Lay Members in Biomedical Research

A record of the discussions from a workshop exploring how people experience their roles as public representatives in biomedical research.

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1. Context of the workshop

Biomedical research is increasingly expected to be open and transparent, to translate laboratory findings into new drugs and treatments for humans and animals, and to engage the publics and patients who stand to benefit from this research. These demands have led to rapid growth in new forms of public and patient involvement across health research and clinical delivery. As a result, lay people and patients are being asked to help develop effective and ethical biomedical research at all of its stages, from improving proposals to the dissemination of findings.

At the University of Exeter, Professor Gail Davies and Dr Rich Gorman are working on a Wellcome Trust Collaborative Award, which is exploring changing opportunities for public and patient involvement in biomedical research, and how lay involvement in biomedical research may change conversations around animal research. This research seeks to gather together different perspectives to understand how these involvement activities work, what they contribute to research practices, and what might be done to improve them.

2. Why did we run this workshop?

This workshop was funded by the Wellcome Trust and facilitated by the independent facilitator Dr Jo Welsman. Specifically the workshop aimed to:

- Bring together 'lay members' from across the biomedical research sector. This included different research committees, patient and health service user groups, patient involvement panels, and animal welfare and ethical review boards.

- Provide a safe space for lay members to meet as a group to discuss the issues that concern them and build dialogue across their perspectives, with a particular focus on the opportunities and challenges of discussing and shaping biomedical research.

- Enable people to have an opportunity to set an agenda (outside of our existing research) for how such challenges might be addressed

As patient and public involvement is a focus of our work, we are aware of the criticisms that patient and public involvement is generally organised to reflect existing institutional interests. In this case, we wanted to run a process allowing people involved in biomedical research review to meet and make the connections that were most meaningful to them, with the potential to follow this up in our future research.
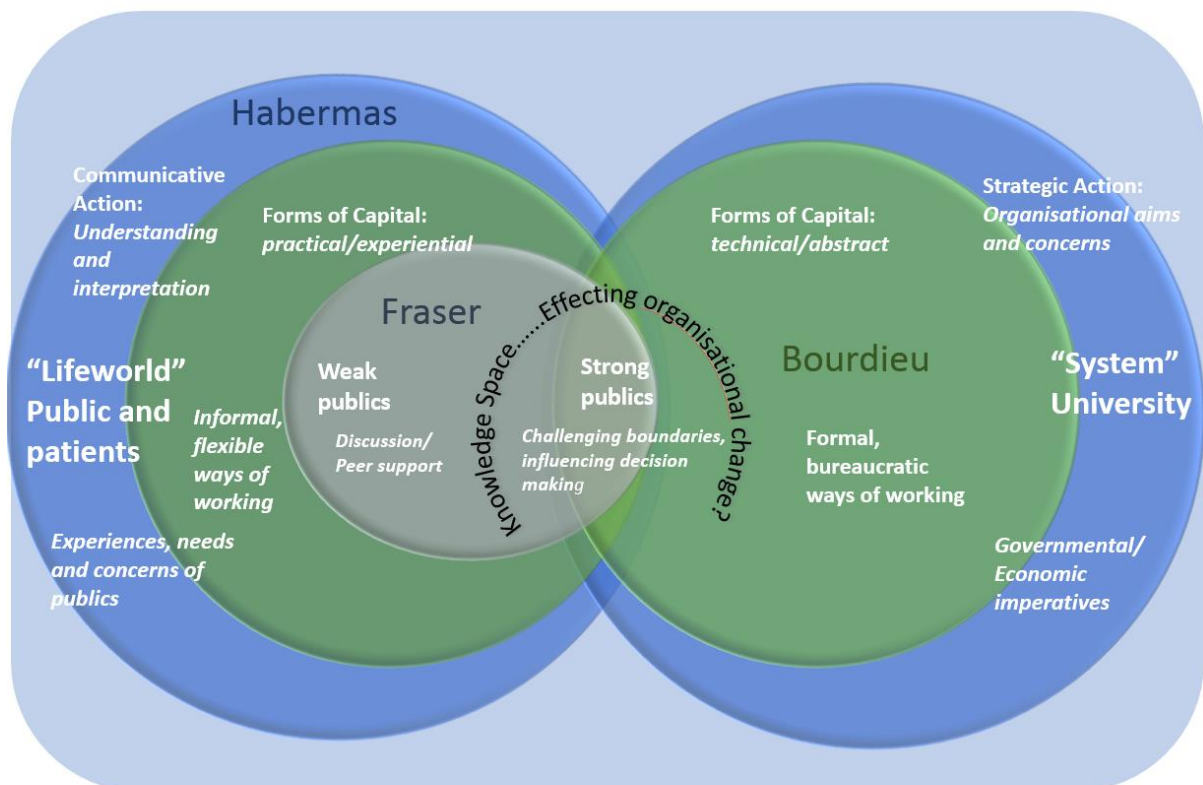
3. Who attended?

