Care Alliance
Ireland

Public and Patient Involvement

A Guide for
Not-for-Profit and Community Groups
New to Research

Acknowledgements

What is the purpose of this guide?

This guide has been designed with small not-for-profit groups in mind, in particular those who are run largely on a volunteer basis, with little funding or in-house research expertise. These groups often find themselves approached by researchers who may see not-for-profit and patient-led groups as fertile ground for data collection.

These small groups (and larger organisations alike) often feel pressure to agree to any and all requests for participation in research – in particular if the condition or issue is under-researched. This can lead to research being undertaken which does not sufficiently involve the intended beneficiaries – the individuals with a specific condition, their family carers or those experiencing a particular challenge.

Public and Patient Involvement (PPI) in research aims to challenge the traditional ways research has been carried out. You might be familiar with the phrase 'Nothing About Us Without Us', which has long been a rallying cry of the disability sector in their request for inclusion. That same mantra applies here – we want to ensure that all research about people is undertaken with their greatest possible involvement. A great deal of very useful guidance has been produced regarding PPI for organisations and researchers; however, this is usually aimed at larger organisations that have a distinct research function or experience. For this reason we have produced this concise guide aimed directly at smaller organisations.

The topics covered in this guide are:

What is PPI?
What are the stages of research?
What can PPI contribute to the work of your organisation?
What can your organisation contribute to research?
So your organisation has been approached by a researcher –
what next?
Challenges faced by PPI researchers
Resources for organisations
Glossary of terms

This guide should not be seen as a static document – as knowledge and understanding develops, this guide may well be superseded by further works in the area. It has been produced by Care Alliance Ireland in early 2021 as part of the Health Research Board-funded PPI Ignite project at the University of Limerick, in consultation with the project partner organisations.

What is PPI?

For many years, research was undertaken ON people with health conditions. Scientists and academic researchers were seen as the 'experts', and those being researched were passive respondents in research. However, this experience **can** be very different. PPI research strives to meaningfully involve patients, carers and members of the public at all stages of research.
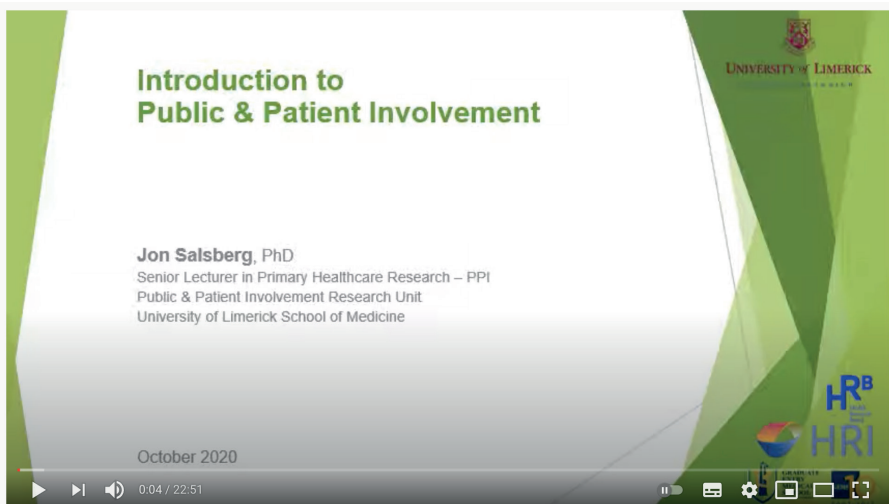
Introduction to PPI Research - Dr. Jon Salsberg (University of Limerick)

By way of introduction, Dr. Jon Salsberg from the University of Limerick presents a comprehensive 22-minute introductory video on the basics of PPI research – see YouTube https://youtu.be/SqnvZ6f51Bc.

Stages of involvement

Patients and the public feature in research through engagement and participation. PPI is focussed on active involvement. Here is a more detailed description of these three terms (taken from INVOLVE UK: https://www.invo.org.uk/posttyperesource/what-is-public-involvement-in-research/):

Engagement → Participation → Involvement

Engagement

Where information and knowledge about research is provided and disseminated.

