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Lay summaries of open-access journal articles: Engaging with the general public on medical research

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Abstract

This study investigates attitudes to 'lay' or 'plain-English' summaries of open-access journal articles in the context of engaging the public with medical research. It places lay summaries in the wider contexts of patients' information-seeking behaviour and open access publishing activities. It reports the results of qualitative research involving two stakeholder groups: employees of organisations with a stake in communicating open access medical research to the public, and members of the public who have experience of accessing online medical research. It shows that patient access to the research literature is seen as one of a number of important sources of information that can help them manage their health conditions as 'informed patients'. However, accessing the literature was reported to be problematical, particularly because of paywalls, and there were also difficulties in using it, including language barriers. Lay summaries were seen to make a helpful contribution to improving patient access to information. There is, however, a clear need to gather more evidence about the costs and benefits of such an approach and also on the potential ways in which open access can create benefits for the general public.

Introduction

Whilst the move to open access (OA) is normally seen as being motivated by the needs of researchers and students, the argument has been made that OA can also benefit 'lay' readers by spreading knowledge beyond the academy.[1] The general public are often added to the end of lists of possible beneficiaries of OA. For example, recent guidance from Research Councils UK on its OA policy, states that:

> "The Research Councils take very seriously their responsibilities in making the outputs from this research publicly available – not just to other researchers, but also to potential users in business, charitable and public sectors, and to the general tax-paying public."[2]

Whilst critics of this viewpoint have suggested that there is little evidence of demand for scholarly research among the general public,[3] supporters such as Willinsky have argued passionately for public access.[1] Access to medical research in particular is seen as being potentially beneficial to a lay readership.[4] There is evidence, for example, that people are more likely to wish to engage with medical research in response to their own health issues.[5] This can be seen to go hand in hand with drives within medicine to encourage patients to be more actively engaged with their own healthcare.[6] However, it is observed that simply making medical research available may not in itself be enough since scientific articles may be very difficult for a lay reader to understand.[7] The suggestion is that members of the public often turn to plain-English or 'lay' sources of information rather than primary research, at least in the first instance.

The research presented in this paper has been motivated by evidence that some OA publishers are beginning to address exactly this issue by including a summary of the research alongside articles specifically aimed at the non-expert or lay reader.[8] This suggests that the publishers are aiming to attract a lay readership in order to engage the public with medical research. However, there has been very little research which examines either publishers' perspectives, or that of lay readers on this issue. This is the gap that the current paper is designed to go some way towards filling.

The aim of the research was to investigate attitudes towards the addition of lay summaries to open-access journal articles, in the context of engaging the general public with medical research. In particular, the perspectives of two stakeholder groups were analysed:

- Employees of organisations with a stake in communicating OA medical research to the public.
- Members of the public who have experience of accessing online medical research.

The research focussed on the following objectives:

1. To investigate what motivates members of the public to access online medical research.
2. To identify potential barriers for a member of the public accessing medical research.
3. To determine whether the general public should be seen as an important audience for OA medical research.
4. To investigate attitudes towards the addition of lay summaries to OA journal articles.
5. To identify benefits, limitations and problems with producing and using lay summaries.

Literature review

This study is situated at the point of convergence of five areas of research:

- Open access and the general public
- Health information seeking behaviour by the public
- The 'Informed Patient'
- The communication of science to the public
- Lay summaries