Thirteen people attended the workshop. People's experiences of biosciences research were largely reflected through involvement with AWERBS (Animal Welfare and Ethical Review Boards) or membership of specific medical research charity's involvement networks (e.g. The Alzheimer's Society's Research Network or the National Cancer Research Institute's Clinical

Studies Groups). Others were public representatives within biomedical research centres or worked as independent lay/patient representatives.
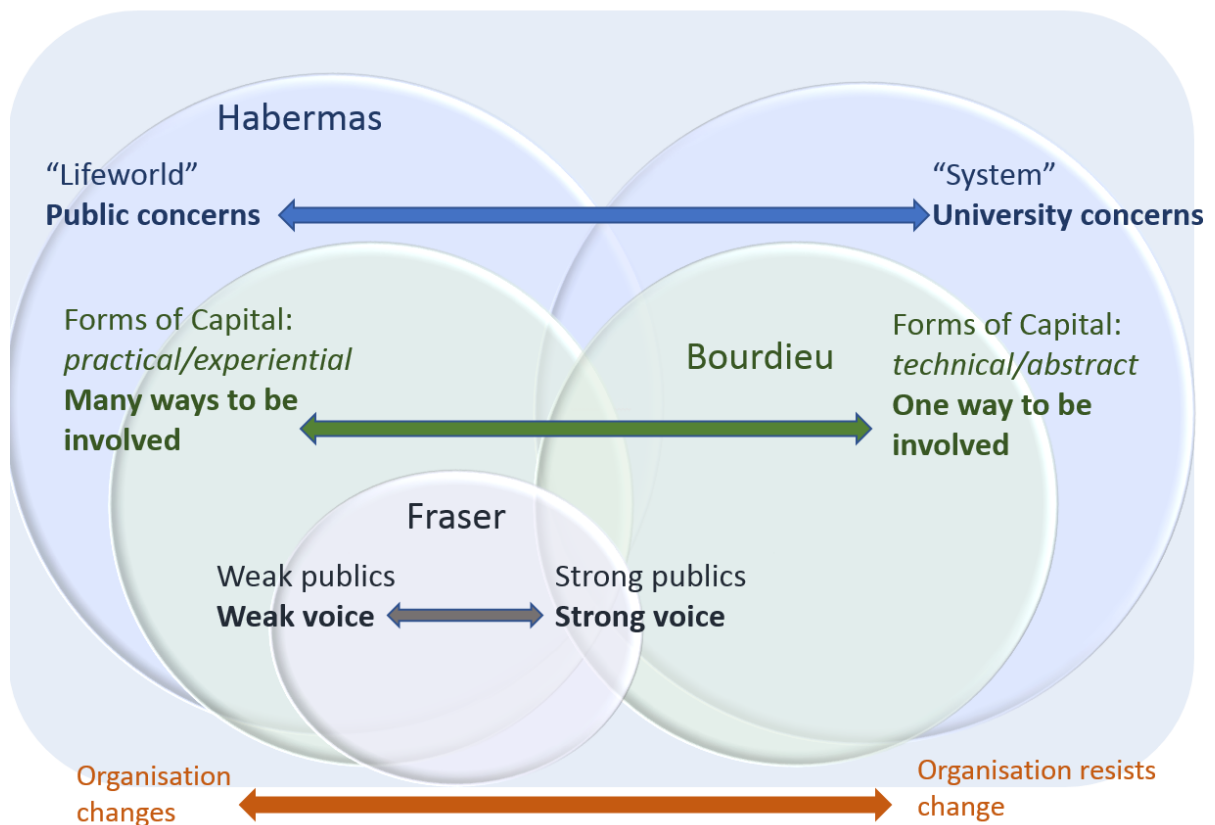
Workshop participants had a diverse range of experiences and roles regarding 'patient and public involvement'. Common activities included: commenting on lay summaries; being members of steering groups; being involved in decision making around funding; mentoring researchers; sitting on committees reviewing project proposals; acting as advocates for a public voice in organisations.

4. What we did:

The workshop was based around a theoretical framework helpful for understanding public involvement in academic research (Gibson, Welsman, and Britten, 2017). This seeks to map the different kinds of knowledges people bring to patient and public involvement and explore its relationship with organisational concerns.

