

## Next steps training handbook - members of the public and researchers working together

The next steps training handbook has been developed for researchers to follow on from attendance at the face-to-face course '[First Steps: members of the public and researchers working together](#)'.

The handbook/ toolkit is continually being developed by the Public Involvement and Engagement and Training teams with lay/ public and researcher scrutiny. It has been developed at the request of course delegates and specifically relates to health and social care research in Wales, but it also signposts to resources that have been developed by other public involvement bodies throughout the UK.

**Please do not print as this is an evolving resource and this document is being continually updated.**

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## 1. Foreword - why is public involvement expected and what impact does it have?

All Health and Care Research Wales activity is underpinned by the belief that the people of Wales have a key role to play in improving the quality and relevance of research. Health and Care Research Wales want to create an environment in which all health and social care research that takes place in Wales happens with the public, for the public.

The [UK Policy Framework for Health and Social Care research](#) is committed to public involvement.

INVOLVE top tips document number four endorses this view: [How can public involvement strengthen research?](#)

Principles and standards for public involvement are threaded throughout the handbook and shape how public involvement in research is approached.

**Principles** - [a set of core principles](#) which guide and shape Health and Care Research Wales' public involvement and engagement activity. In summary, they advocate the following:

- High quality and meaningful public involvement
- Public involvement throughout the research process
- The provision of support
- Transparent relationships
- Mutual respect
- The encouragement of diversity
- Accountability

**Standards are the core elements of PI (public involvement) in research.** They have been developed by a UK partnership and more details can be found [here](#). The standards describe what good public involvement in research looks like and provide a framework for improving quality and consistency. The standards can be used as a self-assessment tool by research organisations, teams or individuals. You'll find more information on the standards in [section 3](#).

In summary they address:

- Inclusive opportunities
- Working together
- Support and learning
- Communications
- Impact
- Governance

## A reminder of the what, why and when of public involvement

Involvement, engagement and participation

It is important to understand the difference between involvement, engagement and participation

### Involvement

Where members of the public are working with researchers on research projects and with research organisations. The research is carried out with or by members of the public, for example as a member of a group developing a research study.

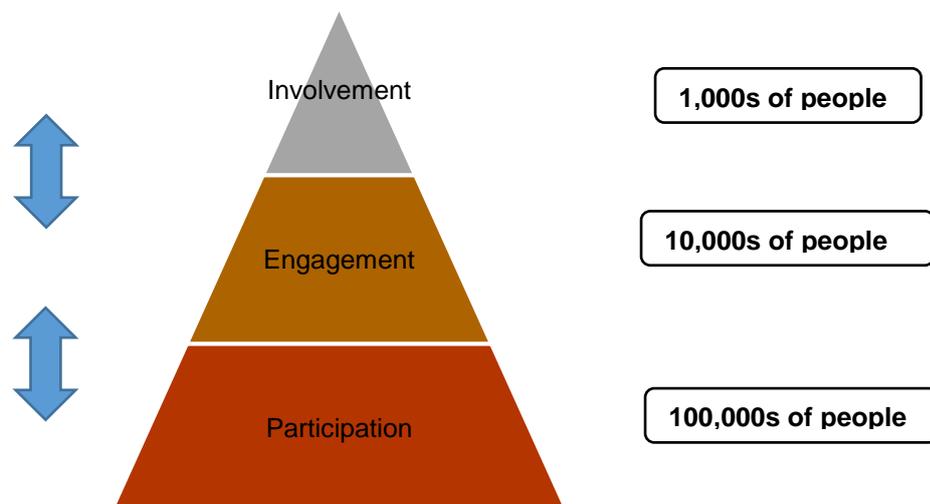
### Engagement

Where information and knowledge about research is provided and shared, for example at a research conference.

### Participation

Where people take part in a research study, for example by giving a blood sample or completing a questionnaire.

## Pyramid of Activity



## Reasons to do public involvement

More information can be found by visiting the Health and Care Research Wales website.

