

Patient and Public Involvement

RECIPE BOOK

*How to approach a PPI meeting around **palliative care** as a public contributor and a researcher*



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Introduction

What is this?

This is a recipe book for Patient and Public Involvement (PPI) in Palliative Care research. It provides guidance and advice about how to approach a PPI meeting about palliative care (or organise one if you are a researcher). It was created after a PPI member for the RE-EQUIPP project.



What was RE-EQUIPP?

A palliative care project that brought together a new partnership of primary care and palliative care researchers from the north and south of England. The partnership was about improving inequalities in palliative care, including in PPI for research.

How does this help?

The recipe book provides information and guidance about how to approach PPI for palliative care. The aim is to improve PPI for palliative care research, and make it more accessible.

It is about palliative care research but the information and guidance can be useful for research in other areas too.

Who is this for?

This is for people considering becoming a PPI member for a research study in palliative care as a patient or carer representative, and for researchers planning their PPI activities.

Why did we create it?

The RE-EQUIPP Care Partnership saw the value in helping all involved in PPI to do it well - the recipe book idea came out of a co-production workshop with researchers, carers, patients and practitioners.

The recipe book is split into three sections to help you find the most relevant information for you:

- **Information for patients and carers**
- **Information for researchers and PPI co-ordinators**
- **Resources from RE-EQUIPP**