The method uses this mapping technique to help share what people think and feel about their involvement. The main aim of this mapping is to create a space for people to explore what experiences they share and illustrate what the differences are so that people can learn across them.
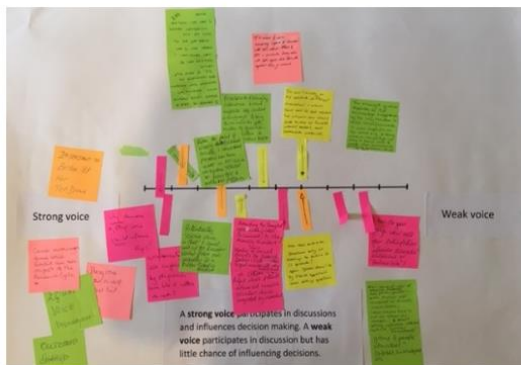
We invited participants to think about their experiences as a lay contributor within their own organisation and experience of involvement and to rate these along a spectrum for four dimensions:

- The extent that participants felt like they had a **weak voice** in influencing research or a **strong voice**
- The extent that participants felt there are **many ways to be involved** in research (drawing on lived experiences) to there being only **one way to be involved** in research (through academic science)
- The extent that participants felt public involvement addressed **public concerns** or **organisational concerns**
- The extent that participants felt **organisations change** as a result of public involvement or whether **organisations resist change**
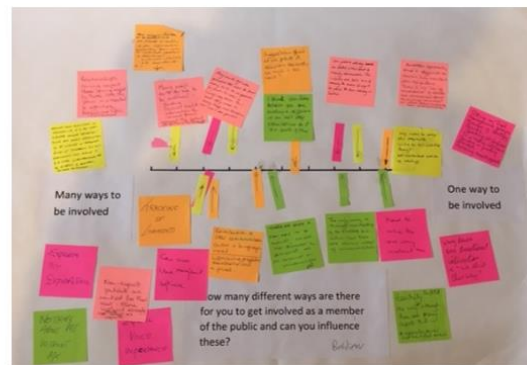
We also invited participants to make brief written comments on sticky notes to explain or clarify their thoughts. These comments can be found at the end of this report as an appendix.

Following the process of placing arrows and comments, participants then discussed each of these spectrums as a group, reflecting on the comments and emerging themes. These discussions were captured by a note taker on the day.

5. What participants said

Strong voice - Weak voice
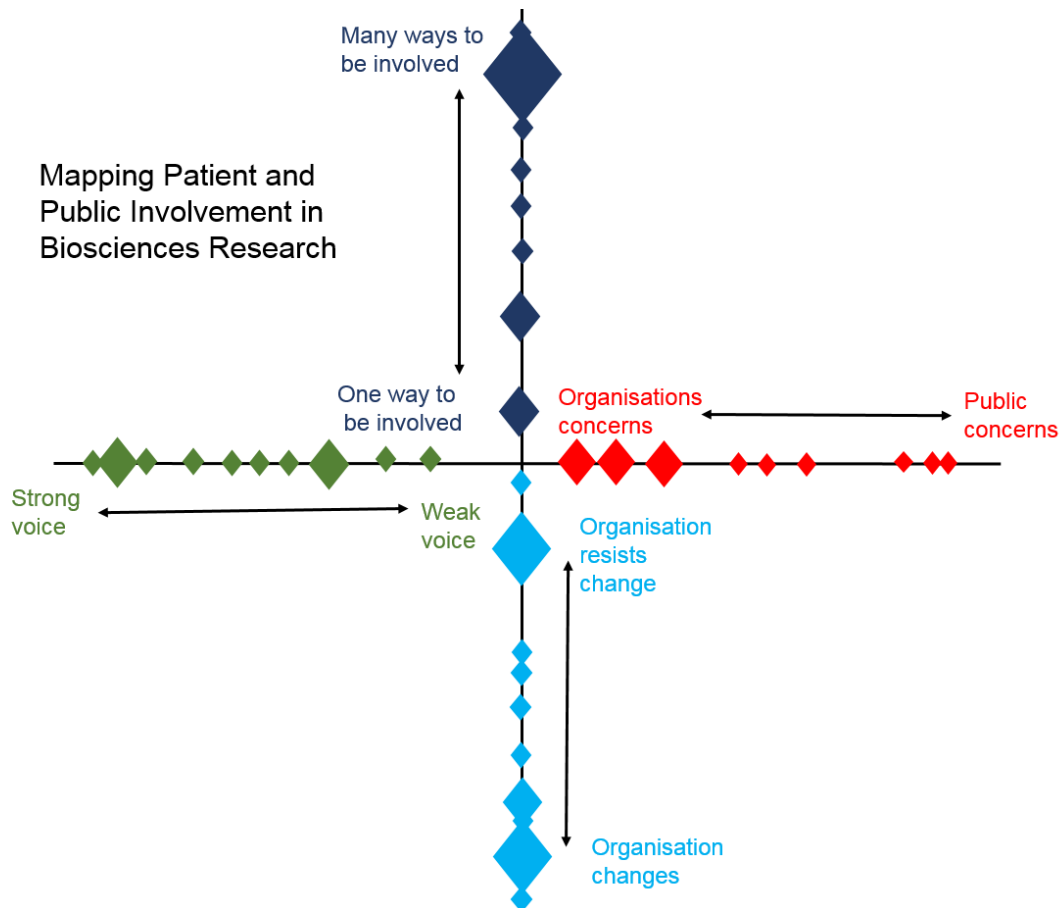

Many ways - One way to be involved

Public concerns - Organisation's concerns

Organisation changes - Organisation resists change

More detailed images and copies of participants' comments can be found at the end of this report as an appendix.

