

Public and Patient Involvement/Engagement Workshop



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For:

Members of the Appearance Collective

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Workshop aim:

- to provide you with the knowledge and skills to enable you to engage in PPI work.

Workshop objectives:

- Identify the benefits of using PPI within your organisation
- Explain the process of conducting PPI and overcoming common challenges
- Design a plan to utilise PPI in your work

Range of terms for PPI

- User involvement
- Lay involvement
- Service user engagement
- PPI- Public and patient involvement
- PPE- Public and patient engagement
- PI – public involvement preferred term. Defined as efforts aimed at involving the public in various aspects of decision making, including issues related to policy, service provision and research

Public

Those providing experiences, knowledge & different perspectives to *help* ensure your endeavours are:

- relevant
- acceptable
- cost efficient

By 'the public' we mean anyone who can provide unique experiences, privileged knowledge and different perspectives to improve the relevance, acceptability and cost effectiveness of our work – whatever that may be.

You may want help deciding what services your organisation could provide or focus on, what research is needed to improve patient well-being, what should go in a leaflet or on a website? In essence, what do your consumers want? How might they benefit? This is about connecting with those who use your service to ensure, for example your interventions or support material, is acceptable and targets their needs. There's no point in investing funds in a project that isn't acceptable to your audience – that wouldn't be cost –effective.

Who are your experts?

Could include:

- Potential patients
- Social service users
- Those with different cultural / religious backgrounds
- Those with specific conditions
- Young people
- Health professionals
- Teachers

Key values

- Active partners in the 'research' process rather than subjects or participants
- Doing research with or by the public, rather than 'to', 'about' or 'for' the public
- Not a tokenistic, last-minute add on: PI should be considered & embedded from the outset

Our relationships with the public and our work with them is underpinned by key values. Individuals are regarded as active partners in the research process or, if the work is not research per se, then within the project team. PI is very much an example of working *with* the public rather than *to*, *about* or *for* the public. Importantly, PI should be embedded within projects from the outset, often PI is criticized for being tokenistic and a last minute add-on.

PI - from inception to dissemination

Rather than working independently as organisations or academics within 'ivory towers' in terms of our priorities, decision-making and project management, the team at CAR work with our partners who have an active role throughout the lifetime of a project. The aim is to involve partners throughout the research process from the initial needs-analysis stage right the way through to the dissemination of the findings.

PI – examples

a. The Appearance Collective priority setting exercise

Your partners may be involved in setting the agenda that your organisation will work towards. The event we held with members of the Appearance Collective at the start of our programme of work in the summer of 2017 was an example of PI and working together to decide upon the areas CAR should focus on over the next few years.

b. The YP Face IT intervention

Partners may draw on their expertise to help design or execute a project. For example, members of CAR worked with young people to initiate and design the YP Face IT online intervention to support young people struggling with appearance-altering conditions (see www.ypfaceit.co.uk). They provided a young person's perspective to help us decide on the best way to test if the intervention worked, and helped disseminate the findings via a video that would appeal more to a younger audience than an academic paper might.

c. The Cleft Collective

This is a good example of using PI throughout the life of a project. The Cleft Collective is the world's largest research programme, investigating the causes, best treatments, and psychological impact of cleft lip and palate (<http://www.bristol.ac.uk/dental/cleft-collective/>). The James Lind Alliance and other organisations were involved in setting the research questions right from the beginning. The Cleft Collective have also partnered with the Cleft Lip and Palate Association to prioritise and design research studies, including the design of all their materials, and are currently establishing a National Consultation Group in collaboration with CLAPA. There are also patient representatives on the Advisory Panel, hosted by the Scar Free Foundation. Finally, and throughout the Cleft Collective programme, patients, clinicians and families have all been involved in interpreting and disseminating study findings at conferences and events.

Why involve the public?

The methodological rationale

- Research shouldn't just measure outcomes considered important by researchers or clinicians.
- PI can help to recruit peers or access marginalised groups e.g.: BAME, disabled, disadvantaged communities
- Patient voice: using PI can help us to disseminate results to ensure changes are implemented

The moral case

- PI embodies principles of citizenship, democracy & equality - public should 'have their say'
- It is enriching & empowering for all concerned.