**For patients/carers considering
or already involved in PPI**

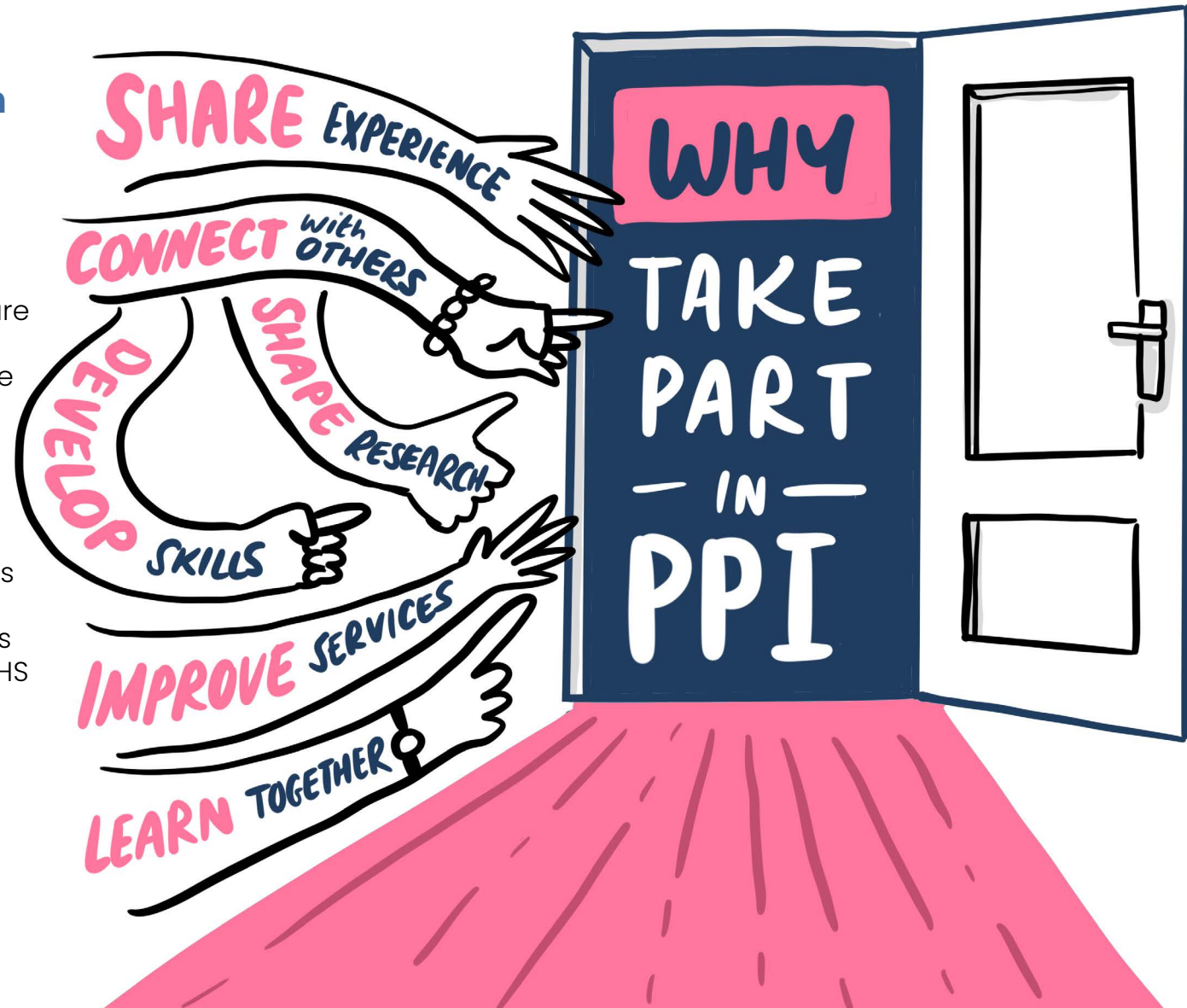


Why get involved

Getting involved in PPI is a great way to share your expertise, experience and develop new skills, all whilst shaping research and services for the better.

You could:

- Share how your experience of palliative care could have been better
- Share what went well in your palliative care experience
- Connect with others who have been through palliative care
- Develop new skills in research methods, communication and public engagement
- Contribute to research papers, policy briefs and public campaigns
- Shape the way new palliative care services are designed in the community and the NHS



What to expect

PPI means that research is done with or by patients and the public, not to, about or for them.

Good PPI means sharing decision-making about the research questions, design, resources and how the findings are written up.

PPI is different to engagement which is about raising awareness of research, and participation, which is about people giving formal consent and taking part in a trial or study.