Examples of engagement are:
- science festivals open to the public with debates and discussions on research
- open day at a research centre where members of the public are invited to find out about research
- raising awareness of research through media such as television programmes, newspapers and social media
- dissemination to research participants, colleagues or members of the public on the findings of a study.

Participation

Where people take part in a research study.

Examples of participation are:

 • people being recruited to a clinical trial or other study to take part in the research

 • completing a questionnaire or participating in a focus group as part of a research study.

Involvement

Where members of the public are actively involved in research projects and in research organisations.
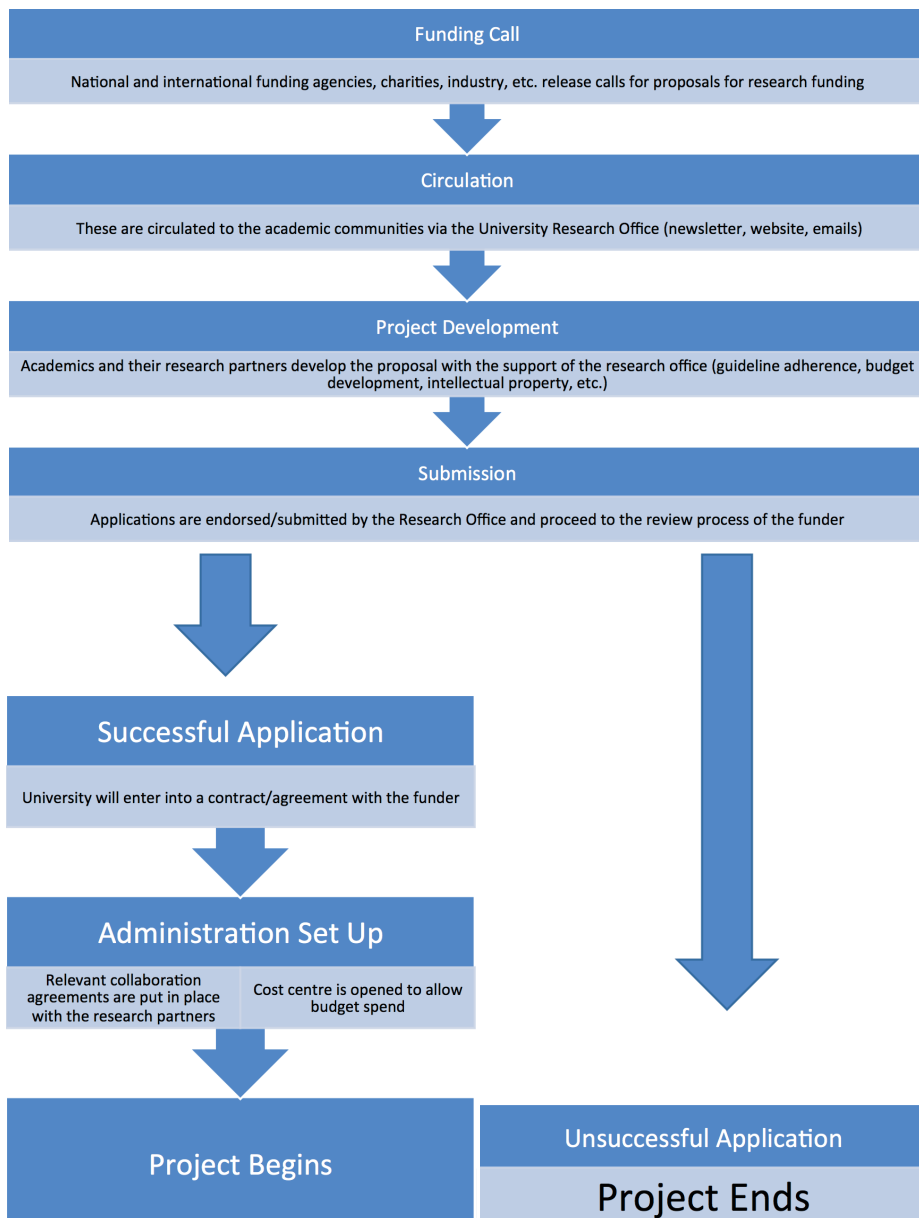
Examples of public involvement are:

 • as joint grant holders or co-applicants on a research project

 • identifying research priorities

 • as members of a project advisory or steering group

 • commenting on and developing patient information leaflets or other research materials

 • undertaking interviews with research participants

 • user and/or carer researchers carrying out research.

