Patient and Public Involvement - approaches and techniques workshop

30th May 2017 Workshop Report

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1. Introduction to workshop and introductions exercise

Workshop objectives

- Explore the techniques and approaches that can be used in successful involvement of patients and the public in four outcome areas; raising awareness, working towards shared goals, developing priorities and/or consensus and identifying and planning to reach target audiences.
- Reflect on the potential benefits and drawbacks of all these techniques, then delegates will experience one technique/approach - in depth
- Reflect on how delegates found the afternoon exercise and how they can use these techniques and approaches in their patient and public involvement activity

1. Introduction to workshop and introductions exercise (2)

- An introductions exercise on each table included participants sharing experiences and perspectives in patient and public involvement - completing a PPI Bingo sheet as they went

- Each table then shared one of their 'Bingo Box' activity and what they had learnt in the process of doing that PPI activity. Sally introduced some ways of working together effectively for the day.

2. Patient and Public Involvement – 'starting as we mean to go on'

Following group conversations about important considerations for good patient and public involvement - the following themes emerged;

- **Remembering the WHY of PPI** - an important consideration for any PPI activity is to keep the purpose and aspirations of the activity clear for everyone, and at stages take a step back and reflect on what is being achieved (or not).
- Important to remember that different people will have different motivations to take part and these are best surfaced and discussed as part of the PPI process.
- **WHO takes part in PPI?** Some participants expressed their frustration in finding people to take part.....it depends on target groups but 'hard to reach' and 'difficult to interest' came up in the conversation. Other participants had had positive experiences of working with diverse groups of people and critical success factors seem to include;

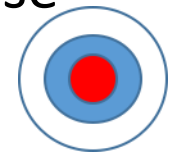
2. Patient and Public Involvement – 'starting as we mean to go on' (2)

- **Be mobile and prepared to go where people are** - shopping centres, elder groups, parent and baby groups, community groups
- **Don't expect people to come to you**.....people are busy leading their lives only a few will be able to come to where you are.
- **Find out what people are interested in and work from there** - don't go in hard with your agenda - find where there is middle ground and shared interests
- **Be open to new ideas**- you (as service provider or researcher) may have a rather fixed view of what needs to happen in PPI - let that go a little bit...you can still be focused on your goal but be broadminded!
- **Beware the 'gatekeepers'** people that want to (and can) speak for others can be very helpful, but may also want to control who you could speak to....
- **Take a broad view of what is representative** - unlike research participants (who may need to fit certain criteria of representativeness) PPI is different - you are after insights and perspectives, ideas and suggestions and these can come from a variety of places but need not necessarily reflect all the areas of interest e.g. if you are co designing a clinic you need to work with people that might use that clinic and a variety of these is preferable

2. Patient and Public Involvement – 'starting as we mean to go on' (3)

- **Be aware of your language and how you communicate** with people that you want to engage or involve. This is a real potential barrier to working effectively together. Most PPI guides and frameworks give advice about this.
- **Manage expectations** - be clear about what can change as a result of PPI e.g. don't consult on things that either you don't want to change, can't change or have already made your mind up about - it's a waste of your time and more importantly the publics'.
- **Keep a handle on the practical and often small things** - they make a difference; don't forget the common courtesies of working with people.
- **Remember to feed back** to your involved people/communities about the impact of their contribution and what might change in healthcare or research

- General PPI guidance and examples of PPI Values and Principles that reflect these themes are in Appendix 4.



3. Topic areas overview

A series of short presentations on the following areas are available at ;

1. **Increasing awareness** - using social media - what's available, how to get your messages across, how do you know you have made an impact?

3. Topic areas overview (2)

2. **Achieving a shared goal and direction** - some theory about appreciative enquiry and coaching and how it differs from problem solving approaches

Co Production

- *Co-production is not just a word, it's not just a concept, it is a meeting of minds coming together to find a shared solution. In practice, it involves people who use services being consulted, included and working together from the start to the end of any project that affects them.**

* Think Local Act Personal (2011) Making it real: Marking progress towards personalised, community based support, London: TLAP.