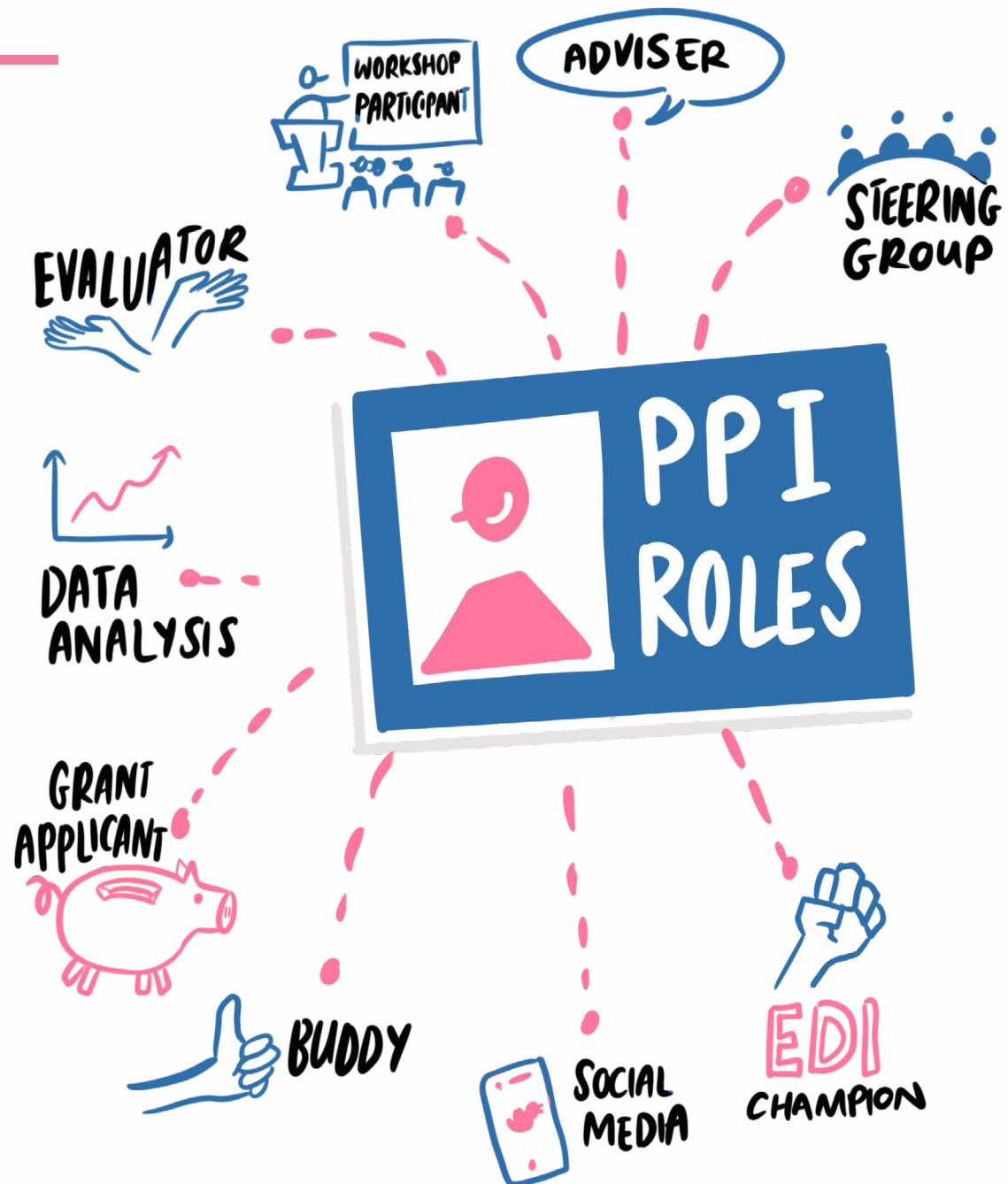
PPI can take place in many forms including meetings and workshops with researchers, online or face to face. PPI members may be asked to read through and comment on sections of research proposals, plans and leaflets, and research papers or conferences.



PPI Roles

There are so many ways to contribute, including:

- Being part of the steering group
- PPI Panel member
- Research adviser or consultant
- Evaluator
- Data analyst
- Grant applicant
- PPI Buddy
- Social media co-ordinator
- Equality Diversity and Inclusion champion



Principles of engagement

For PPI members and researchers to work together well, it is helpful to agree a set of principles for engagement.

These can be helpful for the whole group, both researchers and PPI members. Suggestions from RE-EQUIPP are:

Plan PPI carefully, whether you are a researcher or a PPI member. Think about when is best to work together and for how long.

Be respectful. Everyone has experiences, including researchers, that may have been difficult.

Keep focus on the research study and what advice is needed for the study.

Do not make assumptions about what people know or other's experience.

Everyone has permission to ask questions, and to say "no".

PPI is a chance to listen to and learn from

others, to speak and to observe.

You can offer different ways to contribute.

Support is important when things get tough or emotional, especially in palliative care research.

Know your limits. If you feel uncomfortable it is ok to say so, and to leave.

There are no obligations on people to be involved.

Everyone can champion inclusivity.



For researchers



Key principles

PPI works well when there is:

A shared understanding of the moral and methodological purposes of PPI

A key individual co-ordinating PPI

Diversity of PPI representation and inputs

A research team positive about PPI input and fully engaged with it

Relationships that are established and maintained over time

A proactive and systematic approach to evaluation

(Wilson, Mathie et al. 2015)



Improving Equity, Equality, Diversity and Inclusion in PPI for Palliative Care Research

The RE-EQUIPP Care Partnership was a project designed to build opportunity and develop infrastructure and resources for more inclusive PPI for palliative care research. Principles of good PPI were adapted to produce a new framework for improving equity, equality, diversity and inclusion (EEDI) in PPI as follows:

Demonstrate intention and commitment to EEDI in PPI

Approaches to promote EEDI in PPI can challenge researcher views, norms and power dynamics.

