

Examining the role of patients' experiences as a resource for choice and decision-making in health care.

iPEX Briefing Paper 1 Introduction and background to the iPEX project

What is the programme about?

UK health policy values and promotes patient choice, self-care, and patient and public involvement. These aims cannot be achieved unless people can access high quality information. Until now this information has focussed on facts and figures about an illness, the risks of treatment options, and the likely outcomes. But people seek more than scientific facts. They want to know about the experience of illness – the reflections, insights and practical advice from people who have been there – and to be able to share their own experiences with others.

The team has internationally recognised expertise in making patients' 'experiential' information accessible to the public; but the scientific base underpinning this activity needs strengthening. We remain unsure whether, when and how the NHS should provide information based on other patients' experiences. How do people find and interpret online patient experiences and relate it to their own lives? What are the positive and negative consequences?

How might this affect their health and well-being? How do we measure these effects? This research programme was designed to answer these questions.

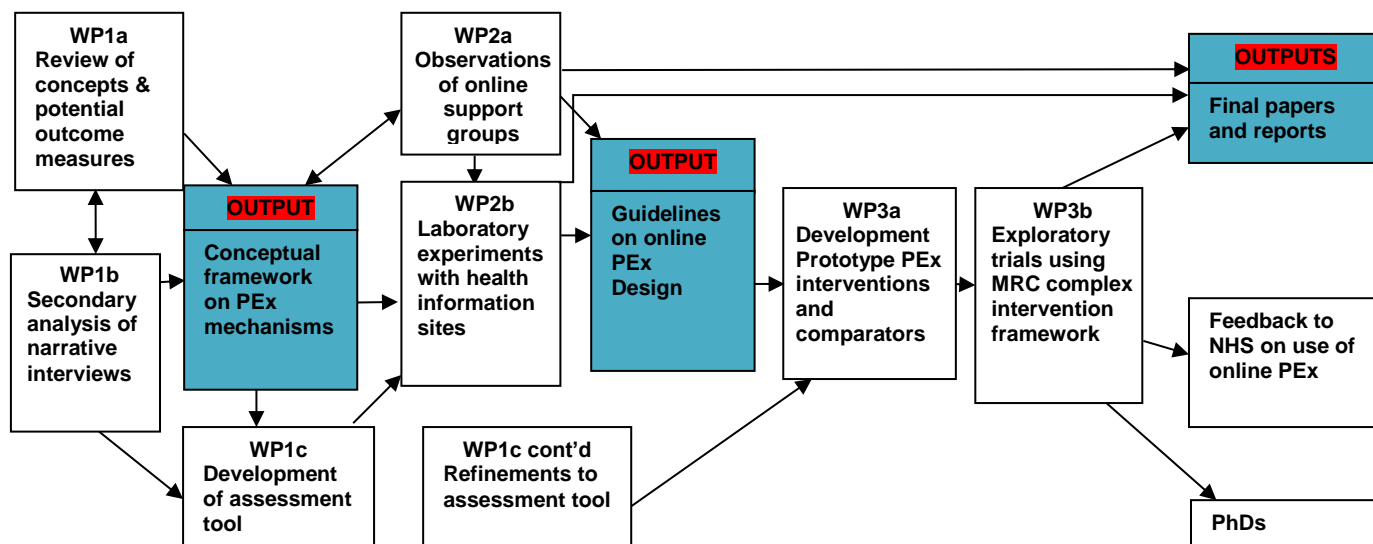
Work packages

Work package 1 developed the concepts and methods to quantify the effects of exposure to on-line patient experiences.

Work package 2 identified how and why people seek, use and interpret patient experiences and establish guidelines for presenting patient experiences on-line.

The outputs of work packages 1 and 2 were integrated to generate a new theoretical framework for the online exchange of patient experiences.

Work package 3 developed on-line patient experience prototype interventions and used exploratory trials to investigate their effects.



The team

Our team comprises researchers and NHS personnel with unrivalled expertise in innovation and research in patients' experiences, internet use, development of health outcome measures, primary care trials of complex interventions, and dissemination of health information.

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