3. Topic areas overview (3)

3. **Developing priorities** - using discussion, ranking and voting for establishing important items, issues, questions - some theory and frameworks

Health research priorities

- **missing in action**; not happening
- **missing the mark**; not resonating with our public
- **missing the point**; sometimes focusing on the wrong thing

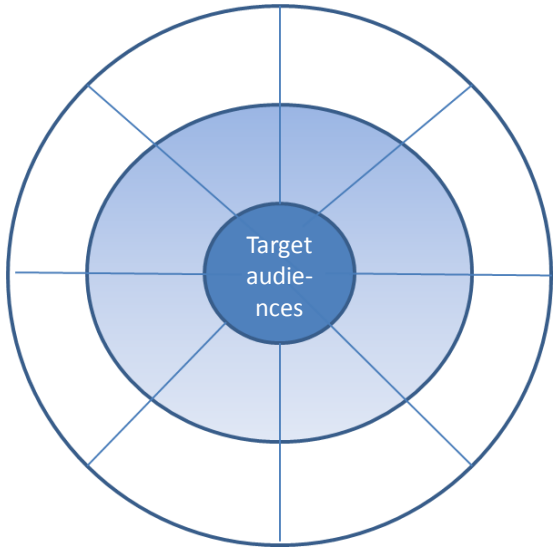
- Adapted from www.cruxcatalyst.com

3. Topic areas overview (4)

4. **Identifying and planning to reach target audiences** - mapping communities of interest and communication strategies

How?

- Map relevant communities of interest, third sector organisations etc. i.e. *routes* in to your target audience(s)
- Design appropriate *communications plans* e.g. flyers in community centres/GPs, talks at local meetings of charity groups, use social media



4. Afternoon group work, discussion themes and key messages

Group 1: Increasing awareness through Social Media

- The group first identified personal barriers and enablers in using social media.
- **Barriers;** being over loaded with information, exposure of personal details, excludes those without technology, fear of sending out inappropriate messages, messages can't be erased, wading through the 'rubbish', needs time to do...
- **Enablers;** easy to use, reaches lots of people (including younger people), messages travel fast, brings people together (maybe from different parts of the world), can we tweaked to meet different types of people.....
- The research under focus for this exercise found that people consistently consume 16% more food or non-alcoholic drinks when offered larger sized portions, packages or tableware regardless of gender, BMI, susceptibility to hunger and degree of self-control in relation to food.

The task was to create a social media plan to increase awareness of this research. Group 1: Increasing awareness through Social Media

What are your aims?

- To reduce childhood obesity.
- To reduce adult obesity
- To educate the population
- To make people healthier.

Who is your target audience?

- Parents
- Children
- School teachers
- GPs
- Manufacturers and packagers

What are your key messages?

- People need to change their behaviour
- People can reduce calories with very little effort

What will you make and share?

- Facilitator's advice was only to tweet with a photo – but to make it impactful. For example we discussed a pizza with a 16% slice taken out of it to demonstrate the findings. We would also try to 'piggy back' onto existing campaigns – so for example on national chip day we would tweet pictures of a portion of chips alongside another portion 16% smaller.
- Consider; clear info graphics, video clips, games or anything interactive e.g. twitter poll where people could say how many calories they thought something had? Before we show what the answer is and what 16% off mean, animals – yes really - as cute as possible!

The task was to create a social media plan to increase awareness of this research. Group 1: Increasing awareness through Social Media

Which groups can help share messages?

- County council bulletins to all schools
- Organizers of Children's Centres
- GPs
- School nurses through their professional body or through 'We school nurses' online
- Teaching unions
- Paediatric dieticians
- Tweet a celebrity and ask them to re-tweet, they may do so if it interests them

What are the barriers?

- Language needs to be simple, non-emotional and not too flippant
- Constraints could be political, ethical or organisational
- Risks might be that you just miss the group you are aiming for, that the message is misunderstood or that there is a Chinese whispers effect on your message.
- It is important not just to rely on your own followers
- Timing, don't post something just before you go on holiday!

