Executive Summary

Background

People in Research (www.peopleinresearch.org.uk) is a website which aims to connect members of the public wanting to get actively involved1 in research with organisations that want to involve them.

The original idea for creating this resource came from two frequently asked questions. Members of the public asking ‘How can I get involved?’ and research organisations or projects asking ‘How do we find people who want to get involved?’

The development of People in Research was led by INVOLVE (www.invo.org.uk) on behalf of the UK Clinical Research Collaboration (UKCRC). The day to day operation of People in Research is carried out by members of the UKCRC team with support from INVOLVE.

At the heart of the People in Research website is a searchable database of information about organisations with opportunities for public involvement in clinical research. Visitors to the site are signposted towards the public involvement pages of these organisations to find out more. The pilot site was launched in February 2007 providing brief information about ten organisations. There are now 27 organisations listed on the site.

Patients and members of the public were involved in most stages of the site’s development – membership on the project steering group, involvement in the design workshop and feedback processes. The site was piloted in January and February 2007 by a panel of members of the public who had not been involved in its development. In April 2008, the search facility on the site was redesigned in response to feedback from site users.

In October 2008 the UKCRC commissioned Minervation Ltd (www.minervation.com) to carry out an independent evaluation of the site.

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1 For the purpose of this report, by ‘actively involved in research’ we mean activities such as where patients and members of the public help to decide what will be researched, or are members of trial steering committees and advisory groups, or work with researchers to develop patient information and questionnaires etc. This is distinct from, though clearly related to, work that is done to raise public awareness of clinical research and to increase participation in clinical trials.
The main objectives of the evaluation were to:

1. Elicit the views and experiences of patients, members of the public and research organisations using the People in Research website
2. Identify opportunities for further development of this web-based resource.

Methods

The evaluation used four main methods:

1. A secondary analysis of the site HTML and CSS code\(^2\), graphic design and usage data
2. An online questionnaire
3. Telephone interviews
4. Hands-on testing.

Data collection for the study was carried out in January and February 2009. Participants were recruited from volunteers from the website, personal contacts and other networks.

The study identified two important aspects of users:

- Users who are members of the public (‘public’) and those who work in or with research organisations (‘researchers’).
- Users who have visited the site before and those who have not.

Twelve individuals took part in telephone interviews whilst eight individuals took part in hands-on testing. These groups contained equal numbers of members of the public and researchers. They also contained equal numbers of people who had visited the site before and people who were new to the site.

A total of 50 online questionnaires were submitted.

Findings

People in Research contains important information about public involvement, and many users expressed approval of the general approach taken. However, most felt that People in Research fell short in terms of delivery.

The key findings of the study were:

1. The site is not heavily used: around 400 visits per month
2. Few users come back to the site having used it before
3. Researchers tended to think the site was aimed at the public, whilst members of the public...

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\(^2\) HTML (HyperText Markup Language) and CSS (Cascading Style Sheets) are the main programming languages of websites.
Use vignettes to explain the role.
Researcher, Hands-on testing

I don’t feel that this organisation is accessible.
Researcher, interview

It doesn’t really deliver in an engaging way. It’s fine for people who are already persuaded and proactively getting involved, but it does very little to win over the undecided.
Researcher, online questionnaire

I suspect any member of the general public who wasn’t already very confident and comfortable with websites, research process and health systems would be put off and/or confused by this.
Member of the public, online questionnaire

For those who are completely new, give a nice introduction, emphasise the positive contribution.
Member of the public, hands-on testing

Use concrete, real-life examples.
Member of the public, interview

It’s very easy to [lose] sight of the fact that when you start out as a consumer representative (or whatever you want to be called) the contribution you could make is almost impossible to visualise.
Member of the public, online questionnaire

[People in Research will be a] central portal for all people searching to take part, ... much easier than going to lots of individual websites.
Member of the public, online questionnaire

I don’t feel that this organisation is accessible.
Researcher, interview
thought that the site was aimed at researchers

4. When given a specific relevant task to carry out, a significant proportion of users were unable to complete it successfully

5. The site needs additional content to be able to achieve its aim effectively

6. The design of the site is generally well-liked and only needs minor changes.

Recommendations

This study has provided a wealth of information about users’ experiences of the People in Research website. It has also shown clearly what can be done to improve it.

The key recommendations for future development are:

1. To provide accessible, user-friendly descriptions of what ‘active involvement’ entails
2. To provide links to current opportunities for involvement
3. To engage with the clinical research community to ensure that they regard People in Research as an indispensable tool to aid them in their work.

There are at least two key management decisions to be made for the future:

1. The scope of any redesign
2. The model for keeping the site up to date.