The political case

- Broader agenda of involving the public in decision making
- Limited funds & services rationalised
- Informs commissioning, planning and service improvement (DoH, 2009)
- High quality care and the personalization of services
- Funders demand evidence of PI

Benefits to researchers and service providers

- It improves accessibility and clarity of language
- It can identify better ways to communicate and disseminate results of your collaboration
- Better enrolment and decreased attrition
- Better relevance and credibility of studies
- Better interpretation of outcomes

Benefits to partners

- Helps make sense of their experiences
- Offers an enriched understanding of research
- Can improve a sense of self-identity
- Can give a sense of purpose
- Boost confidence and empowerment
- Personal development

Common concerns

It's important to be aware of some of the legitimate concerns and critical evaluation of PI by researchers and professionals on the topic. The following perceptions were reported in an anonymous survey by health & social science researchers:

Common concerns	Alternative view/ Tip
<i>"They're biased: One or two people who use the service can't be representative of all relevant groups"</i>	If you want a range of perspectives involve a range of people . All views are biased, this is a given - who holds the power is more important!
<i>"But if they're emotionally engaged in the topic, how can our work be objective?"</i>	No-one is entirely objective. Evidence shows partners keep focused on the fundamental reason for undertaking project. Provide support options
<i>"There are too many problems with confidentiality..."</i>	Agree a confidentiality policy from the outset
<i>"People won't understand the research"</i>	Complex ideas can be readily explained without jargon
<i>"What about tension between us & the public - around the purpose of the work and what makes it 'good'?"</i>	Tension is inevitable & should be acknowledged at the outset & managed openly This can stimulate critical debate & lead to better decision making
<i>"Members of the public may have unrealistic expectations of research & its implementation"</i>	Clarify understandings of what will be involved and what is possible in order to ensure realistic expectations from the outset

It's our job to promote values of effective partnership:

- Communication
- Reciprocity
- Reflexivity
- Trust

How do we involve the public?

Consultation – the public provide advice on a given topic; this might be a one-off event or a series of meetings

Collaboration- we might form more long-term collaborative relationships, with ongoing involvement

User led – the public as active members of the project team who could be involved in bid writing, access to potential participants and recruitment, data collection, analysis and dissemination.

Top tips when planning PI

1. Be clear about the objectives of events: what information do you want, and from whom? Large task needs to be broken down into very small discrete objectives.
2. Don't over burden individuals and groups with too much work.
3. Diversity: Most of those who are 'put forward by teachers' or who volunteer for PI work tend to be white, middle class & well-educated:
 - Those with different backgrounds & learning needs offer different perspectives.
 - Consider those with learning or physical disabilities when designing PI events.
4. What training individuals do need, if any, in order to understand their role & our aims & objectives?
5. Resource planning has to start early, in terms of arranging dates/times for meetings, finding a venue, staff to facilitate events, refreshments, IT and other equipment.
6. For those aged under 16, obtain parental consent and devise a safeguarding plan as you might be discussing sensitive topics & personal experiences.
7. Make events engaging and interactive.
8. Take advice from gatekeepers & the NIHR INVOLVE guidelines on how to incentivise and reward members for their time and efforts (see www.invo.org.uk).
9. All of these factors need to be considered when planning a budget.
10. Maintain communication and update on project progress.

What about payment?

Guidance on payment...

- Acknowledges value of contribution.
- Incentives may allow a broader range of people to be involved.
- Reduces barriers to involvement (e.g. cost and time).
- Supports equity of power - professionals get paid, so the public should too.
- Clarifies expectations and responsibilities relating to involvement.

Identifying and overcoming common challenges

Recruitment

It is important to source a range of different perspectives, to ensure you are inclusive and to offer equal access to opportunities. However, certain groups can find it more difficult to have their voices heard. Depending on your particular project, you might want to pay particular attention to the following:

- Race
- Gender
- Sexual orientation
- (Dis)ability
- Religious beliefs
- Transgender
- Pregnancy
- Marital status
- Age

Other groups who may be under-represented could include (*responses from members at the workshop*):

- Young people
- Older people
- Men
- Low socioeconomic status
- Non-English-speaking
- Those with learning difficulties
- Those with rare conditions
- Children whose parents are not engaged with their condition/care/research
- Those who have only recently been diagnosed
- Those not actively looking for support

How can we create an inclusive environment?