The best type of PPI research is where there is **full involvement** of patients and services users at all stages of the research. The minimum that we would find acceptable is involvement of patients and service users at the start and end of research – for the conceptualisation, interpretation and dissemination of the research.


What are the stages of research?

While each research project will have its own timeline, most programmes that fund research follow the same kinds of steps. Here is an example showing the kind of work a research team must do to apply for research funding.
The timeline involved is generally between 12 and 18 months from call announcement to signing of contracts.

Funding Call

National and international funding agencies, charities, industry, etc. release calls for proposals for research funding

Circulation

These are circulated to the academic communities via the University Research Office (newsletter, website, emails)

Project Development

Academics and their research partners develop the proposal with the support of the research office (guideline adherence, budget development, intellectual property, etc.)

Submission

Applications are endorsed/submitted by the Research Office and proceed to the review process of the funder

Successful Application

University will enter into a contract/agreement with the funder

Administration Set Up

Relevant collaboration agreements are put in place with the research partners	Cost centre is opened to allow budget spend

Project Begins

Unsuccessful Application

Project Ends

PPI participants can make contributions at every stage of the research process; this illustration demonstrates this well.
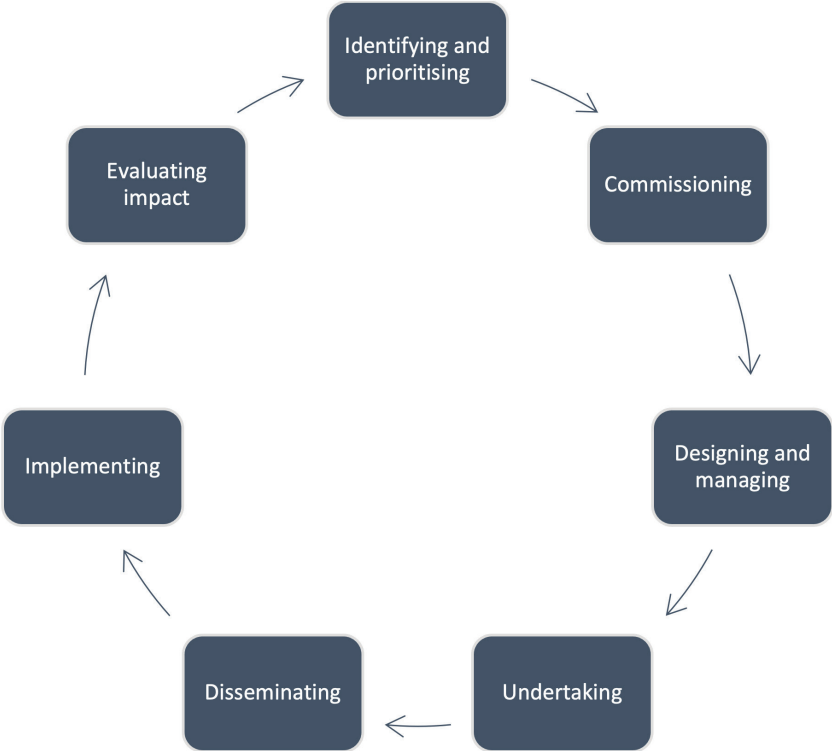
Source: INVOLVE (2012) Briefing notes for researchers.

What can PPI contribute to the work of your organisation?

PPI research is not simply a way to become more involved in research to assist researchers. The results of research rooted in PPI approaches can be used to add significantly to the cause of a patient or carer organisation.

Academic rigour

PPI research conducted in partnership with respected academic researchers and institutions ensures that research results are rigorous, that is, that results are reliable; such results will likely carry more weight with policy makers and others (see below).

Evidence base for interventions and services

As an advocacy or patient-focussed organisation, your priority is to ensure that the patients and carers you represent have access to the best possible supports and interventions. Using the results of PPI-based research can help to ensure that the interventions and supports you supply are seen as effective and useful not just from a purely 'academic' perspective, but also from the perspective of the users of those services. Involving service users at all stages of research keeps the research practical and focussed.

