



PURSUN
The Pressure Ulcer Research
Service User Network UK

Public Involvement and PURSUN UK

Kay Walker and Delia Muir

Leeds Institute of Clinical Trials Research



Session Outline

- Public Involvement in Health Research
- PURSUN
- Kay's reflections as a PURSUN member
- Delia's reflections as a facilitator
- Questions and discussions

Public Involvement

- Not a completely new approach (e.g. community based, participatory, emancipatory research).
- New (ish) in this context.
- Research being done ‘with’ or ‘by’ particular communities, rather than ‘to’ them.
- Partners or leaders, not subjects



Public Involvement

Why the recent growth?

- **Policy** e.g. the Department of Health, Universities
- **Moral / ethical argument** – People have a right to influence research that may ultimately impact on them.
- **Impact on research** e.g. relevant questions, better designs, better recruitment, more impact.
- **Empowerment** – has the potential to be rewarding experience for the people involved.
- **Activism** e.g. the disability rights movement

Public Involvement and Pressure Ulcers

Despite a general increase, there was still little involvement in pressure ulcer research. Why?

- Complex health needs of the patient population
- Previously no infrastructure to support the work
- Often seen as a secondary problem

The Pressure Ulcer Research Service User Network

- Set up by the University of Leeds
- Network of people with personal experience of pressure ulcers or pressure ulcer prevention
- Includes patients, carers and family members
- Members draw on their personal experience to inform research

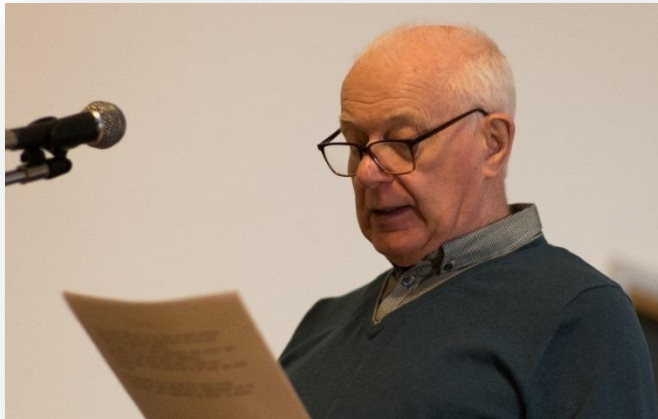


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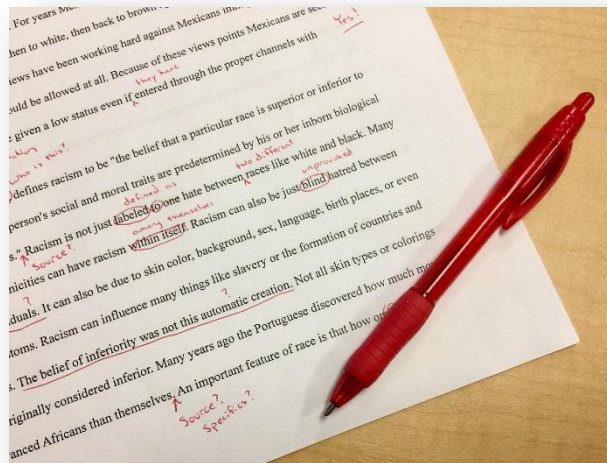
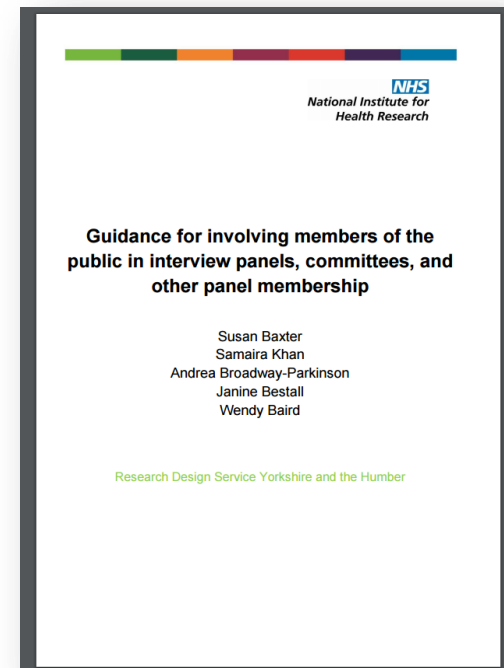
PURSUN activities include:

Designing research e.g



Speaking about our experiences at events

Developing guidance for others



Writing and reviewing

Kay's Reflections

What have I gained?

- Peer support and identifying with others
- Productivity - Something in the diary which isn't a medical appointment.
- You build networks.
- Learning opportunities.
- Get your 'sense of self' back
- The way that it is set up means that you can contribute despite health problems / medical appointments.

Kay's Reflections

What are the challenges?

- Lack of feedback at times.
 - Feedback between PURSUN members
 - Feedback from researchers
- Lack of momentum when we don't get together on a regular basis.

Delia's Reflections

- Members bring different strengths - capacity building approach.
- Need to be flexible
- Trust - pros and cons.
- Funding
- Challenges of working with industry
- What to do when things go wrong e.g. inappropriate behaviour from a member / researcher.
- Lots to learn from other fields

Thank you for listening!

www.pursun.org.uk
d.p.muir@leeds.ac.uk
0113 343 8609