

Public Involvement in Research: Navigating the Labyrinth

- Based in my experiences and observations
- Useful for both applicants and potential lay committee members
- Rise of Public Involvement in Research
- Expectations of Lay Representatives
- Five key areas of research applications

Navigating the Labyrinth

- Seeking research funding is somewhat of a labyrinth
- Public involvement adds another strand to the process
- The culture shift to public involvement gives applicants the opportunity to strengthen their application
- Or indeed weaken it!

Public Involvement in Research

- Public Involvement in research has grown in last 20 years
- And particularly in the last 5 years
- This includes many different groups with different journeys
- For me it has been via the disability movement

Health Interventions and Disability

- Many interventions lacked any serious research
- What there was often neither valid or reliable
- Ignored peoples rights
- No say in what was done to them
- How safe it was
- Long term impact
- Ranged from benign, to dangerous, to the inhuman

Public Involvement via Disability Agenda

- Disability Movement became radical in 1970's
- Successes from the 1995 DDA to 2010 Equality Act
- Still Radical – reflects continuing inequality
- In June disabled people interrupt PMQs
- Shift from Medical Model to the Social Model
- From 'we know what's good for you' to person centred care
- 'Nothing for us with out us'

Empowerment

- There has been general shift towards public involvement in all aspect of health and social care
- This has empowered groups including disabled people
- These groups are more confident , knowledgeable and articulate
- This includes public involvement in research
- Because of their various journeys lay representatives in research funding tend to quite tough and hardened
- But friendly , ultimately fair and importantly want to see good successful research

Lay representation

- Lay people have to represent a wide range of the public
- Many lay reps are white, middle class and of a certain age! Thankfully this is slowly changing
- They particularly want to represent those who cannot easily speak to themselves

Five key areas of an application

- What are the benefits
- The plain English description
- Respondent recruitment and treatment
- Lay representation in governance
- From research to practice

Benefits

- Not always easy or straightforward
- Breath and Depth Test
- Individual, NHS, Socio-economic, VFM
- Not definitive but will influence final scoring

The plain English description

- This is where most lay people will start - so be sure to get it right
- If you can't write what you want to do in plain English do you actually know what you want to do?
- Don't use complex medical terms:
- *A multi-centre double-blind randomised sham-controlled phase-2 efficacy cross-over trial*
- Do: make sure you include all the parts of the project;
- Do test it somebody who has no medical knowledge

Respondent recruitment and treatment

- We all know that one of the biggest problems with research is recruitment.
- Looking for this issue being address both in time, resources and approach
- Active/informed consent – use of advocate
- Identifying problem areas
- Random controlled trials add an extra twist to recruitment.
- Never believe that recruiting from GP practice is the solution!

Lay representation in governance

- For me there are three models of public involvement:
- Co-production –strongest model
- Co-operation – often used
- Consultation – weakest model -even weaker if it is prospective.
- Look out for ‘*We will be consulting with.....*’

Lay representation in governance

- Good Public Involvement would include:
- Co-operation in application development
- Gather the views of patients/carers
- Talking to relevant charities
- Patient/Carer as co-applicant
- Two representatives on Steering Committee
- An Advisory Group
- Training
- Payment and expenses for all those involved

From research to practice

- Key issue for lay representatives
- How does good research become good practice?
- Dissemination includes:
 - Peer reviewed articles
 - Prestigious conferences
 - Information for patient groups/charities
- But need for more thought about how to bridge the gap between research outcomes and practice

Conclusion

- If you pay attention to these five areas
- Benefits, plain English summary, respondents, governance and research into practice
- You could have stronger applications
- More support from lay members
- Better chance for good research



Thank You

Richard Parnell

Email: r.parnell1@ntlworld.com