
Should patients tell researchers what to do? If so, how?

Monday 17 September 2007

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PUTTING THE PUBLIC AT THE HEART OF RESEARCH



BIOGRAPHY

Amanda trained first in philosophy then in medicine and later specialised in public health medicine and epidemiology. As a public health doctor she currently holds the post of Senior Clinical Lecturer in Public Health and Epidemiology at the University of Birmingham. This post is funded by the UK NHS to help promote health policy decision making that is informed by scientific evidence. Amanda has set up and is director of the West Midlands HTA Collaboration (WMHTAC) – a unit that undertakes systematic reviews and economic evaluations to inform policy decisions in the NHS, for organisations such as the National Institute for Health and Clinical Excellence (NICE) and the National Coordinating Centre for Health Technology Assessment (NCCHTA).

Her areas of special interest are patient and public involvement in health care and research, risk communication, the ethics of public health and the promotion of evidence-based decision making. She helped found The International Network for Knowledge about Wellbeing (ThinkWell) programme in order to pursue these interests and put the public at the heart of health research.

ABSTRACT

Public involvement in healthcare and health research is a key objective of national policy in the UK and many other countries. However, there is much debate about the best ways to achieve this. There is also concern that, despite the best policy intentions, practice often lags behind intent and the public are often involved too late in the process. It is important to ensure that the public are not “involved” only in a tokenistic way or only represented by “professional” patients, and patient groups, who are not truly representative of the wider community.

In order to address these problems, a group of consumers, researchers and health professionals met together in October 2006 to discuss ways of using modern communication technologies. The outcome of the meeting was the founding of ThinkWell.

The fundamental goal of ThinkWell is to create an infrastructure that will enable the public to join together to improve health and wellbeing. Specific objectives include:

- To undertake health research to an agenda set by the public
- To identify important gaps in our knowledge and prioritise further research according to:
 - the self-identified concerns and values of the public
 - the potential for health gain
- To find, appraise, synthesise and make accessible, scientific evidence on health and well-being issues of most concern or interest to the public
- To help people understand what makes research trustworthy and relevant, and make sense of evidence
- To undertake primary research, including cohort studies, surveys and randomised controlled trials, into factors affecting well-being, using the internet and mass media

RELEVANT COMPETING INTERESTS

None

CONTACT DETAILS

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