PPI roles including an EEDI PPO Champion provide benefits like role modelling and peer leadership.

Investment in time to build relationships is required to enable communication.

Well planned, funded time is required for co-ordination of PPI

Dedicated time for co-ordination of PPI is required and costed in to grant applications.

Strong professional networks enable effective PPI.

Clear institutional processes are needed to support timely payment.

Time commitment for PPI activities should be agreed with PPI members early.

Multi-disciplinary research partnerships increase EEDI in PPI

Collaborative, multi-disciplinary research partnerships provide opportunities for knowledge exchange and networks to enable equitable PPI.

Co-design of new methods for more accessible PPOI should take place with PPI members who have diverse lived experiences.

Shared understanding of moral & methodological purposes of PPI created with PPI members

Theories including the Inverse Care Law, and intersectionality and symbolic capital are helpful when considering approaches to EEDI in PPI.

An equitable and just approach acknowledges that different approaches and resources are necessary to create meaningful opportunity for people from diverse backgrounds.

Researcher-PPI member relationships must be established and maintained over time

Increasing EEDI in PPI for palliative care research requires trust building through informal discussion and regular feedback as well as more focused or formal PPI events.

Online meetings enable regular conversation for groups who come from diverse geographies, but strategies to address digital poverty are required.

Proactive and systematic evaluation is required

Methods of proactive evaluation include impact logs and PPI feedback on events and activities.

Informal discussion and reflection amongst the research team and with PPI members provides important insights and learning.

Work to promote EEDI in PPI for palliative care should be shared.

Practical considerations

Many resources exist to help researchers to include PPI in their research.

The following suggestions are from the RE-EQUIPP Partnership work:

Recruitment

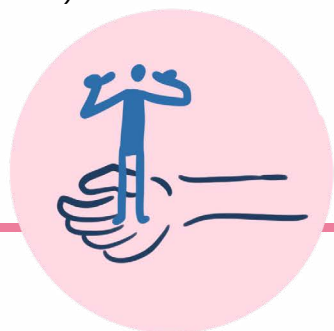
A flyer to share with potential PPI members detailing the commitment and plan for PPI can be helpful. Combining research networks across specialities e.g. palliative care and primary care can help with recruitment.

PPI Meetings

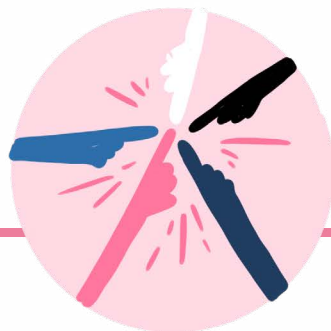
Consider an informal PPI pre-meeting ahead of any more formal PPI activity. This can focus on connecting PPI members and making introductions, and to explain the details of the project. In RE-EQUIPP, a “jargon-buster” for the project was discussed by group members

When to involve PPI

You should include PPI from the very start of the project – you do not need to have finalised your questions or methods in order to present to a group (in fact it helps not to so you can incorporate input from the PPI panel).



RECRUIT



INVOLVE



MEET

Supporting PPI members

Set out clear roles and responsibilities

Create role descriptions for PPI contributors so there are clear expectations from the start on what is involved.

Use the RE-EQUIPP template [here](#).

Set principles of engagement

For PPI members and researchers to work together well, we need to agree to a set of principles for engagement. Use your first meeting to explore these together (see page 8 for more).

Consider different ways to engage

Not everyone can make face to face events. Think about alternative methods of engagement, from text and phone call, to online events or social media takeovers.

The online forum for PPI in RE-EQUIPP allowed researchers to connect with PPI members virtually, including to ask for specific advice or to recruit them to study teams / face to face / hybrid / alternatives (forums/slack group).

