

# Public involvement in research

Andy Gibson, Associate Professor Patient and Public Involvement, UWE

Jo Welsman, Engaged Research Fellow, Centre for Biomedical Modelling and Analysis, and Co-Chair Lived Experience Group, University of Exeter

LEN Network Showcase, December 7<sup>th</sup> 2015

Promoting a strong public voice...



People in Health  
West of England

Better involvement · Better research · Better health

“I have always taken the view that public involvement in research should be the rule not the exception.”

Professor Dame Sally Davies, Director General of R&D,  
Department of Health

# Organ Retention

‘We were quite keen that Kate’s organs should be used for transplant purposes, and I suspect that, had we been asked, we would not have minded her organs being used for educational purposes. We did not know, however, and it came as a terrible shock to me to learn that some of her organs were retained.’

Lynne Lloyd in evidence to the enquiry

# Why involve the public in research?

- Ethical argument – “nothing about us without us”
- Pragmatic argument – evidence of involvement increasingly required by the National Institute for Health Research (NIHR) and other research funders
- Evidence-based argument – involving the public improves the quality and impact of research

# Impact on research design & delivery

- Project design
- Research tools
- Recruitment
- Data collection
- Analysis of data
- Writing up
- Dissemination

# Diabetes Intervention for Agenda Trial (DIAT)

- Question came from someone with diabetes
- Involvement in bid design and as co-applicants
- Ethics application
- Members of project team
- Presenting at conferences
- Qualitative data analysis
- Dissemination

## How and why did I get involved?

### Lived Experience Group (Mood Disorders Centre, University of Exeter)

- Group of 20 individuals with lived experience of depression or bipolar disorder or their supporters.
- Role: To support the work of the MDC through involvement in research, recruitment, teaching and more widely to increase public awareness of mental illness and reduce stigma

### Peninsula Public Involvement Group (PenPIG)

- Support the research of the Peninsula CLAHRC - research projects/research prioritisation/research question generation etc.

# Why is public involvement important?: A personal perspective

e.g.

Understanding of psychological theories  
Neuroscience of depression  
RCTs of talking therapies and drug trials

Symptoms / effects on QOL  
Drug treatments/Side effects  
Talking therapies  
Primary/secondary care

Both are essential if research is to benefit future patients



# Conception to Dissemination (and beyond!)

## How the public can help....

### **Research question generation/prioritisation**

Workshops, Focus Groups

### **Ethical considerations**

Patient information sheets/consent forms

Obtaining ethics in difficult situations

### **Designing research protocols/research tools**

Questionnaire design, Acceptability/feasibility

### **Evaluating research**

Taking part in workshops/conference presentations

### **Dissemination/implementation of research findings**

patient led event/workshops/focus groups

# An example of "End to End" patient involvement

e.g. The BAc PAc Study



Patient involvement included and appropriately costed in the original grant proposal (MRC)

PI in all aspects of the study from logo design onwards:

Management Committee

Trial Steering Committee

Commented on the ethics submission

Run/involved in 3 focus groups around informing the study protocol

Presented a poster at West Hub MHRN conference

# What's in it for me?: Is patient involvement a one way street?

- Opportunities to learn - new skills/old skills, understand own condition
- Opportunities to meet others with similar conditions
- Opportunities to make a contribution - to feel useful/improve experiences for future patients
- Opportunities to experience new therapies
- Opportunities to present at conferences/deliver workshops /lectures etc.

# Resources to support public involvement in research

- INVOLVE – NIHR advisory group and coordinating centre  
[www.invo.org.uk](http://www.invo.org.uk)
- People in Health West of England – regional initiative to support public involvement in research

[www.phwe.org.uk](http://www.phwe.org.uk)



People in Health  
West of England

Better involvement · Better research · Better health

# Thank you

Please visit us at:  
[www.phwe.org.uk](http://www.phwe.org.uk)

---

Better involvement · Better research · Better health