

Catalyst Event Report on

How can we demonstrate the benefits of involving the public in research?

Aintree Racecourse , Wednesday 14th January 2015

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Purpose of the day

This event brought together prominent people from diverse backgrounds across the North West of England who have an interest in Patient and the Public Involvement in research. It is hoped that the event enabled the attendees to begin collaborative work across their organisations, with a view to developing innovative ideas for future research and development.

The event was conducted using 'Open Space'. The method is designed to enable people with mutual interests to meet and progress ideas in a short period of time. Participants have control over what is discussed and can choose to include themselves in various forums generated on the day. At the conclusion of the various forums, decisions are made about outcomes and further steps to progress them. Participants are expected to contribute further via the networks developed on the day.

A summary of the Open Space discussions, including the names of participants and those expressing an interest in being contacted at a later date, form the basis of the workshop summary.

The discussions are not presented in any particular order and do not reflect the popularity or the merit of the research themes. Some themes are closely interlinked and could be collated.

Visual minutes and a comic strip were produced during the event by our associates, "*morethan minutes*" and these are included in the report.



Workshop Summary

Presentations



Dr Stuart Eglin, Director of NHS Research and Development North West, introduced the day and went through the concept of the Catalyst event and how it was a highly participatory event. He stated that everybody attending the event had an interest in Patient and Public Involvement in Research and all would have something to contribute. Stuart introduced the next speakers, Mr Simon Denegri, Chair of INVOLVE and National Director for Public Participation and Engagement in Research and Mr Derek Stewart, Associate Director for Patient & Public Involvement National Institute for Health Research, Clinical Research Network. Both speakers eloquently emphasized the importance of Patient and Public involvement in research and why we need to look at the evidence base.

Our thanks and appreciations go to both Mr. Simon Denegri and Mr. Derek Stewart for giving their time to speak and take part in this catalyst event.



“Thank you, a really good sharing experience. Well organised and a good cross section of people attending. ”



Convenor reports

Group 1: Patient Research Ambassadors

Convenor: Francine Jury

Participants:

Catrin Eames, Jane Martindale, Irene McGill, Andrew Duggan, Maria Boswell, Roger Steel, Martin Morris, Philip Bell, Tinola Odukuabe, Anita Maestri – Banks

Key points from the discussion:

- Naming ambassadors / champions
- Payment for the role
- Role of ambassadors in clinics when people are distressed
- Role of ambassadors in the community through CCG'S



Next Steps:

None recorded

Group 2: Paediatric Research – patient and public involvement

Convenor: Hugh McLaughlin & Teresa Moorecroft

Participants:

Kim Doolan, Tinuola Odukogbe, Nicola Harman, Sue Halton, David Britt, Penny Bee



Key Points from the discussion:

- "What PPI do I need for my research?" Consider whether young children and young people should also be involved and also whether they are current service users or maybe have never used a service.
- There are different models in place for involving young people and children should be asked to contribute but may need a different approach / materials
- How do funding bodies prioritise commissioned call? Does evidence includes children's opinions how are these weighted? What age should children be? More about maturity than age.
- Education about research – are there difficulties in the curriculum. How can educational trial days be incorporated?
- Might focus more on research design but PPI is also important
- Barriers to involving children includes paternalism and gate keeping could be challenging inconsistencies and the approaches taken by research ethics committees.
- Children are marginalised in this process.

Next Steps:

- Consider resources needed to involve children and young people in research. Also how best to educate all children on research in particular human aspects and the role of the public/ patients in shaping research
- Important to involve children but need to think about the best approach





Group 3: How can we support the public when asking for their involvement



Convenor: Anita Maestri- Banks



Participants:

Tracey Williamson, Cara Afzal, Jackie Macklin, Nicola Harman, Peter Lyne, Julian Raffay



Key Points from the discussion:

- How can we support in research (for the first time?) – Incentives, support, training etc how are we funding for this?
- Lay person can miss out financially. Money one aspect of support. Lots of discussions regarding networking but who do people with disabilities turn to for help?
- Good practice examples, depends on funders, if get that funding. Are research charities providing money to follow Involve rates?
- Groups should make clear what payment or not they are offering, then it public members choice once informed.
- Injustice that one receives pay and other cannot have payment or even travel. Should boycott research that doesn't pay Involve rates.
- Myth that professionals are always paid as it is often in their own time.
- Need to make clear expectation e.g. role descriptions, induction etc.
- What about emotionally? Keep in touch by email and phone etc – like on the NIHR choice project.
- Need to support public members learning too. Go to where the public are rather than where your meetings are based. Have consistency of meeting environment and plenty of facilitators to reinforce communication.
- Has support approaches had their impact eradicated? Increasing awareness of need to assess impact. Say what was done and how well.
- Accessibility need addressing – eye on diversity not for researcher to decide, it's a joint discussion.
- Evaluate throughout a study, refer to Involve briefing notes for researchers.
- Examples of important positive impacts, getting fruit tea, staff giving up their sandwiches.
- How equal is the relationship, example of lay reps being part of the team and not just commenting. Depends on how receptive organisation is e.g. a good one is BRAG at Merseycare.
- LDS publication – I'm a researcher 'let me out of here'
- Need a documented framework

