

Patients Participate!

Bridging the gap between information access and understanding



In a world where the volume of health-related information is growing rapidly and access to it via initiatives such as UK PubMed Central (UKPMC) is improving, barriers to understanding remain. The style and jargon of research articles puts much exciting biomedical research beyond the reach of members of the public. Even researchers who are not specialists in a particular field are required to interpret professional or expert language and understand the context and implications of research. In parallel, the emergence of crowd-sourcing methods and citizen science initiatives, using online technologies to create and capture scientific information, provide evidence of the power and wisdom of the crowd. It was in this context that the Patients Participate! project, funded by the JISC, sought to explore whether lay summaries could assist in the wider understanding of health-related information and whether the crowd-sourced lay summary is a feasible mass-production model.

Definitions

Citizen science

A term used for projects in which volunteers, including the general public and enthusiasts, engage in research-related tasks to collect information or participate in research in other ways. Citizen science increases the resources available to collect or analyse research data, thereby accomplishing tasks that otherwise might not have been feasible, and makes a positive contribution to the public's engagement with science.

Crowd-sourcing

The act of outsourcing tasks, traditionally performed by a professional, to an undefined, large group of people or community (a "crowd"), through an open call, typically using internet technologies.

Patient

Any individual who has an interest in a disease-condition from a personal perspective; they may also be carers, parents, advocates, survivors etc. This is to differentiate them from the general public who may have an awareness of a given condition, but not personal experience of it and its impact. *Natural Ground: Paths to patient and public involvement for medical research charities.* (AMRC, 2009)

Patient and public involvement

An active partnership between the public and researchers in the research process, rather than the use of people as the 'subjects' of research. Active involvement may take the form of consultation, collaboration or user control. Many people define public involvement in research as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public'. (INVOLVE, 2004).

Perspectives on citizen science

The social outcomes of citizen science can be just as important as the science outcomes. *Ecology and Society* (Cooper, 2007)

We need to recognise volunteers as research collaborators. *Astro 2010: The Astronomy and Astrophysics Decadal Survey* (Raddick, 2009)

Ten years ago, it would have been inconceivable that a free collaborative website, written and maintained by volunteers, would dominate the global provision of knowledge. But Wikipedia is now the first port of call for people seeking information on subjects that include scientific topics. *Nature* (Bateman & Logan, 2010)

When thinking about design, ensure citizen science data is fit for the consumers, as well as focussing on the citizen science contributor interface. *2010 Sixth IEEE International Conference on e-Science* (Kim, 2011)

Build your website (PatientsLikeMe) to help answer the patient's primary question 'Given my current situation, what is the best outcome I can expect to achieve and how do I get there?' *Nature Biotechnology* (Brownstein, 2009)

The Patients Participate! findings

Following consultation with representatives from the research and academic communities, medical research charities, patients and other related groups, the following key findings are presented:

1. A lay summary should be published for every UKPMC article.

Medical research charities would value the ability to link to lay summaries on UKPMC. This would help demonstrate the impact of their funding to supporters.

2. Guidelines and templates can help in writing lay summaries.

Sharing existing resources and expertise could be useful. The following organisations have resources available: Arthritis Research UK, Asthma UK, CancerHelp UK, Muscular Dystrophy Campaign.

3. Many people who write lay summaries told us they would value feedback on whether their summaries are pitched at the right level for their audience.

Developing digital tools for rating and giving feedback would be useful. More work is needed to refine the procedures which assure trust and credibility.

4. Engaging with the wider community is increasingly important for researchers.

“Open information has most value when there is a broader community ready, willing and able to engage with it and benefit from it; every researcher can help to make that participation happen.” Chris Lintott, Galaxy Zoo.

“Many researchers struggle to write in lay language. This shows the divide between researchers and patients. More emphasis on writing lay summaries by researchers is needed” Delphine van der Pauw, Epilepsy Research UK.

Some universities now offer PhD students training in communicating with non-scientists. Providing this training more widely would be valuable.

5. New media should be considered for the wider dissemination of research.

Successful examples include Wikipedia and PatientsLikeMe.

6. Proactive support from funding bodies and publishers would help drive momentum if lay summaries are to accompany published articles.

7. All of the sectors that we engaged with were enthusiastic about improving the communication of scientific research.

We hope that we can build on this support and that others can use our findings to continue their own work in this important area.

Case studies

- **CancerHelp UK** – the patient information website for Cancer Research UK, produced by a team of expert nurse writers
- **Asthma UK** – demonstrating the value of patients' input, knowledge and expertise
- **Muscular Dystrophy Campaign** – empowering patients and researchers to produce information
- **EuroStemCell** – public website emerging from scientific collaboration
- **Cancer Research UK and Wikipedia** – embracing existing crowd-sourced and peer-produced health information resources
- **PLoS Medicine** – peer-reviewed scholarly journal has a lay summary with every article.

Resources

Patients Participate! resources are available from the project website:
<http://blogs.ukoln.ac.uk/patientsparticipate/>

- Literature review: Usability and human factors in citizen science projects and associated trust and credibility on the Web.
- Case Studies.
- Information about involving patients and the public in talking about medical research.
- Perspectives from medical research charities.
- Briefing paper on citizen science.
- How to write a lay summary.

Details of references and other resources mentioned in this leaflet are available from the project website.

Contacts

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<http://www.jisc.ac.uk/whatwedo/programmes/digitisation/econtent11.aspx>



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