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Early Detection of Cancer Conference 2023

Patient and Public Involvement (PPI) in Early Detection Research Q&A Resource

Introduction

During the Early Detection of Cancer Conference, patient and carer representatives joined a panel session to start a conversation with the early detection research community. The focus of the conversation was how to go about involving patients and the public in early detection research.

This Q&A resource has been created by two UK representatives that sat on the panel with the aim of continuing the PPI conversation with researchers. They have answered questions asked by the audience during their session, sharing tips and advice based on years of patient advocacy experience.

Thinking about terminology. When CRUK refer to “people affected by cancer” we are referring to patients, people with diagnosis, carers, family, loved ones, supporting relatives. CRUK’s definition of “involvement” refers to the individual having a level of influence, power sharing, shaping and influencing in the work. Involvement can look different for different research projects, and individuals may wish to contribute to a lesser or greater extent. PPI is not a “one size fits all” approach.

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Getting started with patient and public involvement (PPI)

Where to start?

Cancer Research UK's website is a very good place to start – there is a wealth of information about how to work with patients and the public. Please see: [cruk/researchertoolkit](https://www.cruk.org.uk/researchertoolkit)

Contact people already doing it well. Many institutions have links with the patient community too.

How can researchers ensure that they are not asking too much from consumers (PPI representatives)?

Ask anyway! It's up to us to say "no thanks" (and we will). Let us decide what 'too much' is.

How do we build trust with our PPI representatives so that they can challenge and criticise our ideas?

By your behaviour. Be clear in the Terms of Reference or role description what it is that you are expecting from us. If you listen to our thoughts, discuss them with us, explore what may or may not need changing, then let us know what has happened and *why*.

Perhaps your ideas may not need too much challenge and criticism because we happen to agree with them, and we'd rather help shape and steer instead.

Lots of what researchers should do was talked about during the PPI Panel discussion. Can you let us know what we should absolutely not do?

There are things that don't always work in a particular context.

I no longer take part in tokenism and walk away from those situations. If you invite me in, please **don't limit my opportunities to participate as an equal.**

Related to this, please don't stifle challenge (or feel the need to be defensive) but try to see it as coming from a **critical friend.** We do all want the same thing, some of us aren't as skilled as others in demonstrating that fact.

Is it wasting patients time to discuss ideas before funding? The ideas may go nowhere if it's not funded!

There is more than one funder. A pre-funding discussion with PPI representatives may be required by the funders anyway. Also, you may get a proposal more likely to be of benefit to patients or the public OR you may get a completely different steer on what may be needed.

Ask us if it's wasting our time. I think many researchers will be surprised at just how much time and energy we are very happy to devote to generating better research that will lead to better and longer lives. And **if we are getting to talk to researchers who wish to benefit humanity, then it isn't wasting our time.**

How can we best have meaningful involvement if the study methodology, or even the data we have access to, can't really be changed?

PPI is more than study design. At some point there are results to disseminate or patients (or our samples or data) to collect, or those ideas to be promoted and championed. Above all there is *implementation.*

We PPI representatives do PPI because we want research to benefit humanity, so somebody somewhere has to do something with it. If you want to do a really powerful presentation at a conference – turn up with your PPI representative as co-presenter. After all, it's our data and our health!

I take part in data-based studies and there are two points at which my input is most important. The first is the *selection of data being requested* (is the age grouping the right one, have groups that are usually overlooked specified, etc.). The next critical stage is the *analysis of data.* It is often the case that I spot things that are missing and things that beg more questions. So, **although the methods are less susceptible to change, the data we access and how we interpret it are variable.**

Are patient groups all disease-based or are there some in basic science or data?

There are patient representatives and patient advocates (rather than groups) involved in basic science specifically. For data the UK has “use MY *data*,” currently the only patient-led movement in Europe actively championing the use of routine health care data for research. Independent Cancer Patients' Voice is not limited to a specific cancer and its members regularly work with researchers in basic science and data.

Involving members of the general public

In early detection research, there is a need to get the general public's input (in addition to that of people affected by cancer). How can researchers engage with the wider public?

Many institutions have open days, this is a good starting point. Talk to your Public Health peers who always need to engage with the public in their work. Examples I have come across are the use of local radio, newspapers, community groups, faith groups, pubs, sports clubs, supermarkets....

The opportunities are widespread – **you simply need a simple, *inviting* message, some funds and, most of all, an unflinching will to engage.**

Reaching and working with underrepresented groups

How can we best involve patients and the public from underrepresented groups?

Contact those already working with them! For example: local authorities, NHS Trusts, community groups and faith leaders. Local charities (cancer specific or not) and community groups may also be able to help you reach those you need to hear from. Remember you may need to **go out into the communities yourself and build relationships** with individuals, groups or organisations.