The arrow placings from the charts were combined in the diagram below, "Mapping Patient and Public Involvement in Biosciences Research". This provides a simple summary of the arrow positions from the four different dimensions in one place.

Mapping Patient and Public Involvement in Biosciences Research

What does this diagram show?

The diamond symbols are scaled proportionally such that the smallest represents one arrow and the largest represents four arrows clustered at any position. The diamonds are indicative of the spread of views, rather than an attempt to pin down specific positions. This mapping of views helped identify themes for the workshop conversation.

Not surprisingly, given the range of experiences and different organisations participants represented, responses were spread right across the dimensions. Participants had the opportunity to discuss these with each other.

Some trends to note were that a greater number of participants felt that the organisations' concerns were dominating discussions and process of involvement, rather than more public concerns. A large number of participants also felt that there were many ways to get involved in research beyond a purely scientific approach, and that lived experiences and knowledges were taken on board.

a. Common themes

Considering the comments and discussion points generated during the workshop, several key themes and similarities emerged that reflect shared concerns amongst many participants.

- There was a clear and explicit recognition within the group that the participants gathered together were highly reflective of the majority of public involvement groups and practices, largely "white, middle-class and of a certain age". Many participants commented on shared characteristics required within public involvement, being confident, able to fit in and "play the game".

- Many participants reported feeling they had a "strong" voice – but comments and discussion also show that actual public influence on decision making might, in fact, be weak. The use of words like "tick-box", "rubber stamping" "fobbed off" reflect this. There is an important difference operating here between being listened to, and actually having an impact on science. Even participants that felt they had a strong voice and were listened to, recognised that this didn't always result in change.

- A commonly identified issue was feedback. Many participants felt unclear of how and where they were listened to and/or making a real difference.

- It was clear that many participants felt that the "organisation" was firmly in control of the processes of public involvement in research – geographical siting, content of meetings, etc.

- Whilst participants reflected that there are lots of different tasks available within the sphere of 'public involvement in research', these are commonly highly bureaucratic in nature and could require a lot of committee expertise to take part in.

- A common concern was the question of what is 'lay', and whether this a useful term? Participants were interested as to how researchers think about and understand the lay person and their role.

b. Key differences

The people gathered together had a range of varied experiences of public involvement in research. The workshop enabled individuals to share and discuss differing viewpoints and experiences of public involvement. Noting areas of good practice is incredibly useful. Some of the key differences were around the confidence and power to effect change, and whether change was actually effected.

- People's experiences of committees varied from feeling intimidated and reluctant to ask questions, to feeling able to affect decision making and being an equal partner. Does this depend on the organisation you are working within?

- Some participants felt that their participation was tokenistic and so unlikely to change organisations whilst others felt that any involvement was better than none and small "nudges" would have a cumulative effect upon organisations.

6. Feedback and Evaluation

Participants reported that drawing together such a varied selection of participants was very useful in providing a unique space for sharing experiences. Participants enjoyed working across their different groups and valued the diversity. Despite this diversity, participants did recognise shared experiences. One person reported valuing '*understanding how people from such diverse platforms have so much in common and how we can learn from each other*'. The group had useful and meaningful conversations across their shared experiences, particularly around what it meant to be a single lay person on an expert committee and how to manage this role.

Some participants reported that the workshop had enabled them to feel more confident to be involved, particularly regarding asking questions in involvement processes. One commenter suggested that following the research, they now aim to be '*more vociferous in demanding proper lay explanations of the science proposed behind a line of research*'. Others similarly reported that the event had inspired them with confidence in the process of public involvement itself, and the differences that lay representation can make. Despite this, it's worth acknowledging that others found it more challenging: '*I came away with a strong sense of how the bottom line of money, status and reputation [in science] has an overarching impact*'.

Several participants also reported an interest in taking up some of the challenges identified by the group within their local organisations/involvement groups - particularly regarding trying to build more diversity into involvement practices.

7. Going Forward

The discussions that took place at the workshop will be used to inform the ongoing work that Professor Gail Davies and Dr Rich Gorman are doing, exploring changing opportunities for public and patient involvement in biomedical research, and how lay involvement in biomedical research may change conversations around animal research. Our research aims to address and report on the kind of issues identified in the workshop further into the future.

Many of the themes, challenges, and opportunities that were identified by participants within the workshop reflect ideas and comments that have cropped up quite often within Gail and Rich's research so far, which is a really useful form of triangulation and confirmation for the research team.