It was recognised that online access could be a potential barrier to people who experience social disadvantage, including those from areas of socioeconomic deprivation or rural areas, where literacy may be mixed, English may not be a first language and access to the internet is not reliable.

Engage community champions

PPI processes need to work with people from diverse and deprived areas - it is useful to engage community leaders and champions, as well as individuals with knowledge and experience of services.

RE-EQUIPP learnt from previous work which involved approaching community leaders included asking them to identify a person with lived experience to take part alongside them.

Use creative methods

Graphic facilitation and live scribing (illustrators recording the session in pictures in real time) is a valuable way to summarise and shape discussions – consider funding for this. Also consider the use of images in a comic format, or a short, animated video as accessible alternatives to presenting research findings and PPI contributions.

PPI Meetings

Consider an informal PPI pre-meeting ahead of any more formal PPI activity. No agenda is needed but a focus on connecting PPI members and facilitating introductions, to explain the background of the partnership and project plans.

For example, in RE-EQUIPP's early meetings, the background section of the Detailed Project Plan was read out and PPI members asked to interrupt every time they heard language they considered to be medical jargon, to inform the development of a "jargon-buster".

Prioritise regular communication

Schedule regular catch up meetings, workshops and feedback loops, using a diversity of methods to get your messages across.

Recognising the contribution of PPI members

There is a need for someone to navigate processes and be the contact point for PPI members – ideally a named PPI co-ordinator for the project with costed time. Set out early what can be reimbursed and how PPI members would like to be remunerated for their time – it doesn't always have to be money or vouchers.

[More guidance on funding for PPI.](#)

Evaluate experience of your PPI members

Evaluate experiences using impact logs, questionnaires and informal check ins.

Resources



Jargon Buster

For Palliative and Primary Care

Primary care

The first place that people go to for health advice and treatment in the community. It includes disease prevention and treatment, living with long term conditions and palliative care.

Primary care includes a wide range of professionals including community nursing services, therapists, opticians, pharmacists, and dentists. General practitioners are medical specialists in primary care.

Palliative care

A broad approach to care that is person-centred and focussed on quality of life for people with serious illness, and their carers.

End of life care

Care for people with advanced disease who may be in the last year of life.

Specialist palliative care

Palliative care delivered by professionals with qualifications, expertise, and experience in palliative care, for people with complex needs that cannot be met by their current care team.

Multi-disciplinary team (MDT)

A group of health and care practitioners from different organisations (e.g. GPs, social workers, nurses), that work together to make decisions regarding the treatment of individual patients.

Person-centred care

Care focused on the needs of an individual, to ensure the person's preferences, needs and values guide clinical decisions.

Holistic care

Care and treatment of the whole person, that considers physical, mental, social, cultural factors and spiritual beliefs, rather than just the symptoms of an illness.

Integration

The process of combining two or more teams or organisations into one.

Collaboration

Two or more people, teams or organisations working together to complete a task or achieve a goal.

Health Inequalities

Avoidable and unfair differences in health between different groups of people.

For PPI**Patient and Public Involvement**

The active involvement of patients and members of the public in the design and process of research (may also be known as PPIE with the addition and Engagement on the end).

Participation in research

Where people take part and give consent to be in a research study. Other terms that

may be used to describe working with patients and members of the public include "Community involvement and engagement". People who take part in PPI may be called "experts by experience" or "expert patients" often because they have lived experience of a situation.

Engagement

Where the activity and results of research are shared with members of the public.

Lived experience

Knowledge of something through personal experience.

For Research**Dissemination**

The action of sharing information widely.

Methodology

A system of methods used in a study or activity.

Methods

The techniques and processes used to collect data for research.

Qualitative research

Involves collecting data to understand experiences and opinions. Provides new in-depth understanding into a problem or generates new questions.

Quantitative research

Uses numerical data.

Mixed-methods research

Combines qualitative and quantitative research.

Literature review

A paper that describes all the published papers on a subject

Systematic review

A literature review where the process of finding all the published papers follows a system.