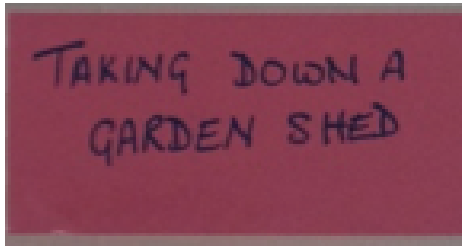
Social media key message: **Remember to share, watch and respond**

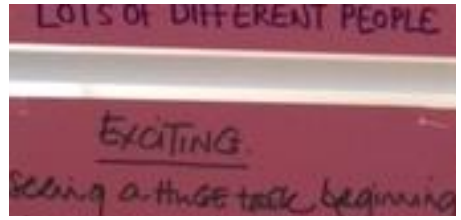
4. Afternoon group work, discussion themes and key messages

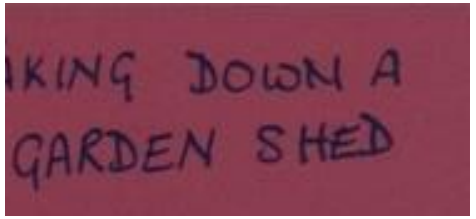
Group 2: Achieving a shared goal and direction

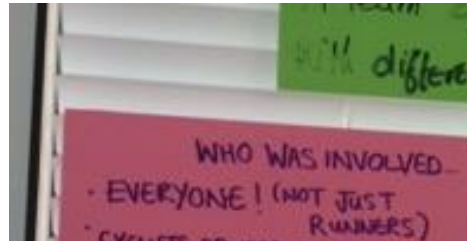
- The group looked at co-production with an introduction that invited people to revisit a positive life experience (possibly the one they had thought about in the main plenary?)
- In relation to the experience we were asked to consider:
  - What made it exciting?,
  - Who was involved?,
  - What strengths did you use?

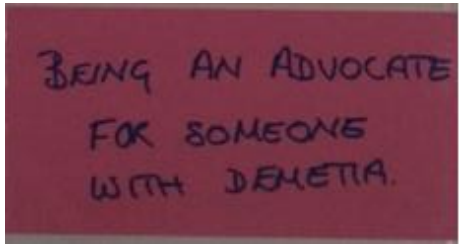
...and we post-it noted the thoughts, some of which looked like this.

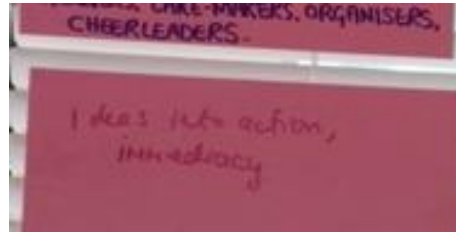












Achieving a shared goal and direction key message : ***Search for and amplify solutions that already exist***

4. Afternoon group work, discussion themes and key messages

Group 2: Achieving a shared goal and direction

An interactive exercise called:

The Hopi Indian Boy Exercise

led us into the principles of Appreciative Inquiry....

A ram belonging to the Hopi tribe..

- **Developed by Cooperrider and Srivastva in 1987**
- **An organisation is a 'miracle to be embraced rather than a problem to be solved'**
- **Inquiry into organisational life should have the following characteristics:**
  - **Appreciative - looks for the positive**
  - **Applicable - practical and grounded in reality**
  - **Provocative - encourages risk taking**
  - **Collaborative - involves everyone**

4. Afternoon group work, discussion themes and key messages

Group 2: Achieving a shared goal and direction

Appreciative Inquiry Assumptions

- **In every group or organization, something works**
- **What we focus on becomes our reality, if we look for problems, we will find them …and make them bigger**
- **Search for and amplify solutions that already exist**
- **People have more confidence to journey to the future (the unknown) when they carry forward parts of the past (the known)**
- **If we carry forward parts of the past, they should be the best bits**

4. Afternoon group work, discussion themes and key messages

Group 3: Developing Priorities

This group decided to develop a process to establish priorities for dementia - a process flow for the priority setting was achieved with post-its of key information and decisions.

Discussion centered on;

- Creating interest and motivation for members of the public to get involved in priority setting
- Identifying who needed to be 'in the room' (relevance to dementia, diversity and who has the power to make change)
- Who could contribute in other ways (i.e. outside the room)
- Addressing all the potential barriers that might prohibit involvement in the process
- Importance of good chairing and facilitation of the process by people who know how to involve the public
- How to build into the process opportunities for reflection and rest (acknowledged that priority setting meetings can be very tiring)
- Ensuring that there is an appeal process for priorities
- Interestingly for the group the methods for prioritization, whilst important, did not take up the majority of the conversation...