On the website you can read the following on [why to involve the public in research](#):

'By involving members of the public in research, it becomes more relevant to people's needs and concerns, and is more likely to be used to improve health and social care treatments and services. **Benefits to research** include making sure research is asking the questions that are important to people who live with an illness or chronic condition

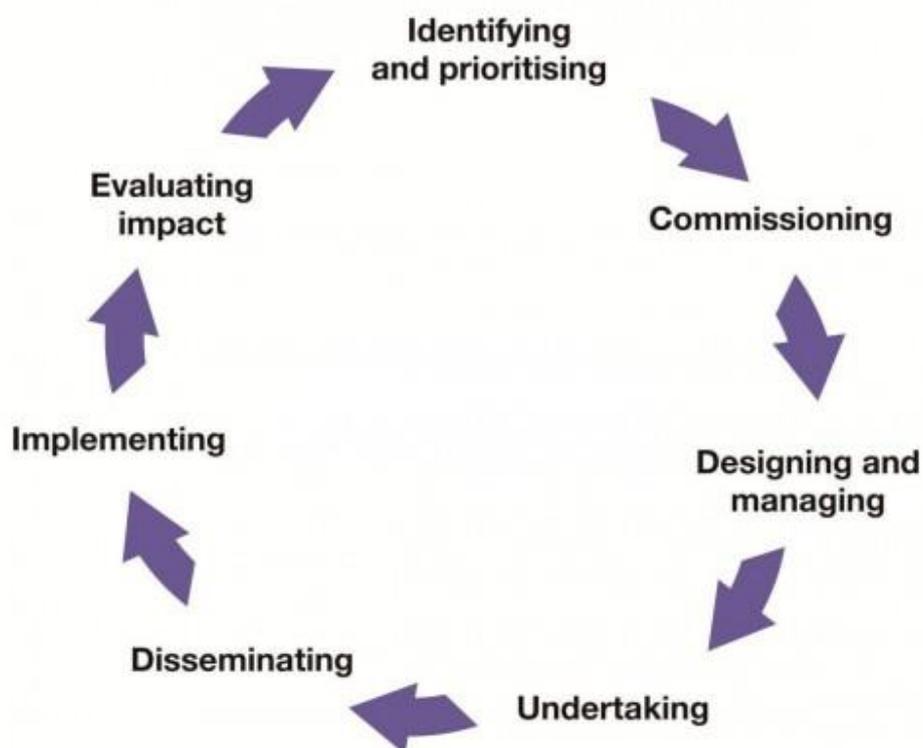
or social situation. **Benefits to members of the public** include making use of their experience to help develop research that may benefit them, their family or friends. It can also be a great way to meet people and develop new skills.'

The third sector also supports public involvement.

'Cancer Research UK firmly believe that working with people affected by cancer increases their understanding of cancer, and that high quality Public and Patient Involvement (PPI) helps to ensure that the work they fund meets the needs of patients'. Log in to the Cancer Research UK [toolkit for researchers](#) for more information.

### When to involve the public - throughout the whole research cycle

[www.nihr.ac.uk/patients-and-public/how-to-join-in/the-research-cycle/](http://www.nihr.ac.uk/patients-and-public/how-to-join-in/the-research-cycle/)



Health and Care Research Wales also provide a [research route map](#) which identifies resources available to support public involvement.

Funders, whether government bodies or charities, will have an expectation that public involvement has influenced the ideas and planning at research development stage and that public involvement has been costed into the delivery of the research as well as the dissemination. For example, during the development of the grant proposal.

Cancer Research UK offer a broad spectrum of [research funding schemes](#) that can be viewed on their website. Many of these schemes, such as the Grand Challenge

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funding scheme, will ask for inclusion of patient involvement plans as part of the application - Cancer Research UK 2017.

The Health Research Authority (HRA) core purpose is to protect and promote the interests of patients and the public in health and social care research. This is done by ensuring research is ethically reviewed and approved. The HRA advise on [best practice](#) for involving the public to support ethical approval.

## 2. National Standards for Public Involvement in Research to guide and aspire to



Up-to-date information is available on the Standards Partnership [website](#).