On the first of these, it is clear that even the earliest formulations of the concept of open access included the general public as a potential audience for OA outputs. The Budapest Open Access Initiative lists the beneficiaries of open access to scholarship as "scientists, scholars, teachers, students, and other curious minds".[9] This position was endorsed by the UK House of Commons Select Committee report on scientific publishing in 2004 which argued for the free availability of scientific literature to the public, highlighting medical information in particular.[10] Willinsky has argued strongly for the benefits of making research available to the public, suggesting it is a moral obligation to do so and that the public should be able to judge scientific evidence for themselves.[1, 11] However, he admits that any evidence about the impact of OA on lay readers is speculative and anecdotal at best. It is easy to find anecdotal evidence of members of the public benefiting from access to scholarly medical articles: the dedicated father helping to develop a cure for his son's condition,[4] AIDS activists successfully challenging the government to approve new drug trials,[12] and the librarian working out a treatment plan for a previously incapacitating illness.[13] But however powerful, these stories, on their own, do not constitute a firm evidence base. Zuccula's work, focused on the Netherlands, has provided some more systematic evidence, and has shown that people were generally positive towards OA scientific research, and believed that it would be useful when researching medical conditions. They also believed themselves to be capable of understanding research without being medically trained.[14] However, Davis sounds a note of caution, arguing that the popular argument that OA will benefit the general public is often a rhetorical device, and that it risks ignoring less appealing but important counter-arguments based on cost and sustainability in favour of utopian visions of free information.[15] In general, it seems that there is a gap in the literature about the benefits of OA to the general public, and a need for further research in the area.

In contrast, Health Information Seeking Behaviour (HISB) is a well-covered field of study focusing on why and how members of the public search for, find and use health information. Studies have found that the internet is a popular source of health information, although certain segments of the population have been identified as being more likely than others to search for health information online (including women, younger people and people with higher levels of education and personal income). [16,17] Motivations for searching for health information include receiving a diagnosis of a new health problem, or attempting to deal with a long-term condition.[17] Some studies also report that dissatisfaction with medical professionals can motivate the public to look online.[18] Seeking health information has been shown to be a positive coping strategy in these situations both because information helps individuals to feel less uncertain about their condition, and because it allows them to become more involved with medical decision making.[19] However, significant barriers to health information seeking exist. These include the time and effort required to find information and the difficulty in understanding scientific and technical language.[16] The ability of patients to appraise and assess the reliability of internet health information has also been found to be of variable quality.[20,21]

HISB research relates to discourse on the 'Informed Patient', which is concerned with the idea that access to health information creates empowered patients. Informed Patients are able to access and evaluate health information and are seen to be able to actively participate in their treatment, act in partnership with clinicians and ultimately be able to manage their health more effectively.[22,23,24] Self-management of chronic illness is seen to be not only medically but also politically relevant, especially now that chronic illness has replaced acute illness as the major health concern in the developed world.[6] Informed patients potentially reduce the costs of healthcare by avoiding unnecessary involvement of doctors.[25] However, despite government support, there is evidence of negativity towards informed patients from some clinicians.[26] Moreover, problems have been identified in informing patients, including lack of information literacy and continued preference for advice from medical practitioners.[22,23] When patients do use published medical information, it is often hard to identify when they are using primary medical research and when they are using secondary sources.[7]

The issue of the informed patient is linked with that of the communication of science to the public which focusses on engaging the general public with scholarly research. Motivations in communicating science vary between a genuine concern that the general public should have a better understanding of scientific concepts such as evidence and an attempt to gain public support and financial donations for scientific research.[27] Discourse in this area has progressed from a model where information is transmitted directly from scientists to an ignorant public, to a more complex consideration of how communication is affected by different social and cultural contexts.[28] Engaged members of the public are seen in certain circumstances as being able to make an important contribution to scientific research, especially concerning ethical issues. This is seen in the specific area of medical research where patients who have been involved in clinical trials are an important audience group for science communication and their feedback is understood to have a positive impact on the future of scientific research.[29]

Interestingly, similar arguments are found in support of both the communication of science to the public and OA. For instance, scientists are seen to be obligated to communicate their research to the public that has funded them, and it is regarded as socially beneficial to counter sensationalist misinformation reported in the mass media.[30] In some cases, the communication of science and OA are directly linked, using the argument that there is no point in making research articles publicly available if the public is not able to appreciate them.[31] Recently, there has been advice published to teach new researchers how to write for a lay public, contradicting the view that it is a way of "dumbing down" the research.[32]

A lay summary is one of the tools that can be used to facilitate communication of science to non-experts. Lay summaries feature in the literature as a way in which research results are communicated back to participants in clinical trials or as a way to pitch research proposals to lay funding boards.[33,34,35] Two recent UK reports, the Finch Report in the higher education sector and Patients Participate project report in the health sector have both suggested lay summaries could be useful in improving public access to the clinical research literature.[36,8] However, a number of problems have been identified with lay summaries, including the cost of producing them, variation in quality, and fears from scientists that they simplify science to the extent that it becomes misleading.[37,38] A survey of researchers has also identified a reluctance to involve lay people's feedback in the production of summaries, and a belief that they are "not difficult to write". [39] However, there is a lack of research on how summaries are received by members of the public, a gap this study is partly designed to begin to address.

