New Avenues for Electronic Publishing in the Age of Infinite Collections and Citizen Science
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Lay Summaries for Research Articles: A Citizen Science Approach to Bridge the Gap in Access

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Abstract. The Patients Participate! project explored the feasibility of a citizen science approach to writing lay summaries for research articles. It involved a range stakeholders: funders of research (medical charities), service providers (the British Library), researchers and patients. Informed by practices within medical charities and the experiences of other citizen science projects, different methods were used to investigate trust, the skills required to produce a good lay summary, and the benefits of citizen science. A literature review into human factors was carried out and platforms for service delivery were analysed. The project was able to synthesise guidelines on participation in citizen science projects and the writing of lay summaries, and to identify challenges. This paper summarises the outcomes and lessons learned.

Keywords. Citizen science, patient participation, lay summaries, widening access.

1. Introduction

This paper describes a feasibility study that investigated some parallel trends in research in general, and in health in particular, to determine how to improve understandability of research articles for the general public. Patient and public involvement (PPI) is an approach that has arisen within delivery of healthcare and medical research. PPI describes processes in which non-professionals are included in medical decision-making that affects them. More broadly, the term citizen science is used when projects engage volunteers (the general public or enthusiasts) to tackle research tasks that might otherwise not be feasible due to scale. Benefits are claimed not only for the project, but also for the participants and society in general. With reference to research literature, including medical research, Open Access refers to a movement to make the results of research (as communicated chiefly through publications) more widely available, mainly by removing cost barriers. The Patients Participate project[2] asked the question: is it feasible to align these approaches for greater openness and involvement of the public in research by providing lay summaries alongside research articles, to improve accessibility, harnessing the effort of volunteers to power the effort?

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[2] Patients Participate! Project website http://blogs.ukoln.ac.uk/patientsparticipate/

The rest of this paper describes the lessons that the project was able to learn from the practices of medical charities and the experiences of citizen science projects, using different methods such as workshops and literature review, to gather different perspectives on the feasibility of providing lay summaries to research articles using contributions provided by patients.

2. The Trend for Patient Participation

Whilst patients have been involved in medical research in different ways, such as participating in trials, donating tissue or analyzing their genes through services like 23andme[3], these can be considered passive roles. In contrast, patients[4] can take more influential roles such as setting research strategies and priorities for medical research charities, evaluating research by taking part in the peer review process alongside scientific experts and contributing to communicating the results of research. INVOLVE, a national advisory group, defines involvement as 'research being carried out '**with**' or '**by**' members of the public rather than '**to**', '**about**' or '**for**' them' [1].

Medical charities fund a significant amount of medical research (over £1 Billion in 2010/11) and see communication with their supporters about the research they fund as one of their key strategies [2]. They are keen to involve patients in the conversations about research so that it meets patient priorities, research is patient-focused and they consider the passionate and committed patient as being a powerful advocate who can act as an ambassador for the charity [3].

3. What Is a Lay Summary and How Are Lay Summaries Used?

Lay summaries are short accounts of research that are targeted at a general audience. Smith and Ashmore [4] recommended the INVOLVE definition as being the most succinct "A lay summary is a brief summary of a research project or a research proposal that has been written for members of the public, rather than researchers or professionals. It should be written in plain English, avoid the use of jargon and explain any technical terms that have to be included".

Besides members of the public, lay summaries can also be used by other researchers from nearby fields. They are often requested as part of grant application processes. Medical charities in particular are involving patients in decision-making: as members of funding panels, in parallel lay review processes, or simply by commenting on the value of research projects and their feasibility [5]. There are also reports that presentations that have been simplified for lay members are also easier to understand for other scientists in panels. Smith and Ashmore have suggested that lay summaries may be the only part of an application that a busy reviewer may ever read. Lay summaries can also be used for the recruitment of participants in clinical trials. CancerHelp UK is a website produced by Cancer Research UK using an experienced writing team to describe cancer trails and studies.

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[3] 23andMe website https://www.23andme.com/

[4] The term patient and public describe a wide range of roles taken by people who may become involved, such as advocates, consumers, survivors or carers. 'Patient' is used to stand for an individual with an interest in a disease-condition from a personal perspective, and may not have had the condition themselves. [5]

4. Open Access and the Public Engagement Agenda – Researchers' Perspective

Due to changes in research communication, arising not only from the movement to open access to publications without charge, but also from funders' directives to consider the impact that research has on different beneficiaries, researchers need to widen their reach. Previously the main audience for research would have been considered to be other academics. With greater emphasis on engaging with different stakeholders, medical researchers have started to consider research patient groups as key stakeholders. Some of the aims of better communication include equipping patients to judge what the research means to them, helping them understand the investment in science, and keeping them better informed about advances.

Whilst academics accept that finding and accessing information can be challenging for the lay person, addressing the technical language and complexity inherent in their research can be a challenge. Researchers need to understand what patients want and what they value, and find the best routes for delivery and engagement [6].

However, the skills required for writing a lay summary are different from other writing tasks which may lead to difficulties when writing lay summaries [4]. Medical charities found that some researchers continued to write summaries that were not sufficiently clear or simplified [5]. Researchers require guidance on what should be provided in a lay summary and clarity about how summaries will be used (for example to make funding decisions) [3]. Other possible barriers that have been suggested are the variation in requirements across funders (e.g. word length) and directions that appear to be conflicting (e.g. brevity versus providing adequate explanation) [4].