4. Afternoon group work, discussion themes and key messages

Group 3: Developing Priorities

Participants in this group reflected on what they had learnt in this session;

- The importance of organization and planning for a priority setting process, in order for it to work for patients and the public additional considerations were made, such as how information for priority setting would be communicated and presented
- The value of including perspectives of people who weren't able to participate in the priority setting workshop and this could be done via a survey
- The value of including different perspectives from patients and the public when planning and designing priority setting processes
- The importance of the small details that enable patients and the public to fully participate in the process e.g. organizing travel, doing ice breakers and exercises to get people working together for the priorities

Priority setting key message:

Don't underestimate planning and detail needed to ensure patients and public can participate fully in the process

4. Afternoon group work, discussion themes and key messages

Group 4: Identifying and planning to reach target audiences

- The group introduced their own projects and plans for PPI and then decided to focus upon one project and worked on a stakeholder map and communications strategy.
- **Project:** Expanding the CLAHRC diet & obesity study PPI panel.
- **Detail:** Expanding an existing PPI panel which arose from participants of the BBC Horizon 'The Right Diet for You' programme with Susan Jebb & Paul Aveyard. Need to recruit more local participants so that we can hold more face to face meetings and activities. Due to the range of studies the group are conducting, this panel will be of interest to anyone who does food shopping, has an illness that can be managed through an aspect of their diet, has lost weight or who would like to lose weight. Men have been harder to target in the past, we would like to increase the number of men on the panel.
- **Stakeholder mapping:** was recorded on a map see example in Appendix 3

4. Afternoon group work, discussion themes and key messages

Group 4: Identifying and planning to reach target audiences

People to target:

- Oxfordshire & wider Thames Valley area
- Are there any publications to help us target people? This could include local public health statistics
- Specific health conditions that can be controlled by diet e.g. diabetes

Existing groups/routes of access:

- Weight loss groups e.g. weight watchers, slimming world – contact leader; could give a leaflet to hand out or do a small presentation
- Men's Shed, Oxford
- Community centres/Children's centres/other family oriented centres – although we are not looking to involve children in our research these places would be an access route to their parents.
- Formal & informal trusted intermediaries/gatekeepers – for example in religious leaders, places of worship, sports clubs
- Information stands/activities in supermarkets
- Cooking groups
- Schools & school linked activities
- Spread message through colleagues and use their connections
- Restaurants
- Gyms/sports clubs/sports games

4. Afternoon group work, discussion themes and key messages

Group 4: Identifying and planning to reach target audiences

Discussion points:

- Targeting a broad group of people is a challenge; time was spent thinking about how we could break this down further which helped identify more specific groups of people.
- Can we reach a diverse range of people in Oxfordshire? We can access minority groups in the Oxfordshire area, e.g. OX4 postcode consists of over 17 ethnic groups, 8 religions and over 79 languages spoken. Ways to access these need to be identified.
- Time and effort can be spent targeting minority groups but we still need to keep the sample representative of the population being studied
- Community asset analysis can help map groups and routes to target in the community. This can include organisations like religious centres, charities, pubs, parks, gyms. Contact community champions e.g. artists, DJs, GPs to get their buy in. Sometimes it might not be appropriate for the researcher to do this themselves, can recruit a volunteer to go into an area/be a contact for the targeted community.
- What time and resources do we have available? Can we adapt to the needs of the PPI group e.g. meetings in the evenings, hold meetings in the community etc.
- Communications strategy should include ongoing communications to keep PPI group informed and updated on research projects.

4. Afternoon group work, discussion themes and key messages

Group 4: Identifying and planning to reach target audiences

Communications strategy

- What is our objective? To increase our PPI panel with a focus on local people and diversity
- Develop activities that meet the needs of the research groups so we can give examples of the things people might be able to get involved in. Communication of benefits of being involved in the panel to potential new members. The benefits to them are likely to be different from our research outputs.
- In designing the communications strategy we could consult current members of the panel.

Reaching target audiences' key message: even if your target audience seems broad you can break it down into segments, with more defined characteristics

5. Workshop Feedback

25 people completed an evaluation form, not everyone answered every question, and scores are in this table

Please tick in the box that most reflects your experience of the day	Strongly Agree	Somewhat Agree	Neutral	Somewhat Disagree	Strongly Disagree
The booking process worked well	16	4	2		
The preparatory information was helpful and adequate	18	7	4		
The venue was easy to find & access, and comfortable	17	3	4	1	
The catering was fine	19	3	1	1	
The workshop was about the right length	18	4	1	2	
The facilitators knew their subject well, helped everyone participate and imparted information clearly	23	2			
There was enough time for discussion	20	5			
Overall I am glad that I attended	21	4			

5. Workshop Feedback (2)

What did people enjoy and/or find useful about the workshop?