Methodology

The study presented here made use of qualitative research methods in order to analyse perspectives on public access to medical scholarly literature in general and the use of lay summaries in particular. Because qualitative research taking an inductive approach is appropriate for examining opinions, perspectives and subjective experience, it was considered to be the best approach faced with a comparatively new and under-researched topic.[40] The research used purposive sampling methods, which allowed the researchers to select participants based on their relevance to their research question. The sample comprised 12 participants in total: six 'OA Stakeholders' (comprising two representatives from OA journal publishers, two from OA subject repositories, and two from medical research funders) and six 'Lay Participants' (members of patient groups of various sorts, all without medical training). Like much qualitative research, this study was designed to provide a rich picture of the issue under investigation derived from data provided by highly-relevant participants with the aim of generating theory or hypotheses which could be tested by subsequent, including quantitative, work.

In order to be aware of possible bias within the sample, it is necessary to draw attention to the problematic nature of the term 'lay'. The definition of 'lay' used in this research in broad terms follows Zuccala, "the mass of people as distinguished from those of a particular profession and those specially skilled."[4] Lay Participants in this study were therefore not medical professionals. However, within this definition as Zuccala acknowledges there is considerable variation: a scientist could be regarded as lay if the research they were accessing fell outside their specialised field. Similarly, the expert patient model suggests that it is possible for members of the public to become 'less lay' as they become more acclimatised to the research. This may be true of some of the participants, whose education levels in any case may mean they also cannot be regarded as representative of the general public. Similarly, it is probable that those OA Stakeholders with more interest and enthusiasm for the topic of lay summaries were more likely to volunteer to be interviewed. These biases were considered when writing up the results.

Data were gathered between June and August 2013, following approval under the University of Sheffield ethical approval process, through semi-structured interviews typically lasting 30 minutes. Different interview schedules were used for the different stakeholder groups. The approach was chosen as it allowed the researchers to identify specific topics, but at the same time encouraged participants to bring up their own ideas.[41] By interviewing both Lay Participants and OA Stakeholders, the aim was to triangulate perspectives aiming not to aim for continuity across different perspectives, but to identify and interrogate differences.[42,43] The interviews were transcribed and open coding carried out on the transcripts as a basis for subsequent systematic thematic analysis.[44,45] Thematic analysis involved in-depth examination of individual transcripts, as well as extensive cross-interview comparisons.

Results

Accessing online medical research

Lay Participants were asked to talk about why and how they accessed medical research online. Responses showed that they were all motivated to access medical research because of experience of specific health conditions. All but one had chronic illnesses, including autism, diabetes, lymphoma, fibromyalgia and HIV. Participants were clearly motivated by wanting to keep up to date on their conditions and treatments. In some cases, dissatisfaction was expressed with information provided by doctors, often because it was seen as not detailed enough or as inapplicable to the particular situation of the participant. Participants also identified an emotional need to feel in control.

> *“What is so horrible is the feeling of it all being out of control […] it’s about getting some control, about getting some hope, getting something positive that you can do” (Participant LAY4).*

Sources of information used by participants varied from traditional academic sources to public search engines.

> *“I started going into Google Scholar and finding papers that scholars had self-archived and then that would often also lead me to PubMed” (Participant LAY2).*

Participant LAY4 accessed lymphoma research through a website managed by a patient with the same condition. This patient kept up to date with the latest research through PubMed and presented it to his network of followers in lay terms, with links to the original articles. In a related example of members of the public sharing research, Participant LAY3 emphasised the importance of online health forums, describing how she translates medical research for other forum users.

