



**Leading education
and social research**

Institute of Education
University of London

Patient intelligence: data, discussions, decisions

MedComms Networking
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- Uhm S, Liabo K, Stewart R, Rees R, Oliver S. (2012) Patient and public perspectives shaping scientific and medical research: panels for data, discussions and decisions. *Patient Intelligence* 4; 1 – 10 DOI: <http://dx.doi.org/10.2147/PI.S17835>.

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
 - choosing areas of life deserving research
prioritising problems
 - ensuring accountability of researchers
- Pragmatic arguments for better research, use of research findings and, ultimately, health justify involvement in:
 - 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
 - respect for different types of knowledge,
 - relevant expertise and the
 - skills to share that expertise
 - 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 (eg, knowledge about governance and regulation);
- Practitioner knowledge that is gained by the experience of professional practice (ie, 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.*