Next Steps:

- Qualitative support to help evaluate impact. Important to evaluate impact of PPI on the researcher but also impact can have on experience of PPI research

"Great event – thought the open space format worked really well. Lots of really great ideas, enthusiasm and determination, thanks for organising it!"



Group 4: Funding gap: Who and how to pay for PPI development prior to grant applications.

Convenor: Katie Bristow & Mick Mckeown

Participants:

Sue Povall, Kerry Woolfall, Ekaete Nquot, Soo Downe, Chris Houston, Rob Walker

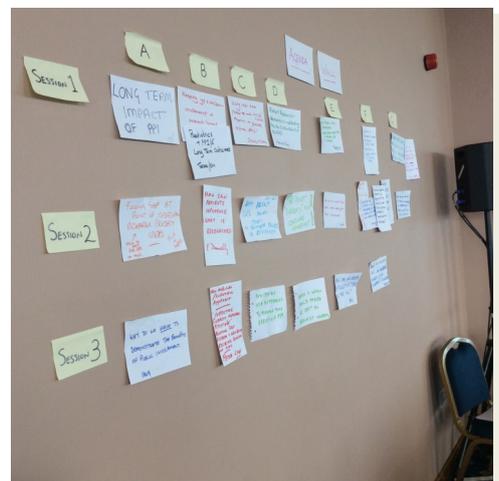
Key points from the discussion:

- Diversity of systems in universities and trusts in engaging with the public
- Do we always need to be resourced to engage – need to be there, whether people take them or not.
- Also need resources (time-losts) for the researchers and trust employee to get engaged.
- Do we need a system at the institution level?
- Possibly become remote/conservative/institutionalised
- Each project needs to develop relationships with people affected
- Needs to be the norm
- Keep Dynamism
- Current system doesn't necessarily support PPI
- Reality is that 10% of people approached will be interested in being involved in research
- Need training for public on research and need training for researchers on how to work with the public.
- If cant get rid of grant funding, treat public involvement as an overhead so that funding exists for provisional PPI activities
- Don't have the ref, spend the money on a block grant for research - employ researchers on permanent funding, have the money to engage with public etc.
- Each university should dedicate a percentage of post ref funding for public engagement pre – during post research, even if not funded.
- Research to evaluate use of social media to engage with public groups
- University approval needs to ensure that public involvement has taken place.

Next Steps:

- Social media can be useful to identify and engage with members of the public, not expensive.
- Use data from public forums to inform patient outcomes (not participatory)
- Be an explicit part of someone's role to develop PPI relationships (in universities and clinical research networks)
- Ask funders to release money up front to fund development of PPI
- More attention to user led research dedicated funding for user led research.

'A good creative day, I enjoyed the open space format, many thought provoking discussion that I will need to digest''





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Group 5: How can we create a collective story in the NW?

Convenor: Mel Chapman

Participants:

Penny Bee, Catrin Eames, Tracey Williamson, Maria Boswell, Jane Martindale, Jenny Irvine, Andrew Duggan, Fran Westwell, Cara Afzal, Carole Bennett, Jackie Macklin

Key points from the discussion:



1. What is a collective story?

A history of where we started, where we are going and how we have done this.

2. Why do we need one?

- To share our successes and what has worked.
- A collective voice is stronger than individual ones.
- To develop links and share stories and information so we aren't reinventing the wheel, repeating mistakes, or starting from scratch.
- Some sense of standardisation across different activities e.g. payment and expectations.
- Create a sharing culture.
- Coordinate and streamlining – we don't want to lose information / expertise/ knowledge as systems and organisations change or through not being part of the 'loop'.
- Could help with funding.