All the Lay Participants gained medical information in their encounters with clinicians but expressed differing opinions about taking medical research that they had accessed to discuss with clinicians. There was no consensus on how such an approach would be treated. Two participants (LAY3 and 4) warned against disturbing the power relationship between doctor and patient. Participants LAY2 and 5 both reported mixed responses depending on the doctor they saw. For example:

> *"My old GP [General Practitioner] wasn't really interested so it wasn't worth the effort, and a doctor at the pain management clinic I attended where I used to live was very dismissive, but my current GP is always happy to discuss any research" (Participant LAY5).*

One participant reported a very positive response from clinicians when bringing research to them. Others reported useful experiences the other way round: clinicians directing *them* to research.

Barriers to accessing online medical research

Both OA Stakeholders and Lay Participants were asked what they felt were the main barriers to the general public accessing medical research. Subscription paywalls were highlighted as the main barrier by Lay Participants.

> *"Often when looking for specific medical research journals, only the abstract is available online unless you pay a subscription to access it" (Participant LAY5).*

Even those participants with subscription access through a university noted that it did not guarantee full access to research, as subscriptions vary across institutions

In contrast, only one of the OA Stakeholders emphasised "cost" as being very significant. Most, in fact, focussed on scientific language as being the main barrier to access and use.

> *"Even with an open access model it's the language used in the articles" (Participant OA2).*

Highly technical language and an impersonal writing style were cited as major barriers. One participant expressed doubts that members of the public would consider looking for research in the first place. On the other hand, popular health websites such as *WebMD* or material produced by charities were seen as more likely to attract members of the public as they had a more recognisable brand than other resources.

Language used in scientific articles was also identified as a barrier by two Lay Participants (LAY 4 and 5). For example:

> *"It gets really complicated. I'm not a scientist – I haven't got a scientific background at all, so it is quite complicated. The language isn't easy." (Participant LAY4)*

The language was seen as difficult and time-consuming to decipher. However, other Lay Participants felt more positive about their ability to understand scientific language. LAY2 and 3 described how they had developed techniques for reading scientific articles quickly focussing, for example, on particular sections such as the introduction and results in order to understand them and their implications.

Open access and the general public

A number of the OA Stakeholders felt strongly that it was important to target a lay readership. Reasons given included the argument that public money deserved public access, and that research funders had an obligation to spread research outputs as widely as possible.

> *"The main rationale we give is this idea that the public paid for it so the public should be able to read it" (Participant OA3).*

Another participant (OA2) suggested that targeting a lay audience was a popular argument that aligned with political drives towards transparency and accountability, but cited benefits to researchers as a higher priority. Participant OA3 noted that there was a whole "suite of things" on which open access publishers should focus in order to improve scholarly communication, rather than targeting the general public. One participant (OA1) felt that it was not the publisher's responsibility to engage the general public at all.

Two Lay Participants showed a high level of awareness of OA, with one (LAY1) arguing in favour of OA in terms of transparency and accountability, whilst another being ambivalent towards it (particularly OA publishing using article processing charges). The other Lay Participants did not put forward any theoretical arguments for or against OA. Instead, they discussed practical problems with finding OA material, and expressed the opinion that there was not enough OA research online.

> *"I would definitely find it useful to have more freely available research" (Participant LAY5)*

Participant LAY6 commented that the arguments in favour of open access "always seem a bit academic to me". Although supportive of OA as a principle, he was more interested in the practicalities of accessing material relevant to his condition.

Attitudes towards lay summaries

Both groups of participants were asked about their views on lay summaries as a tool for engaging the general public with medical research. The OA Stakeholders displayed very positive attitudes towards summaries. The view was generally held that making research more understandable was a logical progression of the OA movement.

> *"In a way [lay summaries] flow naturally from the idea of open access and it's taking it to some extent to its logical conclusion" (Participant OA3).*

The same arguments relating to public accountability were made in favour of lay summaries as they had been for OA. This was particularly relevant to the research funders who were entirely financed by charitable donations as they felt an obligation to communicate the results of their research to the people who had directly funded it. Such an approach might also increase the possibility of future support for their work.