The six standards are:

- A description of what good public involvement looks like
- Designed to encourage self-reflection and learning
- A tool to help people and organisations identify what they are doing well and what needs improving
- Intended to be used with any method or approach
- Adaptable to your own situation

Each standard has a set of indicators - statements describing ways in which a standard can be met.

2018 - 19 will see a period of piloting the standards, however the tool is available on the Standards Partnership website.

The Public Involvement and Engagement team and Training team have also developed an [audit tool](#) to assist you in meeting the standards.

### 3. How do I find members of the public?

Currently in Wales, the Health and Care Research Wales Support and Delivery Centre has a Public Involvement and Engagement team who facilitate the public involvement and engagement function. The overall aim of the function is to facilitate the involvement and engagement of members of the public in the research process and provide support to implement public involvement and engagement activities as part of the Health and Care Research Wales infrastructure.

The team manage an involvement community and provide an advisory role for the health and social care research and development community in Wales. They work collaboratively with the other teams in the Support and Delivery Centre, in particular the training and communications teams, they liaise closely with UK colleagues and of course involve the public in their work. The team also have representation on the Health and Care Research Wales [Public Involvement Delivery Board](#).

Extensive information is provided on the website for [members of the public](#) and for [researchers](#) wanting to involve the public.

The team can be contacted via e-mail at [research-involvement@wales.nhs.uk](mailto:research-involvement@wales.nhs.uk) and by telephone 02920 230457.

Researchers can request support from the Public Involvement and Engagement team via our [online form](#).

Although it is acceptable to identify members of the public from other places such as clinics or support groups, the team advise that those people also register to get involved as they are offered access to training, peer support and the enabling involvement fund:

- Prior to registering members of the public can view an information sheet [here](#), which explains what being involved in health and social care research is, and what the member of public can expect if they register to get involved.
- Access to a fund (referred to as the Enabling Involvement Fund). This allows research development to be supported by offering honorariums and managing the payment or reimbursement of expenses for health and social care that is aligned to the Health and Care Research Wales infrastructure.

#### **Other ways to identify members of the public**

There are many organisations, online resources and networks that can help you connect with patients and the public such as [People in Research](#) who are hosted by the National Institute for Health Research (NIHR) in England.

Many charities have networks of patients who are prepared for involvement in research funded by the specific charities, though these are not always in Wales. For

example: Tenovus, Cancer Research UK, Marie Curie, the British Heart Foundation and Alzheimer's Society.

Don't forget a charity doesn't have to fund your research to be able to connect you with people to involve.

Be aware that some people or organisations might choose not to get involved in your work. This might be for a variety of reasons but it might be because their aims do not match yours, they do not have the time, or because the practical costs of either getting involved or finding somebody to get involved in your work is too great. Some organisations charge when they are asked to find people to get involved in research activities.

## **Diversity**

The Public Involvement and Engagement team support researchers and help to identify actions that will find appropriate members of the public and will endeavour to provide support if required, e.g. easy read documents, translation, carers costs and the team endeavour to accommodate any needs related to disabilities. [Guidance for those in receipt of state benefits](#) is provided for the registered community and researchers.

We in Wales are proud of our diverse communities and we strive to involve people from all sectors, areas and backgrounds and welcome their experience, skills and knowledge. We strive to work within an Equality of Opportunity Framework. If you are planning to involve people from what could be considered a hard to reach group then please contact the team who may be able to help you.

## 4. How do I prepare and plan to involve the public in my research?

Plan ahead, it will be tokenism if you do not give yourself enough time. Be clear on the intended outcome of public involvement before the start, what are you hoping to gain from it?

You may find the [standards](#) are helpful.

The following should all be considered prior to submitting a [researcher request form for public involvement](#), but the team are available to discuss any aspect

### Why are you going to involve?

When you start thinking about involving patients and the public in your research, ask yourself the following questions:

- What are your motivations for involving people?
- Are there any specific questions that you would like them to answer?
- What would you want to get out of involving people?
- What impact would you like the involvement to have?