Data analysis

Using techniques (statistics or logic) to describe the data.

Patient / person-centred

Care or research which considers the whole person, is linked to their rights and involves them in decisions.

Other/General**Equality**

Equal access to opportunities, removing barriers and disadvantage for everyone.

Equity

Everyone having equal opportunity.

Diversity

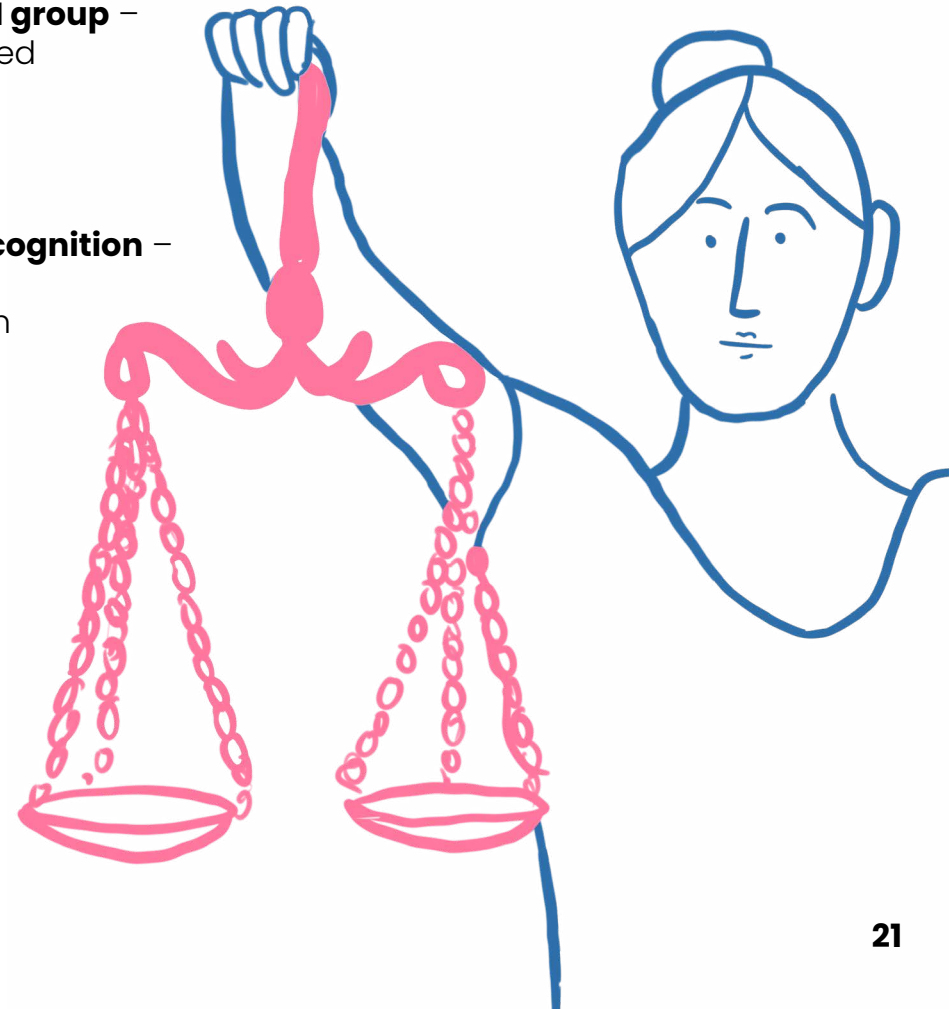
Being reflective of the wider community and supporting representation.