We recognise that this workshop has only just begun to open up questions around involvement in research, and that understanding how people might challenge, shape, and change research agendas will require further discussions, across a much wider range of stakeholders.

In identifying priorities for moving forward, participants at the workshop suggested that we should run a similar event with scientists and research funders. Participants wanted to know 'how their involvement has helped', and understand what does 'lay' mean for the people
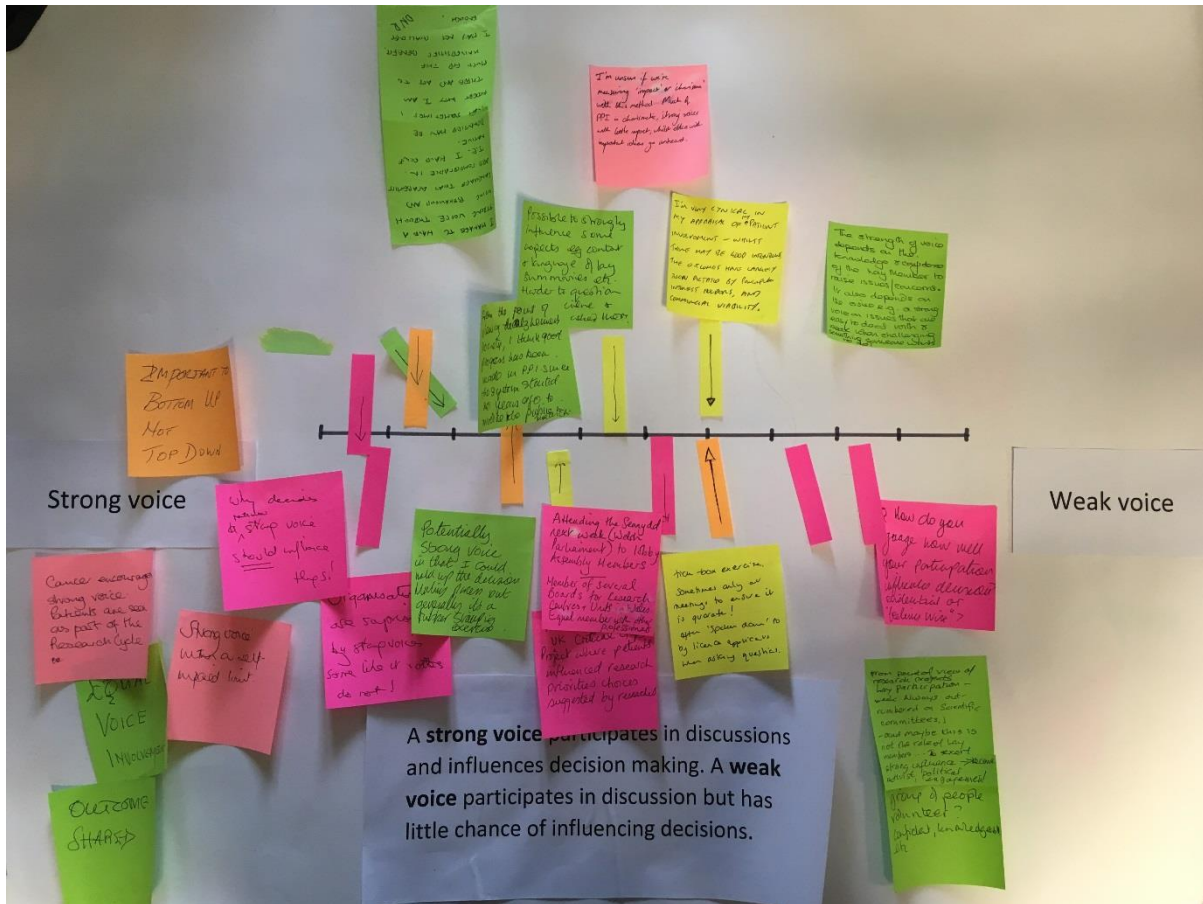
whose committees lay members sit on. Thus, based on the suggestions of participants, within the next phase of our research we aim to take the challenges and questions identified by the group to these additional audiences.

Some participants suggested they might find it helpful to meet again at a future date, perhaps 6 months in the future. This was not unanimous and participants did not identify a specific issue that they would like to address. We will be providing a further update on our research to explore if some members of this workshop would like to contribute to at that stage.