Lay Participants, on the other hand, were divided in their attitude towards summaries. Participant LAY1 felt that a summary would help to clarify the implications of the research for patients. Participant LAY5 felt that summaries would save her time and effort.

> *"I definitely think that sort of summary would be useful. I have difficulty concentrating for long periods when things are complex and it can be too much effort to try to understand it. I like that it gives a broken-down bitesize presentation that helps identify key aspects of the article" (Participant LAY5).*

Particpant LAY4's experience of using a patient-managed website suggested that lay summaries produced by journals could counteract possible biases in reporting elsewhere. However, other participants raised concerns about the issue of trust.

> *"You don't know the biases of the person writing the lay summary unless it's coming from…someone like the Cochrane people or NHS Choices or something" (Participant LAY2).*

These participants stated that they would prefer to read the full article. Participant LAY2 felt that summaries were not much more useful than abstracts, and described their language as "patronising", a fear also expressed by Participant LAY3. Participant LAY2 felt that "researchers should just get better at writing their conclusions". Another criticism (Participant LAY3) was that summaries were the easiest way for journals and researchers to claim that they were engaging the public, even if in reality their use was very limited. In fact, of the Lay Participants, only Participant LAY5 felt that summaries were the most important way to engage the public with medical research. Many of the others felt that other methods would be more useful and effective with suggestions including linking to articles from the NHS direct website, or allowing members of the public to comment on articles.

Several concerns regarding lay summaries were also expressed by the OA Stakeholders. Firstly, it was seen to be impossible to pitch a summary at the right level for all members of the public.

> *"At one end of the spectrum people are saying 'this is fantastically well written and really clear,' to somebody else saying 'this is dumbed down, they're talking too patronisingly, to somebody else saying 'this is really too complicated in places" (Participant OA2).*

Secondly, it seemed inevitable that more educated readers would be the ones to benefit from lay summaries, leading to the exclusion of large sections of the general public. Thirdly, it was also seen as potentially difficult to balance accurately representing science "versus popularising the research" (Participant OA2). Expanding on this, one participant identified a potential danger to lay readers if essential scientific context was left out of summaries.

> *"The concern would be that it's important that [lay readers] understand the limitations of the research so they don't get maybe scaremongering or that kind of thing, you know, if an article is phrased wrongly" (Participant OA5).*

Finally, it was suggested that although lay summaries could be very useful in helping lay readers to understand medical journal articles, they were not an effective tool for initially signposting people to the research in the first place. In this connection, several technical suggestions for improving the discoverability of lay summaries were made, including creating more accessible websites (Participant OA3), making sure that the summaries were indexed by major search engines, and developing a recognisable brand to attract consumers (Participant OA6).

Practicalities of producing lay summaries

The cost of producing lay summaries was raised as an important issue by most OA Stakeholders, and even the most enthusiastic proponents of summaries gave the caveat that producing them was expensive. It would be unfeasible for larger journals to produce (editor-written) summaries for all articles, it was thought.

> *"They are pretty expensive to produce. Or certainly the way we do it, it's not cheap […] it's out of the question to do lay summaries on every paper"* (Participant OA3).

There was a tension it was believed between producing a large number of summaries where quality may be compromised and a smaller number of high-quality ones. There was also disagreement over who should write the lay summaries. Summaries produced by editorial staff were considered very expensive, and Participant OA1 suggested that if this became standard practice costs would have to be factored into APCs. On the other hand, researcher-written summaries, although seen as more scalable, were seen as difficult to produce because of a perceived lack of skills amongst researchers to communicate in this way. Several participants also gave examples of passive resistance from researchers to producing lay summaries. Despite this, Participants OA2 and 5 felt that it was very important that researchers themselves write their own summaries, and argued that communication of science to the public should be part of every scientist's education and training.

> *"I think at the end of the day if you're being funded by a charity or you're doing medical research you should be able to explain to people with that condition how your research is going to benefit them and why it's important" (Participant OA5*).