### Who are you going to involve?

- In deciding who best to involve it is important to think about the knowledge and perspective that you are looking for from the public contributors, and what support you are able to give to people who you plan to involve.
- You may want input from people who have experience of a specific condition, service or treatment. For example, you may wish to involve people who have previously been a study participant, or who have particular expertise, such as experience in sitting on a panel.
- You can create a role description that can help you outline what you are looking for.

### How many people will you involve?

- Involving more than one person will have the advantage of increasing the breadth of experience and skills brought to the project and provide an opportunity for those involved to support and encourage each other.
- A larger group will bring broad and different views and experiences, but then this will mean you will need to deal with conflicting views.

## **Categories of Involvement**

From 1 April 2019 we will have introduced three categories of involvement opportunity, Blue, Green and Red. Each reflecting the level of experience and expertise and time commitment that an individual might need for that opportunity. The categories are linked to a new model of reward for members of the public who get involved in an opportunity. Further guidance can be found [here](#).

## **What method will you use?**

You can use a number of different methods to involve people that would be categorised as red green or blue. Here are some of the more common methods that are used by researchers.

### **An initial sense check**

An online survey to gather the perspective of large numbers of people You can then involve one or two members of public to comment on a draft or study outline

### **An involvement ready group / surgery or panel**

Here a panel of members of the public can be established to comment on projects at the research development stage. Often these are at the pre grant stage where a rapid turnaround is necessary.

### **Focus groups and discussion groups**

This typically involves bringing together (or going to) a diverse group of people with direct experience of the topic being researched, for any time between one hour and one day, depending on the topic/s for discussion. The aim is to find out about the patient, carer or public perspective on a research topic, to bounce ideas off the group and hear about diverse experiences.

### **Advisory/reference groups**

These are typically groups of four -12 patients or carers who provide advice to a specific project. They are separate to the project steering group (see below) but feed into its decision-making. These groups may meet by phone, virtually or face-to-face.

### **Steering groups**

A steering group is a mixed group of experts who oversees a research project to ensure that the protocol is followed and to provide advice and troubleshoot wherever necessary - a trials steering committee is an example of a steering group. Typically steering groups involve at least two patients/carers who provide input based on their

direct experience of the topic under investigation. The steering group usually meets at key stages during the course of a project and influences key strategic decisions.

### **Co-researchers**

Patients and carers can act as co-researchers or co-applicants on a research project - they might carry out tasks including co-facilitating focus groups, conducting interviews, analyzing transcripts and disseminating results.

### **Do you need a terms of reference?**

INVOLVE provide some useful [templates](#).

### **How are you going to finance the involvement?**

- At research development stage, you can access the Enabling Involvement Fund if you are aligned to Health and Care Research Wales. The fund can be used for the offer of an honorarium and payment of expenses.
- For any bid submission, public involvement should be costed in and there is an [involvement cost calculator](#) to help you.
- For funded studies, ensure you are familiar with how your organisations will be reimbursing public members.

### **Does everyone know their role, including you?**

Best practice is to have a named main contact person. Make sure they have enough time to support the members of the public, you should also be able to provide documents in a timely way and paper copies if required. Do you have any training needs in order to involve the public effectively?

### **Ready to advertise your opportunity?**

Now visit the website to submit your [researcher request form for public involvement](#). In liaison with you, an advert will be developed to circulate to members of the public. You will need to give at least four weeks between contacting the team and when you require a member of the public.

### **Choosing a member of the public from those who have expressed an interest**

Review the expressions of interest that the team will send you against the criteria that you have advertised. The advert should include if you require to meet the applicants or to hold interviews. Always be prepared for how to deal with unsuccessful applicants.

## 5. Ready, steady, go

The following checklist is available on the Health and Care Research Wales [website](#).

### Have you just chosen a member of the public to work with you?

Here's a checklist to help you with the next steps.