'Ammunition' for policy change and agitation

If your organisation is involved in advocacy work, having research to 'back up' your requests for a policy or funding change is very helpful. Decision makers need to see evidence before coming to any conclusion, and research that is not only scientifically rigorous but also rooted in the experience of the core beneficiaries of any such change will enable you to develop a strong position.

What can your organisation contribute to research?

One of the most important things to remember when thinking about research is that your organisation, service users, patients and carers have significant skills and knowledge to bring to the table.

Expert knowledge

The patients, carers and others involved in your organisation are the experts in living with the particular condition or in the particular situation that concerns your organisation. **Academic researchers do not have access to that experience except through you** – so don't discount that.

Practical knowledge of the realities of your members

As an organisation, you have built up significant banks of knowledge within your organisation over many years, much of which may not be written down or formalised in any way. This type of 'institutional memory' is very valuable.

When research has been done in the past, it may not have included any kind of dissemination plan, so the academic researchers interested in your topic may not even know it took place. Similarly, involving patient and carer researchers means that more knowledge of the day-to-day practicalities of the situation will be involved at an earlier stage, making the research more robust and more likely to be successful.

Legitimacy

Representation on a research project by your organisation and patients and family carers legitimises that research and establishes a desire for inclusive research on the part of the academic team. Many funding programmes now expect a research team to include PPI researchers. **The research team needs you as much as you need them.**

So your organisation has been approached by a researcher – what next?

Most organisations have some experience of being contacted by a researcher with a request for involvement in their research. However, we regularly hear that that contact is not optimum:

- last minute request for involvement in a funding bid – 'all we need is your signature'

- expectation of involvement in research with no specific budget for your organisation or patients/family carers

- questions already fully formed – no room for meaningful debate

- the researcher just wants you to help them help them with study enrolment, or to facilitate access to respondents (this is known as being a 'gatekeeper').

Organisations, in particular in areas that remain under-researched or ignored, can often feel obliged to agree to take part in these projects. If they don't, when will the opportunity come again? They may also not wish to be seen as 'difficult' or awkward by asking too many questions.

However, it is very important that organisations have the opportunity to make sure that a project they get involved in is a good use of time and resources – both of which are often in short supply.

Questions to ask researchers

You might not know where to start with your questions – and sometimes it can be intimidating bringing up these types of issues with academics and researchers. Here are examples of questions that might be worth asking at as early a stage as possible. This is not an exhaustive list, and not all questions will be relevant for all projects or organisations. The list below has been developed by researchers, academics, patient groups, carers and others.

For projects without a distinct PPI element

• Where did the inspiration for this research come from?

• Where are you in this research currently?

• How do you plan to share the outcomes and outputs of the research with people that took part?

• Have your project materials (surveys, research protocols, interview schedules, etc.) been reviewed by patients or carers in advance of your approaching our organisation?

• Do you have an 'Open Access' publishing policy?

For projects with a PPI element

• At which stages of the research process are you looking for our involvement?

• How do you plan to support our involvement?

• What training will be available to the PPI research team?

• Where did the inspiration for this research come from?

• What other community/patient/carer groups are you involving?
Where are you in this research currently?

• Can you give us an indication of a realistic time commitment per week/month for involvement in the project?

• If we have difficulties as an organisation with the project team, who can we approach within the university?

• How do you plan to reimburse PPI participants for their time/travel/replacement care costs etc. as part of their work on the project?

• Will you be including PPI research team members as authors on publications from the project?

• How do you plan to share the outcomes and outputs of the research with people who took part?

• Do you have an 'Open Access' publishing policy?

Saying 'yes'

Agreeing to take part in any research is a decision that takes time. There is a lot to consider.

Usually, agreeing to take part in research as a PPI partner involves signing a contract. You may need to have approval from a Board of Directors or have your membership vote on it. You should make those requirements clear to any organisation that approaches you to take part in research.

Saying 'no'

It is very tempting to agree to take part in all research that includes your area of work. This is especially true if your organisation relates to a condition that does not have a high profile or is under-researched.