3. What systems could be developed to create a collective story and share information?

- Mind Map.
- A dissemination network learning from each other.
- INVOLVE website can be hard to navigate and find information. There are lots of websites and information out there and websites can be out of date. NE CRN has a user friendly website with links to other websites: www.makingresearchbetter.co.uk .
- Joint website - this will take time.
- Discussion forum – NHS systems can block access to some forums. Does everyone have access to JISC mail?
- Host meeting with representatives from different organisations. These meetings could be carried out using webinars. It would be useful to set priorities for a year (e.g. case study type presentations) and make sure that they include patient representatives.
- NW Metrics – how many projects have PPI? How many awards for public involvement in research have they got?
- 1 big event annually with all organisations coming together to put on a public involvement in research week or congress to include training and sessions for researchers and non-researchers. This could be during clinical trials week or a different week.

Next Steps:

- NWPiRF and organisations to work together to achieve these



Group 6: When and where should there be PPI input to give the most impact?

Convenor: Nicola Harman

Participants:

Rosie Davies, Anita Maestri-Banks, Claudette Wright, Hugh McLaughlin,
Rumona Dickson, Sue Halton, Susan Povall, Katie Bristow, David Britt,
Tinuloa Odukogbe, Heather Baguley

Key points from the discussion:

- PPI input throughout but need to support people differently for different types of research.
- Should the research questions drive involvement?
- Need to think of PPI as part of a research team. Research teams all have different skill that might be more or less needed at different times
- PPI input needs to be meaningful to the group that researchers are working with.
- Important to involve PPI throughout but can be difficult to achieve particularly in early stages
- PPI can lead to new research questions
- Need to think about needs of the trial at different stage and where PPI is needed
- Evaluate individual aspect as the trial goes along and then evaluate as a whole at the end of the study. This approach would work if PPI input is from different people at different times and does not rely on consistency of PPI representatives.
- Important to have PPI reps on management or steering groups to facilitate ownership of the research. This needs corresponding support and training e.g. peer meeting briefing.
- PPI is very important in dissemination and this should be evaluated. Type of dissemination important e.g. patient presenting as part of clinical conference.
- Important to have defined groups to provide PPI input at different stages and agree involvement at funding application stage and be explicit.

Next Steps:

- What about evaluating pre aware input?



Group 7 : Using altmetrics to demonstrate the benefits of PPI involvement

Convenor: Kerry Woolfall

Participants:

Lucy Cooper, Tim Wilson, Julian Raffay, Heather Baguley, Jonathon Boote
Claire Planner,

Key points from the discussion:

- The vast majority of documents (reports, blogs, conference presentations, discussions) are now held online, contract times on output is viewed and by whom? Potentially an alternative to impact points in addition to everything we already do.
- Using social media more effectively and constructively e.g. how many Youtube hits.
- Looking more closely at how people look at information and share it. Wellcome Trust published a document and workshop on monitory output, so we can track the downloads, view and then share.
- Tool to see who is using PPI outputs and to demonstrate impact. Information for how long someone spends on a website is easy to monitor.
- Useful for organisational reach e.g. website hits, but can it be used successfully in individual projects – useful as a persuasive tool.
- Something marketing companies offer - a way to move away from the traditional academic way of doing things but downloading something doesn't prove someone has read and understood it.
- Difficult to sense if someone has really engaged.
- Still a 'crude' tool/idea at the moment.
- Needs NIHR gateway to act as a platform, do researchers use IT to their best advantage
- How could this be used to 'involve' not just communicate
- Good as a monitory /dissemination tool, could be a project in itself to explore this idea more, could be used as evidence for funder.
- Ethical issues surrounding use of Facebook / twitter/ forums - there is a need to link in with communication experts and assist.

Next Steps:

None Recorded

Group 8 : Who trains the researcher?

Convenor: Chris Houston

Participants:

Sally Hellet, Philip Bell, Jess Zadik, Katherine Allen, Derek Stewart

Key points from the discussion:

- Importance of topic – lack of participation
- Research Applications badly prepared (with regard to PPI) despite HRA (NREC) advocating of PPI
- Accessibility for Patient (e.g. today not everyone can pick up from floor)
- Lack of training for patient and public involvement

Next steps:

- Joint Funding from all interested parties must include patients and public in research report
- Simon Denegri will address these issues.



Group 9: Equality and diversity – Reducing costs incurred by NHS in primary acute and A & E – Freeing up more revenue to be channelled into PPI

Convenor: Peter Lyne

Participants:

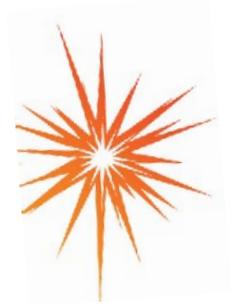
Philip Bell, Soo Downe, Angelina Peterson

Key points from the discussion:

- Identifying specific areas of research – How do researchers select participants?
- PPI involvement normally uses personal experience of patients with appropriate medical conditions

Next Steps

- Benefits of addressing equality and diversity also indirectly creates more inclusive societies and as such also helps towards boosting self esteem and wellbeing of disabled people and individuals with long-term medical conditions. This hopefully would also reduce the need for such patients to undergo further medical or surgical interventions if they have a positive mental attitude.



