Oxford Biomedical Research Centre
Enabling translational research through partnership

healthtalk.org

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Patient and public involvement in health research: a new online resource

Aims

- To explore the experience of being involved in health research from the perspectives of patients and members of the public
- To create an online information resource on healthtalk.org about patient and public involvement in health research

Plain English Summary

Thirty-seven patients and members of the public (20 men and 17 women) involved in health research for various lengths of time (<1 year to >10 years) were interviewed at a time and place convenient for them. With permission, they were filmed or audio-recorded. The interviews covered all aspects of their experience, including how they became involved, the activities of involvement, and their thoughts on key debates such as payment, representation and capturing the impact of involvement. Important themes from the interviews were analysed and written up in plain English for publication on healthtalk.org, illustrated with video/audio/written interview clips. Patients and carers were involved throughout the study (see right).

Patient and Public Involvement Activities

This research was supported by an advisory panel , which included five lay members, who had personal experience of illness or caring for a relative, and who had previously been involved in research. The panel also included representatives of involvement organisations and academic health researchers.

Two face-to-face meetings were held at the beginning and towards the end of the project with the panel and the project researchers (LL & AMB). Additional contact took place by email.

The panel supported the research process in a number of ways:

- Provided advice on key issues including the sample characteristics, recruitment, the content of the interview guide and initial themes emerging from the analysis
- Reviewed the summaries written for healthtalk.org
- Helped to disseminate the findings by reviewing the summaries for publication online and by contributing to academic papers and conference presentations

Following the second meeting, all members of the panel were invited to reflect on the impact of the involvement of lay members. The researchers (LL & AMB) reflected that involving people in the project:

- Gave permission to challenge the current involvement orthodoxy (beliefs and practices)
- Validated some of the views around the table proposed by other lay members and professionals
- Personally demonstrated differing attitudes to payment and motivations around involvement, which reinforced the findings, validated the initial data, and encouraged them to question taken-for-granted assumptions
- Allowed for flexibility with the meeting agendas, leading to rich discussions that provided further interpretations of the emerging themes
- Enhanced enthusiasm among the researchers

A lay member added that there were positive impacts not only on the research and researchers, but also on the lay members: ‘In my own personal case, there is a benefit in the other direction in that my broad understanding of health care has been extended, and then indirectly, that of many of my friends and contacts.’

Outputs

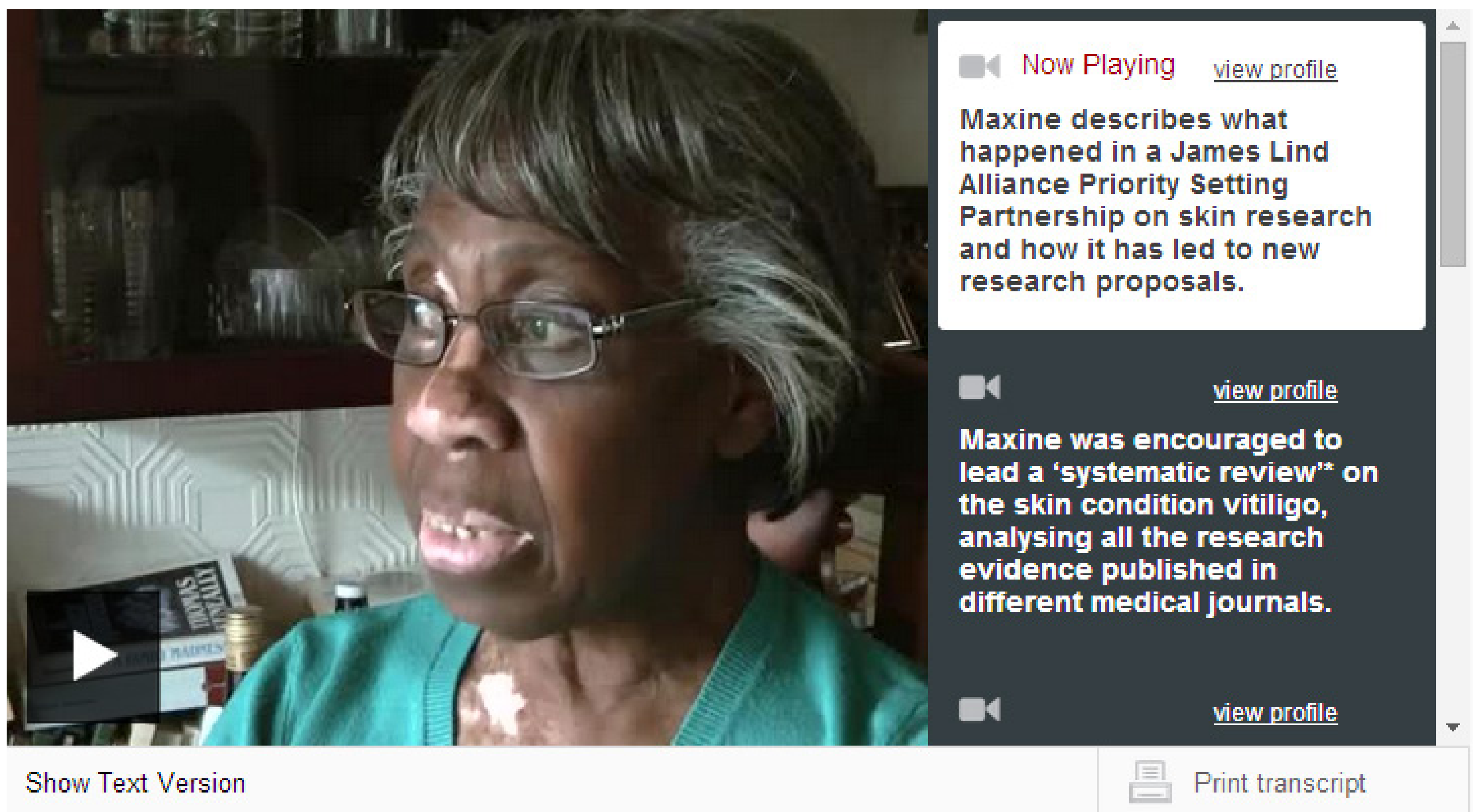
The findings were published in plain English on healthtalk.org, which is freely available to the general public. It serves as a resource to inform patients and members of the public currently involved or new to involvement, and to inform the involvement practices of researchers and academic clinicians. In the 30 days since its launch, the website has received 644 visits.

The findings will also contribute to the growing body of knowledge on involvement through dissemination in academic journals and at conferences.

Three academic papers are planned. They will report findings on understanding the impact of patient and public involvement; relationships between professionals and lay members; and personal benefits people gain from involvement. These publications will be co-authored with lay members of the advisory panel.

In addition, the findings have been, and will continue to be, disseminated at several academic conferences, including the British Sociological Society’s annual Medical Sociology Group conference, and ‘Changing Landscapes’, a conference organised by INVOLVE, the national organisation supporting patient and public involvement.

We have also written blogs about our research for the Oxford Biomedical Research Centre and INVOLVE .



Maxine describes what happened in a James Lind Alliance Priority Setting Partnership on skin research and how it has led to new research proposals.

Maxine was encouraged to lead a ‘systematic review’* on the skin condition vitiligo, analysing all the research evidence published in different medical journals.

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