In contrast, one participant (Participant OA6) reported that the ideal way to produce summaries would be a specialised team of lay authors. Participant OA1 felt strongly that journals should take advantage of OA to crowdsource their summaries, which would not only save costs but also engage the community in science communication.

Consultation

Despite the general enthusiasm, most OA Stakeholders saw it is difficult to gather any kind of meaningful feedback from lay readers about their attitude towards summaries. Either there had been no direct feedback, or feedback had been anecdotal, coming from other publishers and researchers rather than members of the public.

> *"[Feedback] has just been from people – senior people speaking at meetings, it's been in tweets, it's just been in random emails" (Participant OA3).*

However, Participant OA6 was markedly different in her organisation's attitude to feedback from lay readers. She described a systematic feedback project that had consulted with different patient groups in order to find out what patients wanted to see in lay summaries. The aim was to draft a list of standards and minimum requirements to improve the quality of their summaries.

> *"What we found was that some summaries were done really well […] there are some very useful where the information is presented clearly, in not very difficult language, no jargon, and when they use basic frequencies as opposed to risk ratios and odd ratios and more specific statistics" (Participant OA6).*

Discussion

The data presented here relate directly to a number of issues raised in the research objectives, including motivations for seeking medical information, potential barriers to doing so, the relationship between the public and OA, attitudes to lay summaries, and benefits and issues associated with using them. Because this is a little-investigated area to date, this study has also raised a number of issues requiring further research, some of which are highlighted below.

With regard to the issue of motivations for accessing medical research, this study corroborates the findings of Weaver et al. by demonstrating members of the public can be prompted to seek information for a number of reasons, including finding out about the causes of chronic health conditions, seeking emotional support, or looking for advice on practical steps that might improve their health.[17] Also, as anticipated by Tustin, they may partly be motivated by some dissatisfaction with information given to them by clinicians.[18] Participants in this study fitted the model of the Informed Patient, and were therefore able to make use of the information they discovered by discussing it with their doctor. This helped them work together with health professionals to selfmanage chronic health conditions. However, the effectiveness of using research is still partly dependent on doctors' attitudes and reactions. Responses from clinicians as reported by Lay Participants in this study and elsewhere vary significantly.[26] The work reported here could now be usefully extended to cover the attitudes of clinicians, something that could clearly add an important dimension to an understanding of the key issues.

Medical research is accessed by members of the public through a variety of different sources including general search engines, condition-specific websites and academic databases. However, it is apparent that subscription barriers cause significant problems for members of the public, even when they have access to e-journals through university subscriptions. In addition, even if the research is freely available, the organisation of online resources can also act as a barrier to members of the public. This points to the need for further work on how resources might better be organised and signposted for non-experts.

Language is also a barrier. Although this study has illustrated that individuals from both participant groups acknowledge that language issues can discourage members of the public from reading scientific articles, it has shown that the language barrier was perceived as a bigger problem by OA Stakeholders than by some of the Lay Participants. It is unhelpful automatically to regard members of the public as scientifically illiterate, as this can make attempts to communicate scientific results seem patronising. Lay Participants had developed various strategies for dealing with language issues, including particular techniques for reading articles, and calling on the help of other patients through, for example, online medical forums.

Despite these barriers, there was general enthusiasm amongst OA Stakeholders involved in this study for more public engagement with OA research, although they did not regard a lay audience as the primary target audience. The main theoretical arguments put forward for engaging the public with research correspond to the "frames" identified by Davis: "public accountability" (publicly-funded research should be publicly available), "transparency" (the general public should be able to actually evaluate research approaches), and "public good" (social benefits are gained from more public access).[15] These arguments were often articulated at a level of principle by OA Stakeholders and this may have meant that at times the practical experience of members of the public accessing research may not have been fully taken into account. More research is clearly needed on the impact of OA material on the public addressing the extent to which these theoretical benefits can be translated into practical outcomes. What is at least clear from this study is that the Lay Participants felt there was not enough OA material online to be useful and that it was difficult to find. This suggests more work could usefully be carried out by OA Stakeholders on raising awareness of resources that are available and improving their discoverability, as well as working towards making more resources available. Both sets of participants saw the availability of lay summaries and access to the full content of research articles as closely related issues. Summaries were not seen as an alternative to full content but as a complement. This would imply that lay summaries of non-OA material would not be deemed as useful and, in view of their comments on paywalls, might even be seen as creating frustrations for lay readers. However, as this was not the main topic of investigation in this study, it would be useful to pursue this further taking into account issues raised here.