5. Lessons from Citizen Science Projects

5.1. Human Factors in Citizen Science as Reported in the Literature

The project used a small selection of reports in the literature, with a focus on web-based citizen-science projects that conduct crowd-sourced data analysis or data collection (or reported experiences), to extract some factors that need to be considered in planning and delivering a citizen science project. Due to the limitations of space these can only be addressed briefly here, but the full report is available [7].

One of the findings was that involvement is affected by trust and credibility, and credibility is in turn influenced by ease of use and perceived risk. The site's look and feel can be used by users as an indicator of a site's credibility. The choice of factors that has been studied varies, but there is some consensus that perceived trustworthiness and credibility are a function of user judgements of various factors. These include user attributes: cultural factors (like nationality), attitude towards the activity being carried out, and the site usability (like ease of navigation and the level of guidance and support for the user).

Since several projects involve collection of data by participants (rather than writing), discussions on quality of contributions tend to focus on collection of data and techniques for data validity. Paulos [8] and Cooper [9] suggest complementary frameworks for carrying out citizen science projects. Besides planning around data collection, another important (and perhaps obvious) focus tends to be the participants: how to recruit them, train them and motivate them.

GalaxyZoo [10] had a dramatic increase in participation following a launch through the BBC Radio News item with the news spreading through print and online media. The participants were keen not only to contribute to the task, but were also active in helping each other through forums and collaborative research.

Although the subject of participant motivation has been somewhat understudied, Raddick et al were able to compile a set of motivation categories for GalaxyZoo volunteers. Nov et al [11] provide a number of pointers to literature that explores the motivation of contributors in citizen science communities and information-sharing communities (like wikipedia). They group motivation into intrinsic (improvement of skills, enhancement of status) and extrinsic (fun, intellectual stimulation).

5.2. Potential Benefits

Whilst projects that use a crowdsourcing model to increase the manpower available to the project derive benefit, it is suggested that the citizen participants will also enjoy possible gains such as:

- Empowerment: by becoming active participants and stakeholders
- Improved understanding
- Social contact: platforms for citizen science can act as a virtual meeting place, and can help to form communities and connect people who share interests. If researchers get involved in these communities, contact between scientists and citizen participants can also be facilitated.
- Inclusivity: by providing a level playfield where differences (physical or social) may be surpassed.
- Skills development: specific training, knowledge acquisition in a particular field, or confidence with technology or communication skills could be acquired.

5.3. Available Platforms

The features of platforms supporting projects which use a crowdsourcing model of engagement were analysed for suitability to the task of writing lay summaries [12], one class of projects are based around wiki-like platforms. Of these AcaWiki had a closely-matching aim of presenting summaries of academic papers. The WikiMedia medicine portal is written by volunteers and includes links to research as well as other medicine-related topics such as news and images. Of other sites linked to patients and medical information, PLoS Medicine offers lay summaries alongside research articles; the summaries are written by editors following a set of internal guidelines. PatientsLikeMe provided a model of a large site where patients are involved in providing information (mainly personal information on treatments, symptoms, progression and outcomes). Rather than use expert mediation, PatientsLikeMe puts the focus on patients interacting with each other.

Of some other platforms available, GalaxyZoo is an example of a successful initiative in the field of astronomy with many volunteers who help classify images of galaxies. The volunteers are supported through a blog and a forum. The software is available for setting up other projects, however the tasks undertaken by participants and the input gathered are not similar enough to that of writing a lay summary. RunCoCo on the other hand had a focus on creating a community-donated collection of content, either by uploading content or adding information on existing resources. This suggested that the software might be better adapted for the input of a structured description that would be required in a lay summary.

6. Results: Synthesis of Lay Summary Guidelines and Practices by Medical Charities

Charities would like to find out about and access research publications that result from the research that they fund. Medical charities were surveyed about their practices, and the results are captured in some longer case studies [13], an overview of innovative ways being used by charities, for example, use of social media [14], and a table showing which charities are engaging in the production of lay summaries, and how: who writes the lay summaries, whether they provide guidance and the stages of research at which lay summaries are used [15].

Furthermore, some of the charities were willing to share their guidelines for producing lay summaries. Generally speaking, guidance for writing lay summaries comprises a structure or sections to address the questions that patients would like answered about research (which can be in the form of a template) and directions on writing style. The content should include who funded the research and why, the impact expected, concrete everyday examples should be used and timescales given where relevant. Instructions for writing style consist of suggestions such as writing in the active voice, positive phrasing, using simpler everyday words, avoiding jargon, using correct grammar, punctuation and spelling and an appropriate tone.

7. Challenges

By investigating the current practice in lay summary writing and in running citizen science projects, the project was able to identify a number of questions that would need to be addressed:

Current practice suggests that patients are taking influential roles in directing research, however lay summaries are written in the main by researchers or highly trained writers. How could training to patient participants be delivered at scale? One possible model could involve collaboration between researchers and patients, with patients giving feedback to help refine a lay summary written by researchers so that it fulfills its purpose.

None of the available platforms were clearly geared at the task of writing a lay summary, although some offered features that could be adapted (to structure the writing). Moreover it is not known if some of the aspects (such as reputation and ratings to motivate contributions) would be suitable in this context. Further information is also needed about any special needs that need to be met in order to be inclusive.

Although between them charities have compiled guidelines for lay summary writing which were in enough agreement to allow a synthesis [3], it was not clear to what extent existing guidelines had been tested. How can quality assurance of summaries be implemented and what evaluation criteria can be applied? Evidence of impact would also need to be collected.

The infrastructure service delivery model still needs to be explored to find out how to associate summaries with the research article and make it available alongside.

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