Patient intelligence: data, discussions, decisions

MedComms Networking
13 March 2012

Sandy Oliver
Professor of Public Policy
www.ioe.ac.uk/ssru
Acknowledgements

Seilin Uhm, Kristin Liabo, Ruth Stewart, Rebecca Rees

Outline

- Why bring patients to expert panels?
- Innovation in the commercial sector
- Patient panels in the public sector
- Purpose of panels: data, discussions decisions
- Knowledge, expertise and skills
- Guidance for panels and involvement
- Key to success
Why bring patients to public panels
Why bring patients to expert panels?

• Ethical, rights, citizenship arguments justify involvement in
  o choosing areas of life deserving research
    prioritising problems
  o ensuring accountability of researchers
• Pragmatic arguments for better research, use of research findings and, ultimately, health justify involvement in:
  o deciding how the research should be done
    finding solutions
Why bring patients to expert panels?

Different priorities

• Cancer patients favour research about the management of practical, social, and emotional issues over investigating the biology or treatment of cancer.

• People with osteoarthritis want more research about patient education rather than oral drugs.
Why bring patients to expert panels?

Common critiques of medical research
• a lack of functional, social, and emotional outcomes;
• a lack of long-term outcomes
• reliance on scales
• little assessment of adverse reactions
Innovation in the commercial sector
Innovation in the commercial sector

Market research

- Bringing the “voice of the consumer” to every stage of development, engineering, and production
- One-to-one interviews with customers to elicit experiences, with the reflection and creativity provided by multiple analysts reading interview transcripts.
- 20–30 interviews identified 90%–95% of customer needs (and thus the research and development priorities)
Innovation in the commercial sector

Harnessing patient intelligence

• Analytical and articulate long-term users of assistive devices with a variety of disabilities
• Provided valuable insight and careful thought to how assistive devices should be designed, manufactured and selected
• Successive rounds of voting
• Developing questions for wider survey
Patient panels in the public sector
Patient panels in the public sector

Judging services

- 1980s ‘customers’ with rights and choices to influence the quality of public services
- Market research & ‘consumer’ satisfaction surveys
- Patient panels for GP practices
Patient panels in the public sector

Debating research

• 1980s: Patient advocacy and campaigning groups
• 1990s: NHS Research and Development Strategy
• 21st Century: 27 formal studies of patients involved in research agenda setting
• Widespread use of patients to ‘peer review’ research
Panels for data, discussion and decisions
Panels for data collection

- Respondents offer their own ideas
- Based on theories of statistical sampling
- Standing panels for repeated consultations e.g. Alz Soc

- Representative = large numbers to present an image of (represent) a larger population
Panels for data collection

• Respondents speak for others,
• In public consultations or as members of advisory groups
• being familiar with current debates through their affiliation with patient organizations.

• Representative = small numbers with the knowledge and skills to (re)present the opinions of a wider group
Panels for discussion

• Not just for sharing fully formed ideas;
• A safe, legitimate space for sharing and developing collective expertise
• Engages the intellect and emotions
• Emotion and anecdote can be the “motivation to discuss, and to engage with, material and with fellow citizens
• Fair share of discussion or in-depth discussion
• Reluctance to discuss ‘unfairness’ / health inequalities
Panels for decision-making

• Ethics committees, agenda setting panels, commissioning boards or guideline development groups

• Requires
  o respect for different types of knowledge,
  o relevant expertise and the
  o skills to share that expertise
  o willingness to learn from others.
Knowledge, expertise and skills for panels
Different types of knowledge

• Organizational knowledge that is gained by the experience of organizing services (e.g., knowledge about governance and regulation);
• Practitioner knowledge that is gained by the experience of professional practice (i.e., practice skills);
• Service user knowledge, gained from experience of and reflection upon services or situations; and
• policy knowledge, gained from the wider policy context.
Different types of expertise

• Certified experts – professional knowledge
• Skills and competencies
• Problem solving skills
• Experiential knowledge

• Open or closed attitudes to expertise
Open or closed attitudes to expertise

- Ethics studies seeking gaps in public’s knowledge and understanding in order to devise education programmes;
  - the researcher was the expert, applying structured methods focused on objective, measurable aspects of the topic and separating facts from values.

- Ethics studies investigating what the public knows and thinks about scientific developments and applications”
  - the researcher as learner, seeking new insights and understanding, employed open methods to elicit rich responses, and acknowledged that “facts” vary with context.
Who are the experts?

Subject experts bringing

• Understanding about living with the condition
• Understanding about treating people with the condition
• Understanding the nature, potential, limitations and options for research
• Skills for communicating with and for the different groups
Who are the experts?

**Boundary spanners**

- Bringing different worlds together
- Translating between different languages or spheres of expertise,
- Facilitating interactions - emotional and dramatic group dynamics
Guidance for panels
Guidance for panels and involvement

- Social research
- Committee procedures
- Structures, resources and procedures – formal knowledge
- Interpersonal communication – tacit knowledge
Key to success & conclusions
Key to success

From the innovations literature

• An organisation is more likely to adopt an innovation if those people with significant social ties inside and outside the organisation are able and willing to link the organisation to the outside world in relation to this particular innovation.

• Such individuals play a pivotal role in capturing the ideas that will become organisational innovations.

• Organisations that develop and support the execution of boundary spanning roles are more likely to become aware of and assimilate innovations quickly.

Conclusions

Patient intelligence

• Gathering information and analysis about patients
• Harnessing knowledge and analytical powers of patients

• Both require analytical skills, communication skills and an interest in learning about patients
• Working in partnership with patients also requires facilitation skills and a willingness to learn from patients.
Thank you