The afternoon group work was popular with many participants with a smaller number valuing the morning session and presentations. As usual networking played an important part to the day, especially for those new to PPI. The insights of service users was positively mentioned several times and general sharing of ideas and approaches helpful. For some the opportunity to take a step back and reflect on PPI was valuable. The different skills, perspectives and knowledge of the facilitating team received positive feedback

What would people improve?

Despite the high scores for the day there was lots of constructive feedback and ideas for future events including; more depth in some areas, how to translate these ideas to national projects, more practical PPI help, and being able to take part in more than one break out session.

Practically some people wanted copies of the presentations on the day and more information about the afternoon group work and shared contact details, another participant asked for the resources to be sent out quickly.

Some participants wanted a shorter day, but not all, perhaps not helped by the stuffiness of the room and more 'moving around' for refreshments etc

5. Workshop Feedback (3)

What will people do as a result of the workshop?

- Increased social media activity was cited by several participants. Developing relationships and increased contact with PPI group to help encourage their input. Managing PPI astride other roles is a challenge for some and one participant decided that they were going to
- allocate time each month 'to attend to PPI so that it doesn't get pushed aside', others were going to review strategically, develop a strategy and take a more active PPI role in their trust For some it was about 'keeping it simple'.

09.00	**Registration and refreshments**
09.30	**Expectations for today and how we will work together**
10.15	**Patient and Public Involvement 'starting as we mean to go on'** • Shared understanding of terms, values and principles
11.00	**Refreshment break**
11.20	**Four approaches and techniques - overview** 1. Using Social Media - Sarah Chapman 2. Achieving a shared goal and direction - Sian Rees 3. Priority Setting and Patient and Public Involvement - Sally Crowe 4. Reaching target audiences - Sandra Regan
12.30	**Lunch break**
13.30	**Small Group Work - discussion, case studies and group task** • **Increasing awareness using social media** – this could apply in research, health services, key public health messages, calls for consultation etc • **Achieving a shared goal or strategic direction** – this could apply in setting up health projects, research steering committees or community work • **Developing priorities** – this could apply to research priorities, decisions about health services, or deciding important outcomes to measure in healthcare • **Identifying and planning to reach target audiences** – this could apply to seeking changes in health services, or finding out what is important in communities
15.15	**Refreshment break**
15.45	**Highlights from group work experience, what can be implemented?**
16.30	**Workshop finishes**