Activity	Who	Completion details (date/any further actions needed)
Development and dissemination of advert	Public Involvement and Engagement team and opportunity lead	Advertised (date)
Review of expressions of interest		
Selection of individuals		
Inform all of outcome and ensure contact details are added to any contact lists	Public Involvement and Engagement team and researcher	
<p>As soon as possible contact the successful individuals to discuss:</p> <ul style="list-style-type: none"> <li>• Their expectations</li> <li>• Expectations of the research team</li> <li>• Confirm time commitment</li> <li>• Confirm support available from opportunity lead</li> <li>• Check any training needs</li> <li>• Check any accessibility needs</li> <li>• Confirm payment and any guidance available</li> <li>• Confirm commitment to Code of Conduct</li> <li>• Confirm format of the meeting</li> <li>• Confirm meeting premises indemnity</li> <li>• Indicate that if technical terms are used members</li> </ul>		

<p>will be asked to provide explanation</p> <ul style="list-style-type: none"> <li>• Consider requesting a record is kept of how they feel they have impacted on the group in order to evaluate their involvement</li> </ul>		
<p>Send papers two weeks ahead of first meeting, e.g.:</p> <ul style="list-style-type: none"> <li>• Terms of Reference</li> <li>• Agenda</li> <li>• Other papers</li> </ul>		
<p>If financially supported by the Public Involvement and Engagement team, inform the team of the meeting date in order for them to send pre-approval forms to members</p> <p>Or</p> <p>If providing financial support, ensure all processes are in place to allow timely payment.</p>		
<p>Confirm with all attending the first meeting that jargon/acronyms/technical terms are to be avoided or explained</p>		
<p>Consider a de-brief after each meeting</p>		

### **Before the member of the public attends their first meeting**

Communicate the expectations with the team and the public members

- Do the team know what and how the member of the public is expected to contribute?
- Does the member of the public know what is expected of them?
- Do the team know what is expected of them in relation to the public member?
- Don't forget to incorporate an impact assessment so that you can evidence what impact public involvement had on the study. This can be as simple as asking

members of the public to keep a diary of their contribution at meetings and if their comments brought about any changes. If so, was there a difference?

- Refer to the [National Standards for Public Involvement in Research](#) for additional guidance

## 6. Evaluation - has it made a difference?

IMPACT is one of the six standards that have been developed by the UK partnership.

It is important to consider and agree:

- The intended outcome of public involvement before the start, what are you hoping to gain from it?
- How you are going to record and monitor the public involvement?
- How are the public involved in the impact assessment?
- How do you all use the learning?

A Public Involvement Impact Assessment Framework is available [PiiAF](#)

Another tool that is available is the [GRIPP 2](#), which is the first international guidance for reporting of patient and public involvement in health and social care.

## 7. Keeping going

Continue to involve the public throughout the research cycle, from development of an idea to dissemination of outcomes.

Public involvement may change as the study progresses, but the public perspective should continue to be captured. You can find further guidance on this on our [research route map](#).

## 8. Sharing the journey and collaborating

You are not alone, public involvement in research is going on across the whole of the UK in universities, the NHS and social care and in third sector organisations.

- Standards have been developed by a UK partnership to provide a framework to improve the quality and consistency of public involvement
- INVOLVE is a government funded programme to support public involvement in the English NHS and provide a plethora of resources
- The national Institute for Health Research are running a campaign '[the two sides of health research](#)' with one side being the public
- Third sector organisations have joined together to [share their learning](#) in relation to public involvement in research and Health and Care Research Wales are an observer of the group
- Cancer Research UK provide a [toolkit for researchers](#)
- [Future Learn](#) provide free online courses

There are also many tools that can be accessed and are freely available and promoted on the Health and Care Research Wales [website](#). You may also want to [register](#) to receive the Health and Care Research Wales weekly bulletin.

## 9. Continual development of the toolkit/handbook

### Has this tool been helpful?

The Public Involvement and Engagement team are continually developing tools, through consultation, to assist researchers. Please email any comments to [research-involvement@wales.nhs.uk](mailto:research-involvement@wales.nhs.uk) in order for us to continually improve our service.