We would like to thank everyone who took part in this workshop for their time and comments.
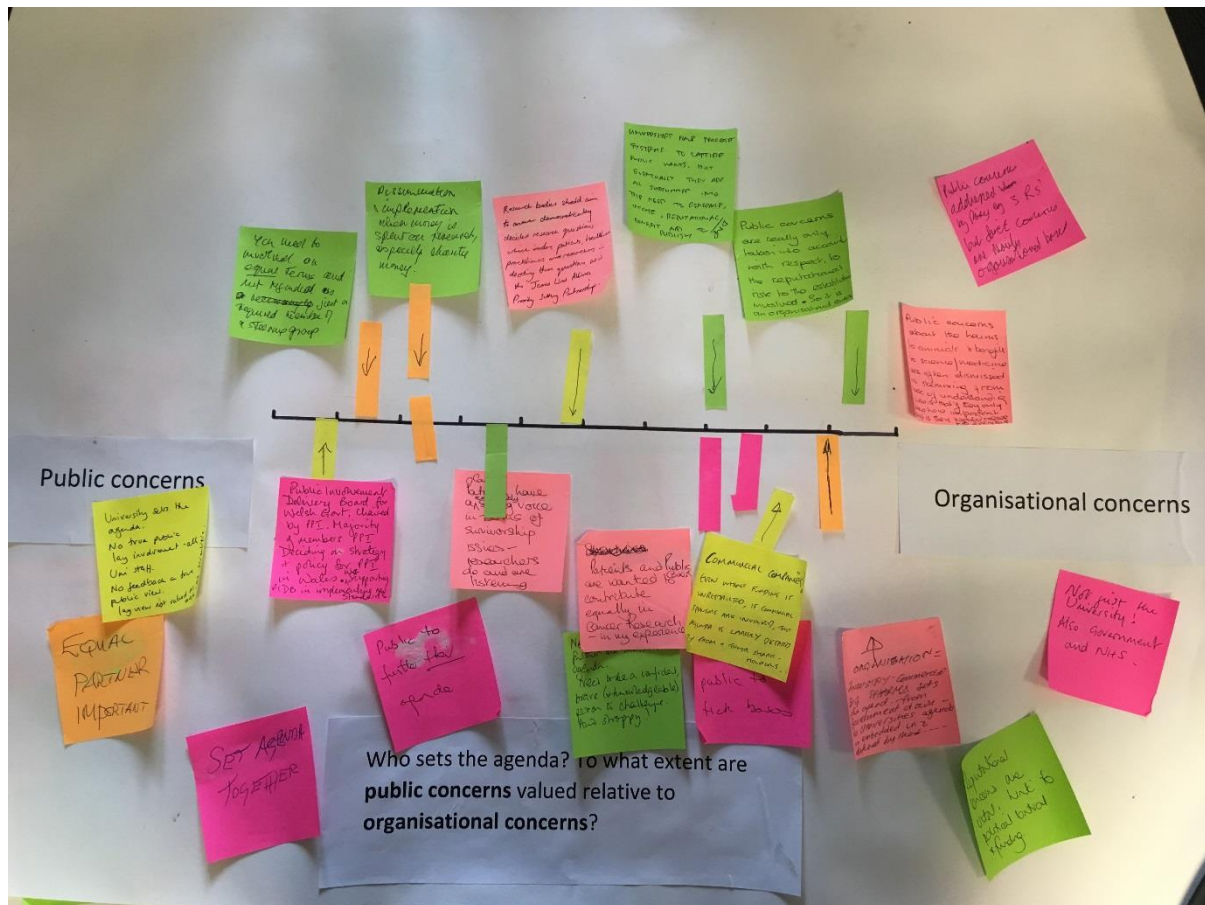
Appendix

Strong voice - weak voice

Comments typed up from sticky notes:

- Cancer encourages strong voice. Patients are seen as part of the Research Cycle.
- Equal voice involvement
- Outcome shared
- Strong voice within a self-imposed limit.
- Why decides? Strong voice <u>should</u> influence things!
- Organisations are surprised by strong voices some like it and others do not!
- Potentially strong voice in that I could hold up the decision making process but generally it's a rubber stamping exercise.
- Attending the Senedd next week (Welsh Parliament) to lobby Assembly members. Member of several Boards for Research Centres and Units in Wales. Equal member with other professionals.
- Member of Bowel UK Critical Gaps Project where patients influence research priorities choices suggested by researchers.
- Tick-box exercise sometimes only at meetings to ensure it is quorate! Often "spoken down" to by licence applicants when asking questions.

- Q: How do you gauge how well your participation influences decisions evidential or "feelings wise"?
- From point of view of research projects lay participation – weak. Always outnumbered on scientific committees – and maybe this is not the role of lay member ……to exert a strong influence become activist, political engagement.
- Self-selecting group of people volunteer? Confident, knowledgeable etc.
- Important to bottom up not top down
- From the point of view of the Alzheimer's society I think good progress has been made in PPI since the system started 20 years ago to involve the public in research.
- The strength of voice depends on the knowledge and confidence of the lay member to raise issues/concerns. It also depends on the issues, e.g. a strong voice on issues that are easy to deal with and weak when challenging something someone wants to do!
- I'm unsure if we're measuring "impact" or "charisma" with this method. Much of PPI~ is charismatic, strong voice with little impact, whilst others with important ideas go unheard.
- I'm very cynical in my appraisal of my patient involvement – whilst there may be good intentions, the outcomes have largely been dictated by powerful interest holders, and commercial viability.
- I manage to have a strong voice through using behaviours and language that academics are comfortable in, i.e. I have Gone Native. Downside may be that sometimes I forget why I am there and act too much for the University's benefit. I may not challenge enough.