Appendix 1. Workshop programme

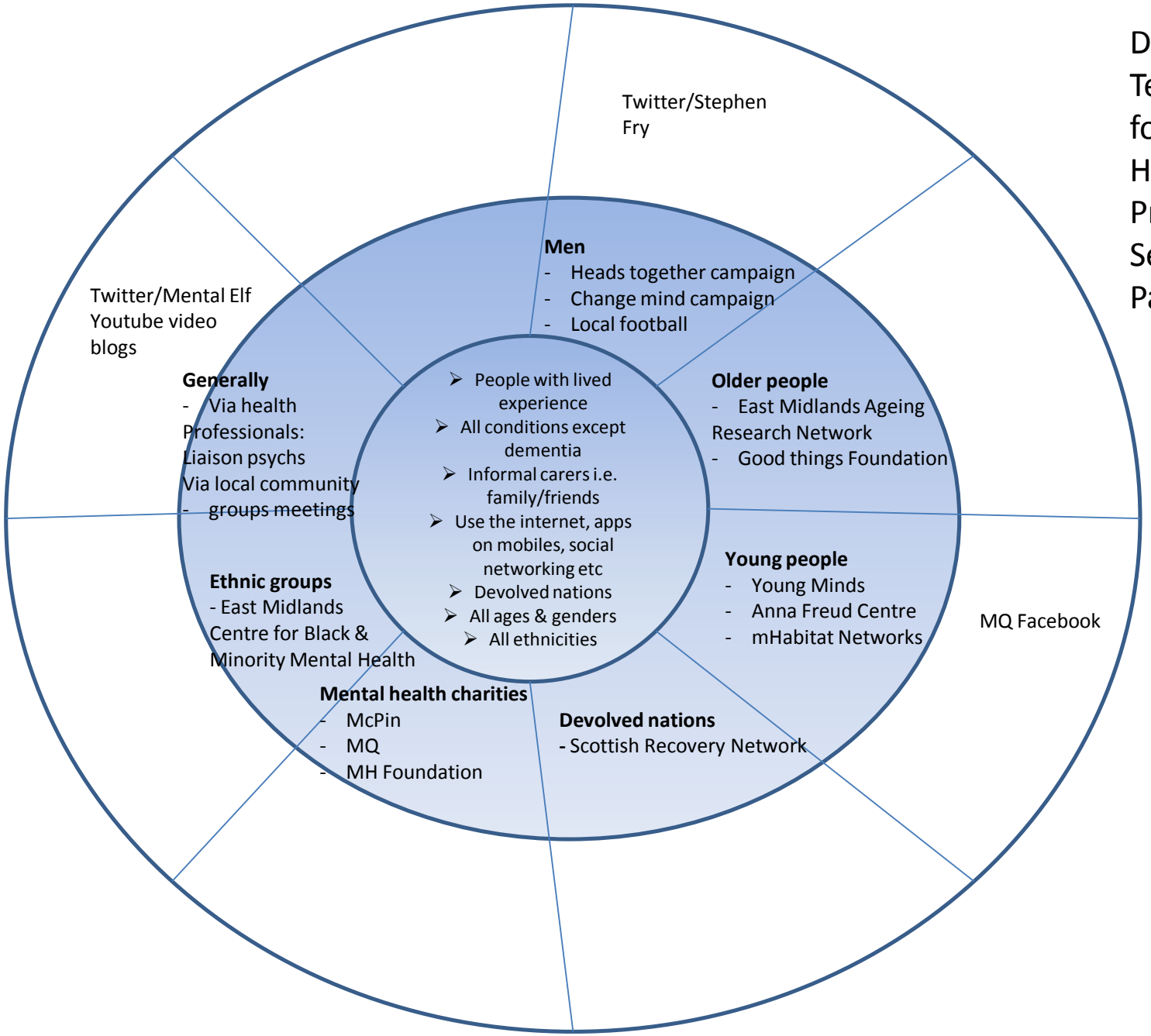
Appendix 2. Introductions PPI Bingo

Patient and Public Involvement (PPI) Bingo

I have chaired a meeting, involving the public	I have presented research and/or PPI work at a conference	I have designed /completed a consultation survey
I have 'manned' a poster or display at an open day		I have co produced a research paper/project report
I have been a healthcare/ research panel member	I have co-produced a research question or plan	I have assessed health services quality & safety
I have organized a public healthcare meeting	I have given feedback about a healthcare experience	I have written a blog or article about patient and public involvement

Appendix 3. Stakeholder Mapping Diagram - Example

Digital Technology for Mental Health Priority Setting Partnership



Appendix 4. Additional Resources

Social Media

- **Cochrane UK** social media resources page http://uk.cochrane.org/social-media-resources
- **Evidently Cochrane blog** http://www.evidentlycochrane.net which has several blogs about using social media for health. I've very recently written about our use of social media to disseminate one review: http://bit.ly/2qeSpyU
- Cochrane **blogshots** and **vlogshots** are shared on Twitter, Facebook and Instagram but are also archived on Tumblr
- Different groups of online health special interest groups
- **WeCommunities** http://wecommunities.org
- For those wanting to get going on Twitter, or improve their Twitter use http://wecommunities.org/resources/twitterversity

- **Values and Principles in PPI, Standards for PPI**
- **INVOLVE Values and Principles for public involvement in research**
- **http://www.invo.org.uk/wp-content/uploads/2015/11/Values-and-Principles-framework-final-October-2015.pdf**
- **Patient and Public Involvement in Quality Improvement (HQIP)**
- **http://www.hqip.org.uk/media/PPI%20in%20QI.pdf**
- **National Voices 'I Statements' for good quality and integrated care**
- **http://www.nationalvoices.org.uk/publications/our-publications/narrative-person-centred-coordinated-care**
- **Public Involvement Standards Partnership (consultation mid June - mid July 2017)**
- **https://sites.google.com/nihr.ac.uk/pi-standards/home**