It could be argued that OA and communication science to the public are not necessarily intrinsically linked. OA research "does not assume an obvious educational role": outputs are available unmediated and free of charge, and members of the general public have the choice to read them or not in their original form.[4] In contrast, communication of science to the public focuses directly on translating the outcomes of research for the general public. Significantly, however, the opinions of the OA Stakeholders in this study demonstrate that some thinking is moving away from the first model towards a “logical conclusion” in which it is necessary to mediate OA research in order to make it understandable to the public.

Lay summaries are clearly partly designed to do this. In particular, they address some of the current barriers to accessing research, including language and awareness issues. Potential practical benefits of lay summaries were identified by both groups of participants in this study, including saving time and effort, simplifying statistics and providing a choice of reading levels for the lay reader. In a health information landscape made up of different sources, summaries could also help play a role in counteracting biased science reporting in the media and online. Some of these findings could now be usefully tested in quantitative studies and also used to inform investigations of how the benefits might apply to a wider range of lay stakeholders, including journalists and policymakers – two other groups sometimes included amongst potential beneficiaries of OA.

Clearly, the decision to invest financially in producing lay summaries signals a significant attempt to engage a lay readership with research. However, this study demonstrates that there is as yet no consensus among OA Stakeholders about the most cost-effective way to produce summaries. This is an obvious area for further work investigating different approaches to producing and funding lay summaries, including modelling costs and scaling issues. Practical issues such as who should author lay summaries and, in particular, the role of the researchers themselves, and the implications of authorship of summaries for quality assurance, merit further investigation and experimentation. Further work could also be usefully carried out in investigating the issue identified in this study of the ideal reading levels associated with a lay summary in order for it to appeal to a broad audience. In particular, testing the view expressed by a number of participants in this study that it is likely that lay summaries will largely benefit a more educated section of the general public could help to determine the future direction in which publishers take lay summaries.

All of this points to the importance of the need for communication between OA Stakeholders and members of the public. Carrying out further consultation with members of the public about their (potential) use of OA outputs in general and the usefulness of lay summaries in particular is likely to achieve the most useful outcomes and reduce the risk of summaries appearing a ‘box-ticking’ exercise in public engagement. This work could also be extended beyond medical research to include other scholarly outputs in science and technology as well as the social sciences and humanities. It has often been observed that open access has the potential to benefit the general public, and now there is more scholarly material becoming available in OA form, this claim can begin to be tested.

Conclusion

This study has investigated attitudes to lay summaries of OA journal articles in the context of engaging the public with medical research by the placing lay summaries in the wider contexts of patients’ information seeking behaviour and OA Stakeholders’ research and publishing activities. It has provided an early perspective on this to date little-investigated topic and highlighted a number of key issues which would benefit from further investigation. It has shown that patient access to the research literature is seen as important as one of a number of sources of information that can help them manage their health conditions in line with the informed patient model. However, accessing the literature was reported to be problematical, particularly because of paywalls, and there were also difficulties in using it, including language barriers. Lay summaries were seen to make a helpful contribution to approaches to improving patient access to information. Further work to test these conclusions is now needed investigating both patients’ and providers’ perspectives. In particular, there is a need to develop an evidence base associated with the costs and benefits of such an approach. Further studies could also usefully extend the scope of research from medical information to other areas of scholarly research examining the question of whether research can reach beyond the academy, and if so, how this can be achieved. The extent to which the arguments deployed to support OA (such as transparency, accountability and public good arguments) lead to OA reaching the public being seen as a “logical conclusion” of the movement is an interesting dimension of the OA debate that merits further exploration. It is often claimed that OA can benefit the general public. As OA begins to enter the mainstream of publishing, now is a good time to test those claims.

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