- Commit to diversity at an organisation level.
- Learn about the groups you want to involve (identify barriers and facilitators, and consider specific training in these areas).
- Develop relationships and engage with gatekeepers.
- Offer a phased introduction.
- Offer flexible ways of working (work to your PI members' needs, don't expect them to fit into a pre-existing structure).
- Improve accessibility (e.g. the venue, a budget to cover expenses, ensure materials are written in lay language).

Training

Once you have recruited your collaborators, you need to help them to develop their knowledge, skills and experience through training. This could be provided by someone from your organisation and/or a peer and/or an external trainer. When considering training options, try to think broader than just holding a one-off event. For example:

- Group training sessions
- High quality written materials
- On-the-job learning
- Conference attendance
- Networking and shared peer learning
- Online activities
- Formal training courses

Remember that members of your organisation may also need training!

Training could include:

- How the organisation works.
- Understanding the wider context of the project, and how they fit into this.
- Understanding their role.
- Opportunities to discuss needs.

Remember to acknowledge the value of each individual's contribution, and consider how best to capitalise on their unique skills and experiences. Tailor your training to reflect the nature of the project, the remit of the group, the needs of your collaborators and the resources you have available.

What does/could your organisation do to meet the training and support needs of your PI representatives? *Responses provided by members at the workshop:*

- Jargon buster
- Communication training/presentation skills
- Cascade training
- Peer support (e.g. befriending service)
- Training in basic statistics
- Guidance in how to manage being a 'professional patient'
- A survey to gauge training and support needs
- Ask for feedback at all training events

Power (im)balance

Historically, the healthcare experiences of patients have been dominated by an 'expert' point of view (e.g. health professionals or researchers). More recently, there has been a move toward patients having more control over the services that are provided. The integration of public involvement in itself demonstrates a shift in the power balance.

Tips to minimise power imbalance:

- Agree upon a shared language
- Arrange meetings on neutral ground
- Match patient and professional needs
- Attach tasks to group members based on their skill set
- Be mindful of dominant group members

The aim is for everyone to be involved as equal partners when making decisions which will impact them.

Safeguarding

Safeguarding means protecting people's health, wellbeing and human rights and keeping them free from harm. This may be most evident when working with certain groups, such as young people or those with disabilities, but also applies more generally, for example if you are discussing sensitive topics or storing confidential data.

You will also need to provide support for your PI representatives. This could include:

- Practical support
- Financial support
- Emotional support
- Supervision to support professional development

Remember to have a plan in place to protect anyone who may be vulnerable and to manage any risks.

Assessing impact of PI

AIM: *“To determine whether your organisation is effectively carrying out planned activities, and the extent to which it is achieving it’s stated objectives”*

How do we know that our PI efforts are effective?

You may want to measure:

Inputs (costs)

- Monetary
- Non-monetary
- Risks

Outputs (benefits/impact)

- Changes to policy/organisation
- Improved services
- Changes in people
- Continued learning

Output (products and activities)

- Numbers attending
- Event feedback received
- Materials circulated

PI in Action

Using the example of a mobile app intervention that members of CAR are currently developing for adults with a visible difference experiencing appearance anxiety, the following different types of PI activities were carried out during the workshop:

- Focus groups: Groups were asked for their views on health apps, how their organisation may make use of the new app, and any concerns with it.
- Testing an app demo: Each member was given an early demo version of the app, and asked to give spoken and written feedback.
- Generating intervention material: Members created content for ‘mindfulness’ prompts to be sent through phone notifications.

These activities involved different examples of methods for collecting PI input:

- Audio recordings (the focus group)
- Written surveys (the app demo)
- Spoken feedback noted by facilitators (the app demo)
- Post-it notes (generating material)

References and helpful links

- Centre for Appearance Research: www.uwe.ac.uk/car
- INVOLVE: www.invo.org.uk
- Public Involvement Impact Assessment Framework (PiiAF): www.piiaf.org.uk

Thank you for your input into the workshop.