'I love the 'open space' theme and attended the catalyst event on PT safety in Lancaster, have held many in house events at my trust successfully. A good day, would of liked a few more diverse speakers to talk about their experience in order to help generate more diversity, would of also liked more diversity in attendees but the enthusiasm and commitment to the subject was fantastic!'





Group 10 : Should any research be funded that does not include PPI?

Convenor: David Scott

Participants:

Ekaete Nquot, Sally Kellet, Sarah Galvani

Key points from the discussion:

- Yes, if there is a good enough reason not to e.g. context, nature of research but generally PPI expected in most circumstances

Next Steps

None Recorded

Group 11: How can we use 'evidence' as part of continuous improvement in PPI

Convenor: Roger Steel

Participants:

Hugh McLaughlin, Rumona Dickson, Andrew Horwood, Heather Baguley, Laura Norburn, Jess Zadik, Marisha Palm

Key points from the discussion:

- Asking the right questions, what are we measuring, changing the system or being part of the system?
- Planning from beginning, who is the audience, what is the evidence?
- Why evaluate, who for?



Visual Minute Session 2...





Group 12 : How can patients influence what is researched?

Convenor: Peter J Donnelly

Participants:

Catherine Allen, Carole Bennett, David Scott, Catrin Eames, Michelle Stephens, Jane Martindale, Abdul Hussein, Jenny Irvine

Key points from the discussion:

- Mental Health – what gets researched? Where are RCT studies delivered?
- Where are service users?
- MS Society – What do you want to research?
- Carole Bennett on hack day?
- Engage a professor
- Do something radical; give power to patients/carers by giving them all the health research resources and they can then commission research based on their priorities.

Next Steps:

None Recorded



Group 13 : How best to engage with the public about research

Convenor: Andrew Duggan / Fran Westwell, Christine Birchall

Participants:

Francine Jury, Lucy Cooper, Rita Long, David Britt, Christine Birchall, Jane Martindale, Maria Boswell, Sue Halton, Tinuola Odukogbe, Sally Kellet, Philip Hammond, Tim Wilson, Teresa Moorcroft, Kim Doolan, Claudette Wright, Sarah Graham, Angelina Peterson, Jonathan Boote

Key points from the discussion:

- Journal of engagement and involvement
- Citizen Scientist (Salford Royal) opportunity to get involved in event – 2000 people on desk list
- Cancer research needs to be promoted (PR exposure)
- National campaigning needs interest in PR and promotion
- NHS free care receiving initial incentive – public role taken for granted
- Benefit of research is not sold effectively
- Need a push to put research on a standard health agenda – not separate
- Close links with other sectors (local charities and schools) to collaborate and explore the message.
- Be more proactive with opportunities.

Next Steps

None recorded



Group 14 : How a disease model of mental distress can be replaced by a social model of mental distress

Convenor : Tim Wilson

Participants: Katherine Allen

Key points from the discussion:

- Ideology and myths of Psychiatry
- Discussed illness ideology
- Chemical imbalance ideology
- Diagnosis ideology
- Drug illness model as opposed to drug induced model
- Compulsory treatment order
- Medicalization of mental distress
- Marriage of convenience of neo liberalisation
- Vested interest of industry of psychiatrist and psychological professions (some)
- Big pharma – bad research – profits
- Alternatives to diseased model – have a social model, open dialogue, reduce income gap.
- Governance (individualising issues)
- Control of population – stopping of distress leading to social change
- People are annoyed, angry, discontent, agitated – should be a catalyst for social change
- Politicise – not medicalise
- Issues of power and knowledge
- Peter Sedgwick (1982) psychopolitics and legitimacy crisis
- Psychiatry and mental health services now in crisis
- Welfare now in crisis
- Failure of left (no left left) to engage with mental distress (relevant to 2015)
- Social issues – Richard Wilkinson last 40 years talked about relevant income differences
- Gap between rich and poor widening
- Class social inequalities in health widening since 1979
- Food banks, poverty nearly a million people sanctioned by the DSS last year
- Many critical groups wanting changes in mental health services e.g. hearing voices network
- All implications for research need new perspectives using social model

Next Steps:

None recorded



Group 15 : Using real time experience to generate research ideas

Convenor : Jackie Macklin and Cara Afzal

Participants:

