

Health and Care Research Wales

Key messages for public involvement

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Introduction

This document has been developed for use by members of the public involvement community when they are asked about how public involvement in health and social care research happens in Wales or want to explain their role to other members of the public who are interested in joining the community.

Researchers and the wider research community can also use this when they wish to engage with members of the public about becoming involved in their research.

With grateful thanks to the involvement community who reviewed and provided comments during the development of these key messages.

What is health and social care research?

- Research provides the evidence that ensures the treatments and care we are offered are safe and effective
- Without research many of the treatments and types of care that we routinely receive today in the NHS and our communities wouldn't be available
- Members of the public play an essential role in making research happen across Wales by taking part and by getting involved in research

Who are the public?

By members of the public we mean all of us who use health and social care services, for example patients and carers.

What is public involvement in health and social care research?

Public involvement is where people are not taking part as participants in the research but are working with researchers to plan, manage and carry out research. Involvement can take many forms, it can include:

- helping to decide which problems are most important to answer through research
- contributing to the writing of patient information sheets
- becoming a public contributor on a group running a research study
- decision making about which research studies should be funded
- assisting with the sharing of research findings
- research governance which is a process for ensuring the quality of research, and for protecting the rights, dignity, safety and wellbeing of those involved. This could be research management, or board representation.

Why become involved as a member of the public?

- Benefits to those getting involved include the opportunity to shape research that might affect you, your family or friends
- Using your personal experience of a condition, illness or service gives the research study team an understanding of how these experiences affect people in everyday life
- Contributing your perspective can benefit research by making sure research studies are asking the questions that are more relevant and likely to improve

treatment and care

- Involvement in research can also be a great way to meet people
- It can be a step towards developing useful, new knowledge and skills

How can you get involved?

You can join the public involvement community at Health and Care Research Wales by:

- Registering online at www.healthandcareresearch.gov.wales/involvement-form/
- Or by contacting the public involvement and engagement (PI&E) team for support with registering at:
 - email - research-involvement@wales.nhs.uk
 - phone - 02920 230457

What do I get if I join the public involvement community?

Once registered you will receive:

- A weekly bulletin containing research involvement opportunities in which you can express an interest.
- Access to training and guidance about research and public involvement. Examples include the UK Standards for Public Involvement and support from the public involvement and engagement team, who are your main contact for any problems or queries
- Payment of expenses and offer of payment for time for some involvement opportunities
- Access to benefits advice

What are research involvement opportunities and what do they look like?

- These are usually adverts from researchers or research organisations who are looking for members of the public to get involved in a research project or committee
- Involvement opportunities are advertised on the Health and Care Research Wales website under current opportunities (www.healthandcareresearch.gov.wales/current-opportunities/) and in the weekly 'Your involvement matters' bulletin
- Involvement opportunities fall into one of 3 categories: Blue, Green and Red. The colours help you know the level of knowledge and experience required, as well as how much time will be needed from the member of public throughout the involvement (see page 5 below)

How do I express an interest in an opportunity?

- Each advertised opportunity comes with an online link that you click on to express your interest
- To express interest, you will be asked to describe in your own words how you match the requirements set out in the opportunity
- The researcher leading on the opportunity will review all of the expressions of interest and choose the required number of individuals
- You will be told if you have been chosen or not and then be contacted by the researcher if successful to discuss next steps

During an involvement opportunity

- Your main contact will be the researcher leading the opportunity
- For involvement opportunities during the research development stage the PI&E team will be in contact with you to agree and manage expenses and offers of payment for time.
- For involvement opportunities that are with funded research studies the expenses and offers of payment for time will be managed by the research organisation

- Offers of payment don't have to be accepted or can be taken at a lower amount
- If you are concerned that getting involved may affect your benefits then there is free access to the benefits advice service if you are registered with the involvement community
- The payment you will receive may be considered taxable income. It is your responsibility to ensure that all measures and declarations for your individual circumstances are in place (further advice regarding income generated taxation can be obtained from HMRC: www.gov.uk/hmrc-internal-manuals/employment-income-manual/eim71105)
- You may need to report on the impact/effect that your public involvement has had on you and the research.
- It is important that we strive to continuously improve the service we provide and your experience of getting involved. The PI&E team will request feedback every six months from you and the researcher about your involvement experience

Definitions and characteristics of the three categories

Category blue

Public members knowledge, experience and time commitment

- Experiential knowledge
- No experience of public involvement required
- Limited time commitment and no requirement for travel or personal attendance
- No expenses incurred

Examples

- Surveys where large numbers are required
- Short telephone interviews
- Researcher attending community events to gather opinions

Reward

- Contribution valued
- Opportunity to access training and support
- No offer of payment

Category Green

Public members knowledge, experience and time commitment

- Experiential knowledge
- Evidence of some experience and understanding of public involvement
- Basic training/ introduction to public involvement
- Able to commit their time
- Commitment to confidentiality, an 'Opportunity Agreement' and possibly a 'Code of Conduct' or 'Charter' is required
- Attendance at meetings, skype or teleconference
- Could involve researchers arranging a mutually acceptable venue and time

Examples

- Public involvement with research development (e.g.: advisory panel or surgery, research development group)
- Commenting on public facing material, study conduct (e.g.: Trial Management/ Steering groups etc)
- Dissemination of results to bring a consumer/ public perspective
- To include public involvement panels/ surgeries that can be accessed by researchers
- Infrastructure public involvement groups
- Lay faculties

Reward

- Opportunity to access training and support
- Peer support
- Reimbursement of expenses and or booking of travel etc.
- Offer of up to £20 per hour or equivalent token/ voucher/ time banking for the public involvement undertaken (time to be stipulated)

Category Red

Public members knowledge, experience and time commitment

- Evidence of experience and training in public involvement as well as specific expertise or experience such as chairing or reviewing documents for a research funding application
- A clear commitment of their time is required which includes preparation, such as reading documents
- Commitment to confidentiality, an 'Opportunity Agreement' and possibly a 'Code of Conduct' or 'Charter' is required
- Attendance at meetings, skype or teleconference
- Less likely to involve researchers arranging a mutually acceptable venue and time

Examples

- Public involvement governance, strategy and policy development
- Member of board
- Member of management group
- Member of review panel
- Member of interview panel
- Presentation development and delivery
- Facilitation of public involvement training

Reward

- Opportunity to access training and support
- Peer support
- Training specific to the opportunity if required
- Possible secretarial support
- Reimbursement of expenses and or booking of travel etc.
- Offer of up to £20 for per hour of public involvement undertaken including preparation (the time to be stipulated)