Even after you have asked questions and encouraged researchers to include some level of patient and/or carer involvement, some researchers will not take on your recommendations. You then need to decide if you still wish to be involved, whether by helping the researchers to recruit participants or sharing details of their study with your members through your newsletter or social media.

Don't forget that your involvement in this stage of the research is important to the success of the project, so you are not powerless. Your involvement can also be seen as a form of endorsement of the research.

If, for example, you feel that the proposed research involvement is tokenistic, then it may be the case that the researchers are not abiding by the terms of their funding contract – many funding bodies now require an element of authentic PPI research to be included. So your involvement is very important! Ideally, you might wish to decline to get involved but remain open to future collaborations. In that case, having a pre-approved response which indicates that may be helpful. Your organisation could adapt the text below to your own needs:

Thank you for the opportunity to consider becoming involved in this research. It is part of our values as an organisation that research we are involved in respects the contribution and expertise of patients and carers as equal members of the research team. In this instance we are not in a position to collaborate on this particular project – but we remain open to collaboration in the future.

Challenges faced by PPI researchers

It is important to understand that researchers in university settings face challenges in conducting research – especially high-quality PPI research. Some of these are outlined below, as examples which are useful to remember in your negotiations and work with researchers.

Funder lack of understanding of PPI

Many different bodies fund research in Ireland, and while many understand the benefits that well planned and executed PPI research brings to practice, specific funding for PPI activities is often first to be cut from funding applications. This gives rise to unreasonable expectations about what can and cannot be achieved by the research team with the funding they receive.

In addition, the financial reporting requirements for and within universities can be onerous, and are often not compatible with the way in which small organisations work. Systems in universities and large research centres are often set up to account for traditional work practices, and less so for the work

of small, nimble not-for-profits. An example of this is a requirement for partner organisations to account for an hourly rate and to provide timesheets, while not-for-profits may be organised more toward a task-based system. This requires extra negotiation on the part of the research team when working with small organisations, and can cause significant challenges to a positive working relationship between PPI partners.

Having a clear contract set out in advance of the project, which outlines the reporting requirements of PPI partners, is critical to avoiding these issues, in particular with a university partner that may not have experienced this to date.

Skills development

Developing the skills to do good PPI research is challenging, and takes time. It can be very intimidating for a researcher to walk into a room full of people who have direct experience of the issue they are interested in – especially for graduate students or early-stage researchers. Skills like group facilitation, using accessible language, writing and dissemination are not necessarily something that researchers have yet developed.

Time

Undertaking good PPI research takes time, and often academic researchers have teaching responsibilities, student supervision and other demands on their time. In addition, if funding bodies or departments do not understand the benefits of PPI research or the time required to produce good PPI research, pressure may be put on researchers to produce results within really challenging timelines. This does not mean you as a PPI partner should feel rushed, however.

Resources for organisations

There are a number of resources which organisations can access for more information on research and PPI research in particular. Some of these are focussed on researchers and academics; however, the information is likely to be of use to organisations:

National PPI Ignite Network: At the time of writing (February 2021), the new National PPI Ignite Network (funded by the Health Research Board and in collaboration with the Irish Research Council) is in the process of being established. In the coming years, it will be the main Irish hub for PPI support and resources.

Health Research Board (HRB): The HRB funds a number of research schemes in the area of health research in Ireland. It is the funding body for PPI Ignite, and has made advances in the last number of years in encouraging the advancement of Involved Research. https://www.hrb.ie/

Irish Platform for Patient Organisations, Science & Industry (IPPOSI): IPPOSI is a patient-led organisation that works with patients, government, industry, science and academia to put patients at the heart of health policy and innovation. https://www.ipposi.ie/

Health Research Charities Ireland (HRCI): HRCI, previously known as the Medical Research Charities Group (MRCG), is the national umbrella organisation of charities active in medical and health research, together

representing over 1 million Irish patients. Through support and advocacy, they seek to represent the joint interests of their members, working to improve health and prevent illness through research. https://hrci.ie/

Published reports

Alzheimer Society of Ireland (2019) *Guidelines for working with the Dementia Research Advisory Team.* ASI. https://bit.ly/2NwhOFQ

Arthritis Research UK. *Patient and Public Involvement – A Researcher's Guide.* Arthritis Research UK. https://bit.ly/3qQkBbh