Comments typed up from sticky notes:

- Experts by experience
- Nothing about me without me
- Non-expert patients are wanted for their views – those involved already can be valued as "experts".
- Equal voice important
- Can use Idea Management Software
- Tracking of comments
- Contribution is clear communication content and language used. Interviewing prospective researchers and voice on panel.
- There are quite a few ways to be involved but are they different to each other and all controlled by universities etc.
- The only way is through membership of the AWERB but within that there are various ways of communication.
- Need to value the one way involvement too.
- Very much one directional interaction i.e. "we do it this way".

- Speaking from experience in haemophilia, it is an over-surveyed patient population. There are ample opportunities to be involved in different areas of research, but how meaningful that really is and a clear understanding of its purpose is another discussion altogether.
- Relationships, earning respect, "giving" respect by those with the "power" is essential to effective patient and public involvement.
- Many ways but hard to be EFFECTIVE as member of the public. Your organisation promoting your area of interest/concern. Political activism – via MPs etc. Committees etc.
- Many ways exist for me to be involved – funding, clinical trial design, information sheets, consent forms. Represent the patient perspective in the research cycle.
- Many research organisations orchestrate PPI around the "formal meeting" but the research opportunities for patients in this context are (usually) really diverse. This is almost always outside the meeting through email /teleconference work which is more specialised.
- Suggestions offered at all points of seed corn research; how much is this used?
- Some patient advisory boards are limited in their remit to reviewing documentation. This is essential work, but in terms of measure "the number of ways to be involved" these advisory are limited.
- AWERBs generally find it difficult to recruit lay members from the public. There is no "list" of candidates, and institutes are concerned about recruiting "activists" or others who might be too challenging.
- Sitting on trial management groups, member of strategy boards, speaking at conferences, TV and radio interviews, deciding on funding priorities, reviewing research proposals.
- Essentially AWERB* are one way although there are any aspects to it. *Application review, mid-term and final reviews.
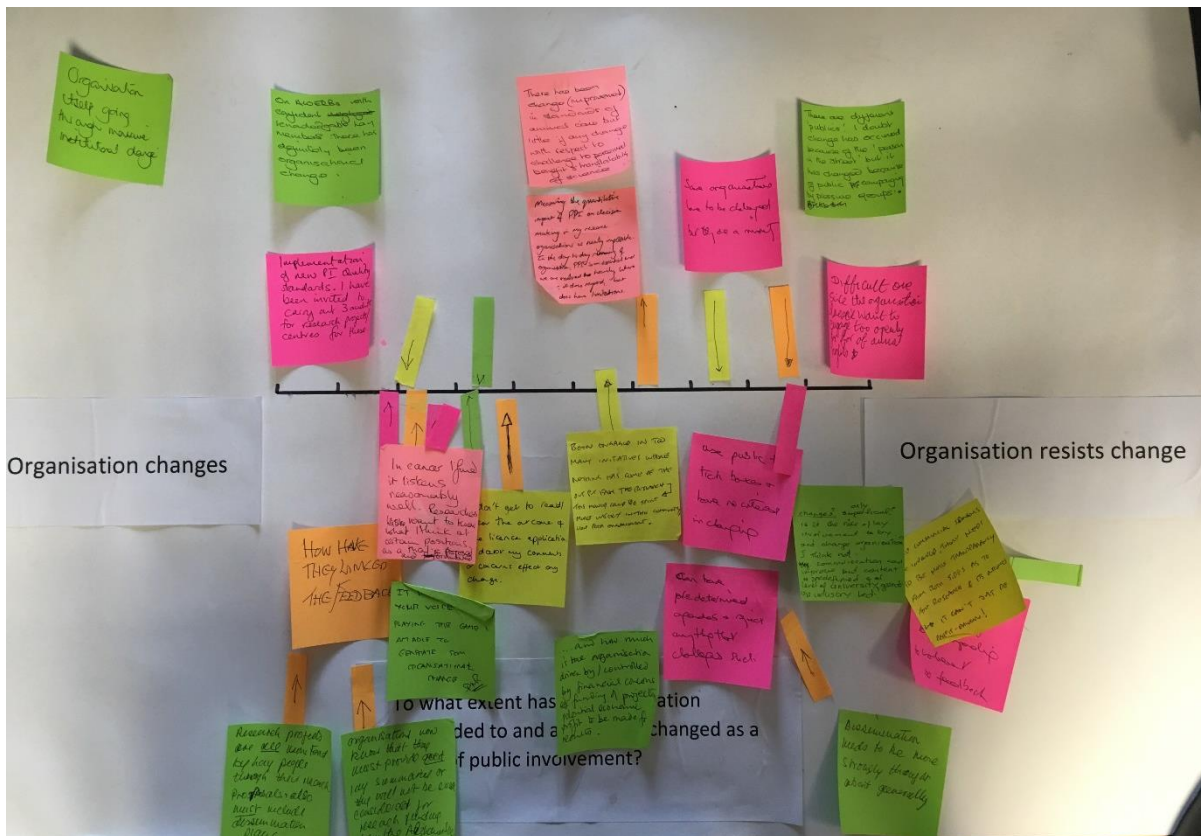- Only invited to every other month. Invited to this workshop though! Not contacted outside of meetings.

