meeting where researchers inform community members about proposed research

A public exhibition giving feedback on the results of research

A discussion to find out whether the research is acceptable to the community

A workshop to agree appropriate compensation for research participants

A participatory session where community members plan a research study
It is important to note, that while the activities above may have different levels of involvement, they may all be important components in an engagement strategy.
In this section, we will learn about the range of CEI goals and how it is necessary to incorporate different levels of participation to succeed.
As mentioned earlier, a good CEI plan will probably require a balance of ‘informing’, ‘consulting’, ‘involving’, ‘collaborating’ and ‘empowering’.

CEI activities may also address additional goals, for example improving healthcare.

CEI has a wide range of goals.

Match the term to the definition.

*Drag and drop the term onto its definition, then select 'submit'*. 
Levels of participation

Reflect on the 14 goals shown in the diagram below. Which levels of participation (inform, consult, involve, collaborate, empower community members) do they require to best succeed?

You may well have found that the goals require multiple 'levels of participation'.

Each goal can be addressed through informing, consulting, involving, collaborating and/or empowering. Sometimes informing is more appropriate than collaborating and in different contexts collaborating is more appropriate than giving information. Often, a combination of two approaches are necessary.

For example, 'involving' the public in the design of a research study might involve 'informing' them about the problem first so that they can share their informed views, and 'collaborating' with members of the public in a joint research project might involve 'consulting' other stakeholders.

<br>

**Many goals make CEI complex.**

We have just seen that CEI has so many goals. Sometimes these goals don’t align well with each other. For example, raising community members’ awareness of the risks involved in research participation may make potential participants reluctant to take part, working against a recruitment goal.

This wide range of goals makes the evaluation of CEI challenging, so mixed methods might need to be used. For example, different methods would need to be used to:

- Find out if CEI activities raise the community’s understanding of research.
- Enable community members to have their views included in the way in which research is carried
out.
The depth and width of engagement depends on the size of the group of community members involved in the activity and the amount of time and resources researchers have available to engage with them. In this section, we will look at the differences between 'deep' and 'wide' CEI, and their advantages and disadvantages.

CEI may be described as being either ‘deep’ or ‘wide’ and the goals of each are different.
'Wide' CEI activities aim at reaching large audiences, usually for relatively short periods of time, and are often aimed at raising community awareness or understanding of research.

The time allocated for ‘wide’ engagement activities may be relatively short and the opportunities for individuals to share their views may be limited. However, these activities could reach a diverse range of people from various backgrounds. Though not always the case, ‘wide’ CEI activities might be more appropriate for sharing information about research or raising awareness of ongoing research.
On the other hand, 'deep' CEI involves spending a longer amount of time over several meetings (longer time period) with individuals or smaller groups of people.

The extended time and the fewer people involved enables a greater opportunity to build a long-term relationship and stronger mutual-understanding between researchers and community members. It also offers more opportunities for participatory approaches aimed at including community insights into research. However, involving fewer people can mean there is less diversity and representation of all community members.
A CEI strategy may combine both wide and deep approaches.

**Deep CEI**
- Forming longer-term relationships
- Small outreach
- More participatory
- More opportunities for mutual learning
- Limited representativeness

**Wide CEI**
- Shorter encounters
- Greater outreach
- Less participatory
- Raising public awareness
- Greater representativeness
Adapted from Davies et al. (2019).

Deep or wide CEI?

Read the CEI activities below. Each activity fits somewhere on the arrow's line between deep and wide engagement.

*Drag and drop the CEI activities onto the 'deep to wide' spectrum below then select 'submit'. Keep referring to the information diagram above if you get stuck.*

A CEI strategy may combine both wide and deep approaches
Some key points about CEI

Both deep and wide CEI may enable community members and the public to:

- Share their views and any **concerns** they may have about research projects
- Offer their **views** on whether the research proposed is acceptable to the community
- Offer **ideas** and suggestions which may be incorporated in the design or implementation of the research
- **Ask** important questions about research
- **Negotiate** research benefits
- Keep researchers aware of community views or rumours about the research throughout, and many other things

Deep CEI over a longer period of time with fewer people is likely to better enable participants to have a better understanding of research, its benefits and risks. Because of this, it may lead to more informed views about research.