Elliott, J., Lodemore, M., Minogue, V., and Wellings, A. (2019) *Public Co-Applicants in Research – guidance on roles and responsibilities.* INVOLVE, UK. https://bit.ly/3uoR22O

HRCI and Trinity College Dublin (2020). *Making a Start: a toolkit for research charities to begin a PPI relationship.* HRCI, Ireland. http://bit.ly/2UAObTG

INVOLVE (2012) *Briefing notes for researchers: involving the public in NHS, public health and social care research.* INVOLVE, UK. https://bit.ly/2ZVtHrD

INVOLVE (2019) *Guidance on co-producing a research project.* INVOLVE, UK https://bit.ly/3qNMiBE

INVOLVE (2019) *Starting Out – Essential information for members of the public who are thinking about getting started in involvement in research.* INVOLVE, UK. https://bit.ly/3kdwGF7

Lynch, B., Dunne, C., Aherne, F., Kennan, A. (2019). *Evidence for Advocacy: A Practical Guide. Guidance on the generation and use of evidence in charity advocacy campaigns.* Health Research Charities Ireland. https://bit.ly/3kg4FMV

Medical Research Charities Group (2018) *Developing a PPI Strategy: A Guide. Practical advice on developing a patient and public involvement (PPI) strategy for research activities.* MRCG, Ireland. https://bit.ly/2NzROJJ

Mental Health Research Network and INVOLVE (2013) *Budgeting for involvement: Practical advice on budgeting for actively involving the public in research studies.* Mental Health Research Network and INVOLVE, UK. https://bit.ly/2NPXxuE

Turk, A., Boylan A., Locock, L. *A Researcher's Guide to Patient and Public Involvement: A guide based on the experiences of health and medical researchers, patients and members of the public.* Oxford University. https://bit.ly/3dFmnYZ

Appendix

Glossary of terms

	Types of Research
Action research	Action research is used to bring about improvement or practical change. A group of people who know about a problem work together to develop an idea about how it might be resolved. They then go and test this idea. The people who take part in the testing provide feedback on their experiences. They may also identify further actions that need to be researched and tested. This cycle of developing solutions and testing them is repeated until the problem has been solved.
Emancipatory research	With emancipatory research, people who use services, rather than professional researchers, have control of the whole research process. They plan and undertake the research, and interpret the findings. The main aim is always to empower people and improve people's lives. 'Professional' researchers may be brought in as advisers or have specified roles within the project.
Participatory research	This is a type of research where people experiencing an issue or those who use services or their carers are the researchers. They identify the action and knowledge gaps to be filled, design and conduct the actual research, and disseminate and apply the findings to promote real change and improve people's lives. This may be conducted in conjunction with professional researchers acting as partners or consultants. Participatory research is often defined as an approach to research rather than a methodology. Within the tradition of participatory research, Participatory Health Research (PHR) is defined as 'Systematic enquiry, with the collaboration of those affected by the issue being studied, for the purpose of education and taking action or effecting change'.

	This is the definition used by CDC and Institute of Medicine, USA, following the Royal Society of Canada Study of Participatory Research in Health Promotion.
PPI – Public Patient Involvement	An active partnership between patients and the public and researchers in the research process, rather than the use of people as 'subjects' of research. Patient and public involvement in research is often defined as doing research 'with' or 'by' people who use services rather than 'to', 'about' or 'for' them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, and undertaking interviews with research participants. When using the term 'public' we include patients, potential patients, carers and people who use health and social care services as well as people from organisations that represent people who use services.
Research	The term 'research' means different things to different people, but is essentially about finding out new knowledge that could lead to changes to treatments, policies or care.
	Research Participants
Community group	A community group is a group of people who are interested in a particular issue, and who come together to meet others with the same issue. Often these may work to progress knowledge or give support to others in the same situation