Other projects and organisations that the patient representatives have highlighted that you can look at include:

- National Institute for Health and Care Research (NIHR): NIHR has Patient Research Champions in most Trusts, five Patient Recruitment Centres and a team finding hard-to-reach groups.
- London School of Hygiene & Tropical Medicine: the “ICON project” which looks at groups with poorer outcomes.
- “Our Future Health” project: it aims to build a community of volunteers to create an incredibly detailed picture of the nation’s health.
- Genomics England: they do work with under-represented groups.
- “B’Me Against Cancer” is an outstanding campaigning group, with a particular interest in data that is known but not acted on.

You can also read papers published in “Research Involvement and Engagement,” the only journal devoted to this theme.

How can we address practical and financial barriers to involving people from lower socio-economic backgrounds?

Pay travel costs up front, offer baby-sitting costs, or go out to where the people are! Why not have meetings in schools or community centres? Offer tea and sandwiches, and a creche for kids. Do things on days and at times of the day that are easier for working people and others who can’t be free from 9-5. Go out for your meetings: there are people who find academic and clinical environments unsettling.

Talk to local authorities, who will usually have community services teams addressing these challenges and working with disadvantaged communities. Charities too (Rowntree Trust, Children in Need, those running local food banks...)

Write and speak in Plain English. Look at the 2021 UK Census results: some people will be surprised at the size of the non-English speaking population and, importantly, the top languages that non-English speakers use.

How do you engage groups that are not inclined to interact with research, i.e. non-responders?

There are people who don't want to engage or respond and, at some point, there needs to be a decision about how much is enough so that we don't risk wasting resources and becoming intrusive. Recognise people's right not to be engaged.

An individual cannot represent a whole group. How can you get representation in a meaningful and realistic way?

An individual can represent a whole group and many of us do it quite well. If you choose to engage with a larger group, in the end it will come down to interaction between individuals or at least a handful of representatives. As with all things in science, when a patient representative tells you something, ask what the source is for that view. Is it empirical evidence or an opinion? (Either one could be valuable of course.)

If you wish to have representation from a specific group, start with a group and ask them to nominate a representative. Or **choose someone who you know can speak on behalf of others and provide them with the resources to maintain dialogue with a wider group**, to bring you a more representative view.

The biggest challenge we face is the assumptions that a) a small group of people (the smallest I've seen is 6) can be 'diverse' and b) that it's possible to know a group is 'diverse' by looking at it.

A lot of patient representatives/patient advocates who get involved in research are really experienced. This is great, but does this mean that we are losing voices of those less engaged?

Not if they are good patient representatives/advocates. **Good PPI representatives will always stay in touch with grass roots** and many experienced PPI representatives are still having treatment in clinics sitting alongside the people who are less engaged. Those of us who are very engaged can and do act as

ambassadors to less engaged groups – it's an important aspect of advocacy. Having said that, I find it helpful to recognise people's right not to be engaged.

You will find that focus groups or online surveys (especially if you engage via Facebook groups) is one way of keeping in touch with the "non-experts." For the entirely non-engaged, see the first question above.

PPI in basic/discovery research

How to successfully involve people affected by cancer in research proposals about basic science (pre-clinical)?

Decide what success looks like.

For example, Cancer Grand Challenges (CGC) projects ask all research teams to **be clear about what they want the PPI representatives to achieve/deliver**. They write the strategy for doing it themselves. **Clear roles are given from the start: they attend regular meetings, are given Q&A time...** So, you must start with experienced PPI representatives for this task and **have an honest discussion about what PPI might do for your work**. It may be very little and that's okay. But think broadly too.

For example, one CGC project has had the PPI representatives focusing on promoting sample donations and biobanking generally, using the project as an example of *why* it is needed, rather than helping the project *itself*.

The patient representatives suggest you could also look at:

- Independent Cancer Patients' Voice their "VOICE course"
- Cancer Grand Challenges projects
- The work of the Participant Panel at Genomics England
- London School of Hygiene & Tropical Medicine: the "ICON project."

We would also recommend reading [this paper](#) which includes general information about patient and public involvement (PPI) and covers specific challenges, barriers and recommendations for doing PPI in basic research.

What would motivate people affected by cancer to become involved in basic lab or data research? Are there different motivations for different groups or cancers?

There are many motivations. People fall into it by accident, people are desperate for solutions to their own disease, people have lost a loved one, people want to put something back having had their own disease...

Yes, **it does change from cancer to cancer, and it also changes through time**, for those of us who stay involved for a period of years. Time has highlighted those groups left behind and/or the issue of late effects for survivors, and the excellent survival rates in some blood cancers contrast with the opposite picture in pancreatic cancer (and the lack of any change for decades).