While it is important for researchers to listen to all community views and suggestions,
implementing all suggestions may be impractical. Taking up some suggestions may also lead to unethical practice, for example:

A community advisory board member may suggest that all clinical trial participants should be given smartphones to assist with follow-ups. The offer of a smartphone may be too good to refuse and might be considered coercive.
In this section, we describe how social research methods have been used to gain an understanding of community views about research.

**Exploring community views**

As can be seen by some of the goals presented earlier, an important part of CEI is exploring community views to understand whether proposed research is feasible and acceptable. In turn, this can improve the research design and its successful implementation. There are many ways of doing this (as will be described in this module and Module 5: Approaches and Methods for CEI).

 иногда the difference between what is research and what is CEI can be confusing.
For example, research methods (such as surveys or focus group discussions (FGDs)) have been used to gather community members’ views, to help decide the most appropriate ways of doing research (sometimes called feasibility studies).

Unlike CEI, this type of research may follow a scientific protocol (or plan) which has been approved by an ethics review committee. Ethically approved feasibility research findings can then be published and shared with the scientific community.

Surveys and FGDs can also be undertaken as part of the CEI plan to understand the community culture and social structures.

Select each picture to flip for information on the 2 methods.
Surveys – where members of the public are asked questions about their views on proposed research. This type of method gives us an indication of the proportion of people in a community who have a particular view on the research.

Focus Group Discussions (FGDs) – these are facilitated discussions amongst usually 8 – 12 participants. The group participants share their experiences and views about research. FGDs
In this section, we learn about how participatory methods taken from community development have been modified and used in engagement.

**Deliberative approaches for CEI**
"Deliberation is an approach to decision-making that allows participants to consider relevant information from multiple points of view. Deliberation enables participants to discuss the issues and options and to develop their thinking together before coming to a view, taking into account the values that inform people’s opinions."

Involve (2008)

For deliberation, the following are needed:

- A clearly **defined task** for the participants
- A **safe space** for learning and discussion – for example a workshop, or an online space
- Access to different **sources** of information and perspectives
- A facilitated, open and **inclusive discussion** between participants from different backgrounds and with different interests

Through a managed discussion and learning i.e. the deliberation process, participants are enabled to share, develop and modify their views. These views may change as a result of the deliberative approach.
Deliberative approaches can be used for community members and researchers to co-produce items such as guidelines or policies. Examples of these are given in Module 5: Approaches and Methods for CEI.

What method would you use?

Read the scenarios below and decide which approach you would use.

Select your answer then press 'submit'.
Participatory approaches for CEI

Participatory approaches are largely inspired by Brazilian philosopher and educationalist Paulo Freire (1921-1997).

Freire felt that traditional education was based on a ‘deficit model’ we encountered earlier in this module. Freire called it a ‘banking model’ where
learning was compared to adding money to a bank account through providing information.

He argued that education through problem-solving and discussion approaches enabled people to better understand the challenges they faced in their day-to-day lives, and therefore be in a better position to offer relevant solutions.
Developing these skills and what Freire called 'critical consciousness' enables people to reflect on their own context, problems, resources and problem solving. Their learning and reflection encourages individuals to make changes through enabling them to question their own society's practices and the way it is governed.
Tools for participatory community development

Several participatory tools were developed by British scholar Robert Chambers in 1994. These tools include the transect walk, community resource mapping and ranking.