Inclusion

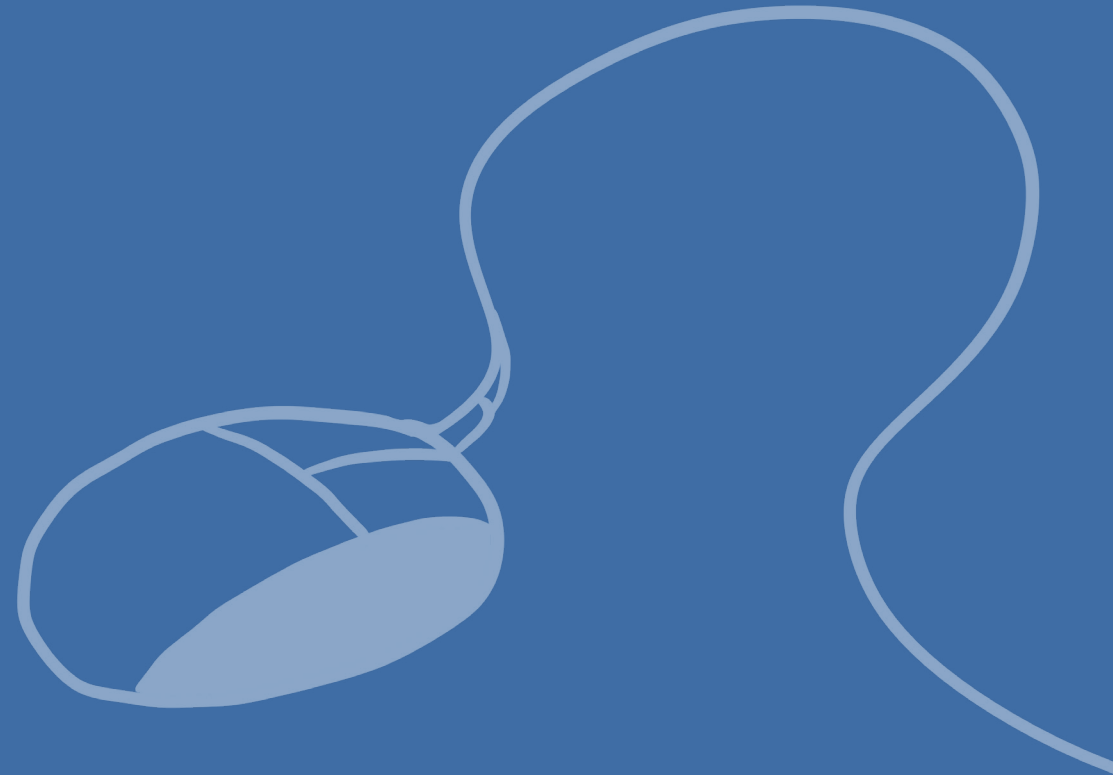
Valuing, respecting, and celebrating difference and a sense of belonging.

Ethical considerations

- **Prioritise PPI** with for palliative care research.
- **Agree language and work towards a shared understanding of tasks** – structured sessions work well.
- **Gain consent for PPI** – ensure understanding of activities and verbal / implied consent to take part / permission to stop anytime.
- **Maximise the benefits for PPI group members** – consider these with PPI members – what do they want from their involvement? Could be publication authorship, other personal development or wanting to make a difference.
- **Ensure feedback to group members** so they can see what difference their input has made and the research has made.
- **Minimise the risk of harm** e.g. people meeting through PPI who may not otherwise have met and risk of hearing distressing stories or bereavement – need to ensure people are briefed on this.
- **Ensure equity of access to PPI and EDI**
- **Provide training for the researcher as needed** – may be bespoke apprenticeship / shadowing as formal PPI training limited
- **Offer training for the PPI group** – bespoke and personalised according to the task, often delivered by the research team.
- **Provide funding and recognition** – guidance on this but special circumstances in palliative care to consider e.g. carer costs.



Useful Links



Reporting PPI

[GRIPP-2 checklist for reporting PPI](#)

PPI Standards

[PIRIT Standards](#)

Payment Guidance

[NIHR Payment Guidance](#)

General PPI Resources

[NIHR PPI Support](#)

[NIHR Funding Guidance](#)

[UK Standards for Public Involvement](#)

[Public Involvement in Research Impact Toolkit](#)

[Reporting Patient and Public Involvement](#)

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