Recognition and payment for involvement

What do you think about appropriate recognition (payment for involvement, authorship etc) for PPI contributors?

No PPI representative should be out of pocket for our voluntary work. **There should always be a clear policy and process for paying expenses.** This could even include fund towards computer and electricity costs. For example, Cancer Research UK offer an extra £5 on top of the honorarium payment. NIHR-INVOLVE has a suggested payment scale. **Whether payment is offered or not, it needs to be made clear upfront.** And please try to avoid offering vouchers etc.

For authorship, **the PPI author should fulfil authorial requirements**, so either being an integral part of the research team or writing the paper (proof reading or sense-checking isn't enough). And why not get (trained) PPI representatives to help write the Lay Summary, Press Release, Results Newsletter for Participants (including tissue or data donors) etc?

Academics receive income, acknowledgement in publications and respect. This should be the same for everyone involved in research.

General questions

What are your bug points with PPI practice?

My main bug point is around language.

When saying “meaningful,” what meaning(s) and for whom? Words like “effective” or “useful” are so much clearer and helpful than “meaningful.” or ask them what meaningless involvement is. Is it adding value for funders, adding relevance for policy makers, enhancing benefits for patients/public, providing some form of emotional reward for the PPI representatives, assisting researchers in obtaining approvals... etc?

Words like **“impact”** can imply something should *change*, but PPI will often *confirm* that the research team is on the right track.

How to ensure PPI is not seen as a tool, but more of a conversation? Good PPI should be useful for the research itself, and thus rewarding (in different ways) for researchers and the PPI contributors. Ultimately, it should influence health care services and patients, families and the public.

We bring non-academic/clinical values that are essential if research evidence is to embody more than just a clinical model of care. We often talk about ‘the patient voice,’ ‘patient stories,’ ‘the patient perspective’... **Remember that what we bring is experiential knowledge.**

How well are the values of researchers and the public aligned? Are we all speaking the same language?

The values are aligned but the language isn’t. Although I think COVID allowed us to make a leap forward, we haven’t been able to apply those lessons elsewhere. Cancer is probably an exception.

What are your thoughts on using PPI to educate those with misconceptions, or who prescribe to misinformation/ conspiracies (so we don't only hear from those who feel positively)?

Many PPI representatives already talk to other patient groups about our work, in life and online. Unfortunately, words like "misconception" or "misinformation" may backfire. The implication is that their thinking is "wrong" and ours is "right." It's also good to know if the issue is misconceptions or *mistrust*.

We need to keep talking about data and evidence. **Rather than educating, perhaps finding more effective ways to communicate would bring about change.**

Is there a "sampling bias" among people that join patient advocacy groups?

Yes. BUT no more than there is a bias among those who go into research or medicine. You may be surprised by those who join but remain sceptical. **Overall most of us advocate FOR patients or the public**, even (or perhaps especially) those who aren't engaged or involved.

I think the more important risk when working with organisations is not recognising those that are populated primarily by patients/carers, and those that are populated mostly by academics and clinicians who speak *for* patients/carers. Some due diligence is necessary if you are to avoid proxies.

How do we ensure the same PPI representatives aren't involved in successive studies? Great as they are, we need a balance with fresh perspectives.

I would suggest there is a place for both and, if nothing else, this will help ensure a kind of succession planning.

The best solution is probably to **appoint PPI representatives in pairs** – one "veteran" and one newbie per committee. Another solution is that you appoint a more experienced PPI representative for one or two years with the specific brief of ensuring "new blood" is recruited and trained.

The big risk of continuous relationships (among any groups or individuals) is the development of complicity. Once you are working with people who are more inclined to agree with you than not, you know that you need to expand your groups or change its membership (in a way that you don't lose important 'memory').

How do we balance what the evidence gaps say we need and what PPI representatives say we need?

I am a pragmatist – if we accept that all research answers questions and thus adds to knowledge and/or understanding, then which option is likely to get funded (and by whom)?

However, there are also **patient priority-setting methods** (e.g. the James Lind Alliance Priority Setting Partnerships) which allow people with lived experience to identify and prioritise research gaps that they want filled. For funders using public money and for researchers bidding for those funds, that's a powerful focus.

How can we realistically fund the time of researchers to do patient and public involvement and engagement (PPIE), when so much is expected before a grant application or funding award?

Make sure your next grant application costs this in. Get an experienced patient rep (you will already have one in your study team to help plan the PPI) to cost the PPI elements, then you cost in researcher time. Is funding really the problem or is it time and other resources? So, you could start asking for funding to hold patient group meetings in the local café and hold regular meetings but feeding in different topics.