*Select the + symbols below to reveal more information about each of the tools.*

The transect walk

This involves community participants walking through a particular area in a straight line, for example through a village. As they walk, they draw sketches of social and spatial aspects of their environment, discussing and taking notes of challenges, problems and potential resources.
Community resource mapping

Community members meet at a workshop and discuss and list their knowledge and resources in relation to a problem. In rural settings with low literacy, a range of symbols or items have been used to enable community members to list and appreciate their own resources. These resource maps have been used to plan development projects allocating appropriate resources for different aspects.
Ranking

In this exercise community members list and prioritise actions towards achieving a goal. This involves discussions about the potential solutions for a problem and placing them in order of the most appropriate or important.
Participatory Action Research (PAR)

Participatory Action Research, or PAR, is an approach which has been used in international and community development for community members and facilitators to plan, implement and evaluate together a project aimed at improving different aspects of life.
PAR is often described as a ‘spiral’ of cycles of planning, implementing and evaluating. In these cycles, knowledge gained from the evaluation of a project can feed directly into the next cycle of improving or expanding the project.

PAR has sometimes been used by researchers to plan CEI strategies. For example, in Module 5: Approaches and Methods for CEI in Health Research, we describe how participatory action research was used to develop a school engagement programme in Kenya.

**Participatory Visual Methods**

Participatory Visual Methods have four elements common to all of them.
There are a range of methods which can be used, for example, photovoice and digital storytelling, participatory art, and participatory video.

Select each picture to turn the card over and reveal information about each method.
Photovoice and digital storytelling - participants take and use photographs to convey the reality of their experience and lives and to develop stories.

Participatory art - participants describe and convey the reality of their experience and lives using art.
In Module 5: Approaches and Methods for CEI, we give examples of how participatory video has been used for CEI.

**Participatory video** - participants create their own films to describe their experiences, feelings and reality.
Patient and Public Involvement (PPI)

This approach was developed in the UK and is becoming increasingly recognised and used within global health research. In this section, we will look at the difference between engagement and involvement, and examples of PPI activities.

Patient and Public Involvement (PPI)

Patient and Public Involvement (PPI) in research evolved in the UK in the mid 1990s in an effort to include patients, carers and service users in making decisions about both health care and research. It has since been made a requirement by key research funding organisations, including the National Institute for Health and Care Research (NIHR) and the Medical Research Council (MRC), and by research publishers such as the British Medical Journal.
The NIHR Briefing notes for researchers (2021) make a distinction between ‘engagement’ and ‘involvement’.

*Select each image to reveal the differences.*
What kind of activities are carried out for Patient and Public Involvement (PPI)?

PPI in research could mean patients, carers, service users or members of the public carry out the following roles or activities:

- being a co-applicant on a research project;
- identifying research priorities;
- supporting a project by being part of a PPI advisory group;
- helping to develop communications and research information materials;
- undertaking interviews with research participants;
- carrying out the research.

Other examples of PPI roles in the research project life cycle are shown below.

*Select each of the ovals to reveal the different roles.*
Adapted from: An interactive course for new and experienced patient/public reviewers of health and social care research, NIHR (2019).

PPI should be integrated into the research lifecycle at appropriate points. This means PPI can occur in various ways from the initial identification of a research question to the sharing and implementation of research results.

More information about PPI can be found in Further Resources in Lesson 10: Summary.
Good Participatory Practice (GPP) is a guide to involving and engaging communities and stakeholders with clinical trials (a particular type of research design). In this section, we will look at the importance of engagement and the range of stakeholders in GPP.

What is Good Participatory Practice (GPP)?
Good Participatory Practice (GPP) was initially developed by the AIDS Vaccine Advocacy Coalition (AVAC) to guide community and stakeholder engagement for HIV vaccine trials. This has been drawn upon and modified to support clinical trials in emerging infections to produce GPP-EP (Good Participatory Practice in Emerging Pathogens research).

There are three key documents guiding GPP. These documents give detailed guidance on the type of engagement required at different trial stages – before, during and after. The documents also give advice on which stakeholders to engage.
Good participatory practice guidelines for trials of emerging (and re-emerging) pathogens that are likely to cause severe outbreaks in the near future and for which few or no medical countermeasures exist (GPP-EP).