Comments typed up from sticky notes:

- Equal partner important
- Set agenda together
- Public to further their agenda
- You need to be involved on <u>equal</u> terms and not regarded as just a required member of a steering group.
- Dissemination and implementation when money is spent on research especially charity money
- Public involvement Delivery Board for Welsh Gov't chaired by PPI. Majority of members are PPI, deciding on strategy and policy for PPI in Wales. Welsh Government supporting PIDB in implementing new public involvement standards.
- University sets the agenda. No true public lay involvement – all Uni staff. No feedback on true public view. Lay view not valued as much as scientific.
- Cancer patients have a reasonably strong voice in terms of survivorship issues – researchers do and are listening.
- Patients and public concerns are wanted to contribute equally in Cancer Research – in my experience.

- Commercial companies! Even where funding is unrestricted, if commercial sponsors are involved, the agenda is largely dictated by them and their share-holders.
- So often use public to tick boxes
- Organisation = Industry Commercial Big Pharma sets the agenda from government down – so universities agenda is embedded in and defined by these……
- Reputational concerns are vital link to political control and funding.
- Not just the university also government and NHS.
- Public concerns address by proxy e.g. 3 Rs but direct concerns are mainly organisational based.
- Public concerns about the harms to animals and benefits to science/medicine are often dismissed as stemming from lack of understanding. View is that if they only know how important stuff is they would agree to everything.
- Public concerns are really only taken into account with respect to the reputational risk to the establishment involved. So it is an organisational control.
- Research bodies should aim to ensure democratically decided research questions which involve patients, healthcare practitioners and researchers as in the James Lind Alliance Priority Setting Partnerships.
- Universities have systems to capture public wants. But eventually they are all subsumed into the need to generate income, reputational benefit and publish.
- Nearly always to further the institution's agenda. Need to be a confident, brave (and knowledgeable) person to challenge. And stroppy!

Comments typed up from sticky notes:

- Organisation itself going through massive institutional change
- On AWERBs with confident knowledgeable lay members there has definitely been organisational change.
- Implementation of new PI quality standards. I have been invited to carry out 3 audits for research projects/centres for these.
- There has been changes (improvement) in standards of animal care but little if any change with respect to challenge to perceived benefit and translatability of science.
- Measuring the quantitative impact of PPI on decision making in my research organisations is nearly impossible. In the day to day running of organisation, PPI is an essential and we are involve heavily, where relevant, it does respond, but PPI does have limitations.
- There are different "publics". I doubt change has occurred because of the "person in the street" but it has changed because of public campaigning by pressure groups.
- Difficult one since the organisation doesn't want to engage too openly for fear of animal rights.
- Some organisations love to be challenged but they are a minority.
- In cancer I find it listens reasonable well. Researchers want to know what I think of certain positions as a trial is proposed and formulated.

- It depends on your voice. By playing the game I am able to generate some organisational change.
- I don't get to read/hear the outcome of the licence application. I doubt my comments or concerns effect any change.
- Been engaged in too many initiatives where nothing has come of the output from the research. This money could be spent more wisely in the community like peer engagement.
- Where commercial sponsors are involved, there needs to be more transparency from both sides as to the research and its outcomes. It can't just be profit-driven.
- Use public to tick boxes and have no interest in changing. Can have predetermined agendas and reject anything that challenges such.
- Changes, but only superficial. Is it the role of the lay involvement to try and change organisation? I think not. Communication could improve but content tis predefined at level of university, agenda is industry led.
- Dissemination needs to be more strongly thought about generally.
- …..and how much is the organisation driven by/controlled by financial concerns e.g. funding of projects, potential economic profit to be made from results.
- Research projects are all monitored by lay people through their research. Proposals also must include dissemination plans.
- Organisations now know that they must provide good lay summaries or they will not be even be considered for research funding from the Alzheimer's society.