

# Charities' perceptions of open access to medical research: a situational analysis

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**Abstract.** This poster outlines the methodology and preliminary results of a study exploring medical charities' perceptions of open access to scholarly research. It is part of a wider project investigating the use of OA research in different non-academic contexts, and it is based on analysis of eight semi-structured interviews conducted with staff members in medical charities. Interviews were analyzed using Situational Analysis, a form of constructivist grounded theory developed by Adele Clarke. Preliminary results are presented, including the expertise and insider knowledge which medical charity staff use to get access to paywalled research, the values and risks (to different social groups) perceived in making research open access, and the different discursive constructions of the 'non-academic' user who wishes to access research. The study contributes to a small, but growing body of research exploring the potential value of open access outside academia.

**Keywords:** Open Access, Scholarly Publishing, Situational Analysis

## 1 Introduction

'Open Access' has been defined by Suber [1] as research literature that "is digital, online, free of charge, and free of most copyright and licensing restrictions." Campaigns to make research outputs OA have become increasingly mainstream over the last twenty years, and many institutions and funding bodies now have policies and practices in place to encourage open access. Despite this, issues around the value and implementation of OA are still hotly debated [2]. One of these debates concerns the value of OA 'beyond the academy, as there is now awareness that research access could also be useful for people working and living outside an academic context. This complicates the meaning of 'access,' forcing OA advocates to think beyond the removal of paywalls to consider questions of discoverability and comprehension.

This poster describes the methodology and preliminary results of a study exploring the use of research, and the potential benefits of (and barriers to) open access in non-academic contexts. It focusses particularly on a set of eight interviews conducted with staff at medical charities, exploring their own use of

OA research and their perspectives on providing and funding open access to medical research for a wider audience.

## **2 Background**

The Budapest Open Access Initiative (BOAI) stated that that research literature should be accessible to “all scientists, scholars, teachers, students, and other curious minds” [3]. Although Suber argued that the main priority for OA should be access for the research community, with wider access a welcome side benefit, other advocates have focused specifically on the use of OA literature by lay readers [4]. Integral to the discussion of OA for non-academics is the question of accessibility, and the difficulty of specialist or technical language. This type of access has been defined as “conceptual,” as opposed to “technical or material access” [5]. Some OA journals have already taken steps to address the question of conceptual access by adding lay summaries to their research articles [6].

So far, there has been little empirical research focusing on this area. Notable exceptions include Zuccala [7], who used focus groups of members of the public to gauge attitudes towards OA, and a 2015 quantitative analysis of questionnaire data and social media altmetrics in Latin America [8]. Studies have also been carried out investigating the impact of providing access to research to healthcare staff, and to the third sector [9,10]. This study hopes to contribute to this small, but growing body of research evidence exploring the potential value of OA outside academia.

## **3 Research Questions**

The research seeks to answer the following questions:

- How do medical charity staff make use of online scholarly research in their work?
- What are the barriers to research access that medical charity staff encounter, and how do they negotiate these barriers?
- How do medical charity staff perceive ‘open access’ in the context of their own research needs?
- How do medical charity staff perceive ‘open access’ in the context of their work with wider communities of patients, donors and the general public?

## **4 Method/Approach**

The research presented in this poster is part of a wider study focused on access to research in two areas, health and education, selected because of their perceived social relevance. The research was qualitative and based on semi-structured interviews with

different stakeholder groups; staff in charitable organizations, medical and education researchers, teachers, and members of the public with chronic health conditions. Participants were recruited initially using a purposive sample, followed by theoretical sampling once analysis had started, to identify perspectives that had not yet appeared in the data [11]

This poster focuses on the analysis of a set of eight interviews with staff in medical charities. Interviews were conducted with each participant, transcribed and coded using NVivo. Themes were then identified using Situational Analysis, a methodology based on constructivist grounded theory and developed by Adele Clarke [12]. It draws on the inductive approach of traditional grounded theory, using theoretical sampling and constant comparison, whilst emphasizing the constructed nature of both the interview data itself and the insights generated from it. It also draws on Strauss's work on social worlds/arenas [13], to conceptualize society as consisting of "layered mosaics of social worlds" [14]. Individuals participate in different, overlapping social worlds in different ways, and form shared understandings through this participation. Situational Analysis was considered appropriate for this research, as it was possible to identify a number of these social worlds concerned with the issue of open access. Three mapping exercises were carried out on the coded transcripts in order to conduct the analysis. Situational mapping identified key elements in the situation (including human, non-human, political/economic, collective, spatial, temporal and discursive), social worlds/arenas mapping identified the main social worlds in the situation of enquiry, and positional mapping identified the main (contested) positions taken on key issues [15]. The preliminary results presented in this poster are drawn from themes generated using these mapping exercises.

## 5 Conclusions

Preliminary analysis of the interview data suggested that there were a wide variety of motivations for staff at medical charities to access research, particularly for those members of staff involved in the management of research grants, or the communication of research findings. Participants often reported no official access to subscription resources. Instead they were involved in complex networks of access, including making use of their own, or colleagues' university logins. They reported extensive use of open access resources (especially through PubMed), in conjunction with a variety of other 'workarounds' to access paywalled research. A variety of these workarounds were identified, such as contacting the author directly, academic social networking, and using platforms such as SciHub. Differing positions were taken regarding the value and risk of using these platforms.

The social worlds of the staff in large medical charities and academic researchers were close, and had many overlaps. This allowed charity staff to access specialist knowledge and an understanding of academic norms and cultures, which helped them to access and understand scholarly literature. However, it suggested that a lack of this

specialist knowledge would impact individuals and smaller organizations attempting to access research. This became particularly evident in comparison with interview data from the larger project, which emphasized that a lack of time, connection with academia, specialist knowledge and confidence in accessing research could all affect the way people interacted with research.

Members of the public were discursively constructed as potential research users, ranging from the ‘informed’ patient, demonstrating their expertise through involvement in the research process, to the person with an ‘agenda,’ deliberately misinterpreting and sharing research online. The importance of research mediation was emphasized, with doubts raised about the overall value of providing access without a wider context of improved discoverability and science communication. Cost implications were also raised, and participants, despite being generally positive about open access, were sometimes conflicted about the best way to spend charitable funds in this area.

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