This guidance specifically addresses good participatory practices during trials conducted in health emergency contexts where accelerated research processes are needed.

GPP-EP is the only set of global guidelines that directly address how to engage stakeholders in the design, conduct, and conclusion of emerging pathogen prevention and treatment trials.

Good Participatory Practice Guidelines for biomedical HIV prevention trials.

The GPP provide trial funders, sponsors and implementers with systematic guidance on how to effectively engage with all stakeholders in the design and conduct of clinical trials for biomedical HIV prevention.

Draft guidelines were initially drawn up by AVAC and UNAIDS alongside a multidisciplinary international group of community advocates, research staff and NGO representatives, in response to Cambodia’s Prime Minister halting planned PrEP efficacy trials for Cambodia and Cameroon in 2004 due to concerns over the ethics of the trials’ design.

The draft guidelines were further refined through broad stakeholder consultations and published in 2007. A second edition, including stakeholder input, was published in 2011.
Good Participatory Practice (GPP) for COVID-19 clinical trials: A toolbox


The document aims to:
- Inform rapid engagement processes and activities with key stakeholders involved in implementing clinical research relevant to COVID-19.
- Provide user-friendly tools for rapid multi-stakeholder engagement.

GPP and engagement throughout the lifetime of the trial

GPP places an emphasis on the importance of engagement before, during and after the trial.

Select each of the tiles to flip and reveal the information.
Engagement before the trial

For example, sharing the trial plans with community stakeholders so that they can raise questions or concerns and discuss acceptability of what is being proposed.

Engagement during the trial

For example, giving the public information about the trial through posters and radio interviews to support recruitment and meeting regularly with a Community Advisory board.
The range of stakeholders in GPP

To navigate through the example, select 'continue' and follow the instructions.

Please note, CBOs stands for Community-Based Organisations; NGOs stands for Non-Governmental Organisations.
Layers of Biomedical HIV Prevention Trial Stakeholders. UNAIDS Good Participatory Practice: Guidelines for biomedical HIV prevention trials (2011).
During this module, we have learnt that:

- Deficit models of communicating about science are one-way and assume that simply giving information will change people's attitudes and behaviours.

- In contrast, engagement and involvement imply more two-way forms of communication and dialogue.

- CEI has a wide range of goals and they do not always complement each other easily.
CEI can involve a combination of ‘deep’ and ‘wide’ approaches.

Participatory approaches, like participatory action research and participatory visual methods, are increasingly used in CEI.

Patient and Public Involvement (PPI) is a term used for involvement of patients, carers, service users and communities in research in the UK and has some similarities with CEI.

Good Participatory Practice (GPP) is an established set of guidance for undertaking CEI within clinical trials.

Further Resources

Participatory Action Research

Web page
Centre for Tropical Medicine and Global Health (2018) KEMRI–Wellcome Trust Research
Programme (KWTRP).


Participatory Visual Methods


Ethox Centre, Oxford Population Health (2020) REACH.

Video

Web page
Oxford University Clinical Research Unit (OUCRU) and Fact and Fiction Films (2015) Health in the Backyard.

Web page

Patient and Public Involvement

Guidelines
Hankins, C. (2016) ‘Good participatory practice guidelines for trials of emerging (and re-emerging) pathogens that are likely to cause severe outbreaks in the near future and for which few or no medical countermeasures exist (GPP-EP).’ World Health Organization.
Guidance document
NIHR (2021) Briefing notes for researchers - public involvement in NHS, health and social care research.

Guidelines

Guidelines

References
All references for the module are available to download below.

Select the grey box to download.

Reference list_Module 4.pdf
955.4 KB
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.

Please find below details of those involved, and details of the images and their credits.

Select the grey boxes to download.

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Congratulations!

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

Module 4 Quiz: Principles and Models for CEI