Experts by experience	The term 'experts by experience' refers to service users and carers who are experts through their experience of illness or disability and services.
Patients	People who use healthcare services and their carers.
Public	Everyone who has an interest in health and social care as a public service including potential users of services. Within the definition of PPI, this is often used to acknowledge that not everyone effected by health research is a 'patient'; for example, public health research aimed at disease prevention hopes to impact the public before they become patients, yet they still should be involved.
Researcher	Researchers are the people who do the research. Traditionally these are people whose job description includes conducting research and who are employed in a university, hospital or other institution, but equally can be a patient, service user, carer or other member of the community involved in guiding a research project.
Service user	A service user is someone who uses or has used health and/or social care services because of illness or disability. Some people do not like this term because they feel it has negative connotations.
	Types of Involvement
Collaboration	Collaboration involves active, ongoing partnership with members of the public in the research process. For example, members of the public might take part in an advisory group for a research project, or collaborate with researchers to design, undertake and/or disseminate the results of a research project.

Consultation	Consultation involves asking members of the public for their views about research, and then using those views to inform decision-making. This consultation can be about any aspect of the research process – from identifying topics for research, through to thinking about the implications of the research findings. Having a better understanding of people's views should lead to better decisions.
	Researchers are the people who do the research. Traditionally these are people whose job description includes conducting research and who are employed in a university, hospital or other institution, but equally can be a patient, service user, carer or other member of the community involved in guiding a research project.
Empowerment	Empowerment is the process by which people who use services equip themselves with the knowledge, skills and resources they need to be able to take control of decisions and resources. It often involves people building confidence in their own strengths and abilities. It does not always mean people take control over all decisions or all resources.
Engagement	Where information and knowledge about research is provided and disseminated, for example, science festivals, open days, media coverage. Tends to be one-directional.
Involvement	Involvement in research refers to active involvement between people who use services, carers and researchers, rather than the use of people as participants (or 'subjects') or mere sources of data in research. Many people describe involvement as research with or by people who use services rather than research about or for them.

	Research Terms
Data	Data is the information collected through research. It can include written information, numbers, audio/video and images. It is usually stored on computer, so that it can be analysed, interpreted and then communicated to others, for example, in reports, graphs or diagrams.
Data protection	Data protection is making sure that the data collected during research is kept safe and used only for the purpose it was collected for.
Dissemination	Dissemination is a multi-layered process of moving research findings into action, including: diffusion: the simple one-way communication of research findings (e.g. articles, conference presentation); dissemination: active engagement with a target audience to make sure that they have received and understand the research findings (e.g. websites, webinars, workshops); application: activities in targeted areas to put the research findings into action (e.g. interventions).
Ethics	Ethics are a set of principles that govern researchers and the institutions in which they work who are carrying out research with people. Ethical principles are designed to protect the safety, dignity, rights and well-being of the people taking part. They usually include the requirement to ask each individual to give their informed consent to take part in a research project.
Evaluation	This involves assessing whether an intervention (for example, a treatment, service, project or programme) is achieving its aims. A project can be evaluated as it goes along or right at the end. An evaluation can measure how well the project is being carried out as well as its impact. The results of evaluations can help with decision-making and planning.

Implementation	Implementation involves putting research findings into practice. This means using research findings to make appropriate decisions and changes to health and social care policy and practice.
Methodology	The term methodology describes how research is done, and covers both how information is collected and analysed as well as why a particular method has been chosen.
Mixed methods research	Mixed methods research uses a combination of methods (like qualitative and quantitative) as part of the research.
Open Access publishing	Making research outputs openly available online and free of charge to the reader.
Ownership of the research	This refers to the question of who has ultimate decision making power over the research including, but not limited to, who 'owns' its data and research products. A partnership needs to negotiate these terms at the beginning of each new project.
Participant	A participant is someone who takes part in a research project. Sometimes research participants are referred to as research 'subjects'.
Perspectives/ user perspectives	A user perspective is often what people with experience of using health or social services are asked to bring when they get involved in research. They are asked to provide ideas, comments and suggestions based on the unique insight they have from their knowledge and experience of life with a health condition.
Qualitative research	Qualitative research involves the collection and analysis of non-numerical data. This type of research includes information gathered from interviews, focus groups, observation and some types of surveys (e.g. where respondents can write down their opinions).

Quantitative research	Quantitative research is research conducted using numerical or 'quantifiable' data, like typical surveys and checklists.
Sampling	Sampling is the process of creating a subset of people from whom you will gather your data.