Philip Hammond, Jess Zadik, Claire Planner, Derek Stewart, Mel Chapman, Philip Bell, Sally Kellet, Neville Gregory



Key points from the discussion:

- Capturing patient experience in real time using apps for audit to be linked to research
- Mixing community with specific health needs
- What is real time data?
- Concerns around promoting feedback and how it impacts care
- Suggestions box – How can it be better?
- Encouraging NHS and use information collected everyday e.g health app data
- Incorporating patient generated data into the clinical record
- Creating a research active population, engaged in research including staff
- How do we engage the 'seldom heard' Demystifying research – taking research to the community, cultural differences on the views of research
- Empowering staff to use patient data to generate research ideas (not excluding professionals)
- How do we collect real time data?
- Ethical issues around collecting real time data

Next steps

None recorded



Group 16 : Why do we have to demonstrate the benefits?

Convenor: Irene McGill

Participants:

Laure Norburn, Jess Zadik, Philip Hammond, Peter Donnelly, Roger Steel,
Katherine Allen, Mick Mckeown, Chris Houston, Martin Morris

Key points from the discussion:

- We don't we evaluate other clinicians etc?
- Why do we have to evaluate when PPI is so good?
- Legitimate reasons – we need to learn from what we do
- Funders don't value PPI
- Complex
- Always measure the intrinsic value
- Moral status- measure impact
- Is it about justification
- Moral or ethical reasons democracy ownership
- Expert Patients
- Reference models of democracy to reach consensus
- Improves quality of the research and patient benefits
- Changing outline / legislating change along with public consciousness
- Please stop asking us to justify ourselves



Next steps:

None recorded

Great Day, innovative and thought provoking, very creative – visual minutes were a great idea to keep key points in mind and revisiting. Nice collaborative and networking feel, thanks!

Visual minute Session 3...



Summary

This summary is for the purposes outlined at the outset; that is to make notes of the dialogue and to circulate this to the participants as a reminder of discussions and to locate individuals who were involved or who have since expressed an interest to be kept informed.

There are several themes common across different groups. These include:

- Engaging patients and the public in evaluating the impact of their involvement in research.
- Measuring the long term impact of Patient and Public Involvement in research
- Enabling patients and the public to set the research agenda

It is also suggested, to further increase the success of the event that those who want to lead research or who have some ideas for a new project could provide a short summary to be sent to attendees of the event in case any of the research ideas were missed on the day.



Next steps

The Event Report will be circulated to participants and other interested parties. It will also be available to the general public on our website. Contact details can be circulated to Discussion convenors on request to facilitate the further development of the proposals outlined. NHS R&D NW may contact discussion convenors to ascertain what additional support is required to maintain momentum and track progress of bid development / successful application for research funding.

NHS R&D NW will be working closely with the Northwest People in Research forum to consider the further development of the topics discussed on the day.

NHS R&D NW would appreciate ongoing feedback with regards to the progress of any of the issues raised on the day from any of the people who attended the event even if they were not a discussion convenor.

Thank you to everyone who attended and contributed to all the discussions detailed in this report and a big thank you to the convenors for raising their questions.



Postcard feedback from the day

- *Great Day, innovative and thought provoking, very creative – visual minutes were a great idea to keep key points in mind and revisiting. Nice collaborative and networking feel, thanks!*
- *A good creative day, I enjoyed the open space format, many thought provoking discussion that I will need to digest and develop learning from*
- *An informative event, thank you!*
- *I love the ‘open space’ theme and attended the catalyst event on PT safety in Lancaster, have held many in house events at my trust successfully. A good day, would of liked a few more diverse speakers to talk about their experience in order to help generate more diversity, would of also liked more diversity in attendees but the enthusiasm and commitment to the subject was fantastic!*
- *It has been an excellent day with a lot of ideas to help improve my research and patient involvement, thank you very much.*
- *Great event – thought the open space format worked really well. Lots of really great ideas, enthusiasm and determination, thanks for organising it!*
- *Thank you for a great day. This was an excellent opportunity to network with various organisations involved in PPI. A food for thought is the venue is absolutely gorgeous but occasionally throughout the day it was hard to hear others speak and sometimes drafty.*
- *Thank you, a really good sharing experience. Well organised and a good cross section of people attending.*
- *Whilst I thought the open space approach was interesting I felt that there was a lack of guidance on the agenda setting session. This resulted in a number of discussions that were off topic and not particularly useful. It would have been much better to have had someone provide oversight of the agenda items and either amend them to bring them back to the topic or to suggest that they are saved for another meeting.*

