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Title: The 'innocent collection of details' and journal requests to make qualitative datasets public post-consent; open access data, potential author response and thoughts for future studies

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Introduction

'There are some circumstances where, for example, in a talk to a support group there is a risk of revealing your identity through a combination of apparently innocent details – such as a job title, a rare diagnosis, age group and family status' (Participant Information Sheet; ref)(Participant Information Sheet; see, Branney et al. 2017)

This 'innocent collection of details' qualifier of anonymity is likely to be at the forefront of many qualitative researchers minds as they consider how their research practices must adapt as we move towards what is termed *open access data*. Informally, we are hearing from psychologists who are finding journals asking them during manuscript submission to confirm that their data is available in a public archive (and/or inviting them to concurrently submit their data to a repository supported by the publisher). In this article, we shall consider post-consent requests for data archiving, outlining some of the background before considering how they can be rebutted. We argue that the agreement and in particular the specific conditions related to participant consent should be given priority but recognise that researchers now need to consider building in data management and archiving conditions into the design stage of future studies. In focusing on post-consent requests for data archiving, we mean studies that have completed and concluded all consent procedures. From our perspective, this means opportunities for the researchers to re-negotiate anonymity, confidentiality and publication agreements with participants are limited. For example, researchers may have implicitly agreed 'no further contact' with their participants after sharing a summary of the findings. Overall, we are optimistic about open data when it is considered at the design stage and recommend some resources for data curation that may limit the 'innocent collection of details' risk to anonymity and confidentiality.

Background

There is a growing movement calling the archiving of research data in public repositories to become a routine practice of science. The archived data is therefore able to take on a life beyond the original study, potentially re-used through secondary analysis by other researchers. The British Crime Survey, Census and General Household Survey are examples of open access quantitative datasets of research that are freely available and re-analysed across the world. Rather than these standing out as exceptions, there are a range of calls from public and research institutions - such as the Economic and Social Research Council (2013) The Royal Society (2014), the European Commission (2012) and the Organisation for Economic Co-operation and Development (2004) – calling for the routine preparation of and subsequent sharing of research data in publicly available repositories, albeit with different levels of 'access'. This means that research studies now need to consider data management and archiving as a step within the research design, ensuring that governance, ethical review and consent with participants are negotiated appropriately whilst meeting the demands of publishers and funding bodies. Researchers will have to think about how they curate their data, ensuring the archive is fit for re-use. UK institutions are already outlining funding policies (e.g., Economic and Social Research Council 2013) and governance processes (e.g. NHS National Research Ethics Service) which in some cases now make the availability of open data a mandatory aspect to the grant conditions. Quantitative data in the form of large scale surveys and 'big data' are generally over-represented in comparison to

qualitative data in more well-known open access archives such as the UK Data Archive. However, there is growing awareness, investment and crucially, researcher support, in representing qualitative data within archives such as Timescapes¹, UK Data Archive Qualibank² and the UK Data Service³. Along with Nollaig Frost, we have recently conducted an interview study exploring the ethical, pedagogical and practice issues qualitative researchers are negotiating in relation to open access data. While the analysis is underway at the time of writing, there is, for example, a view that the those who collected the data have a privileged relationship with it although this does not extend to determining how it is interpreted. This point speaks directly to the issues that we are facing as qualitative researchers as we try to protect and honour our relationships with participants while recognising that the data collected has potential beyond the researchers' intention.

Journals and publishers are increasingly requesting authors submitting manuscripts to confirm that data underlying their findings are available publicly or to archive them concurrently, sometimes recommending approved or proprietary repositories. The Public Library of Science (PLOS)⁴ have a policy across their journals that all data should be available without restriction. Interestingly, PLOS are explicit that charging for accessing the data does not count as a restriction and it is therefore not a fully 'open' policy. Rather than an explicit policy, the publisher Nature⁵ 'believes' that "wherever possible data should be open, accessible and reusable". Wiley⁶ have an 'open data' plank of what they call their Open Science agenda, which is likely to filter through to their individual journal policies, including invitations for authors to use the publisher's repository. It is important to note that these policies include exceptions; privacy is one that we want to highlight because even in anonymised data there is a risk that the innocent collection of details might reveal participants' identity. Indeed, in the study we are, at the time of writing, analysing that explored open access with qualitative researchers, participants' anonymity was an important reason for arguments against archiving their data.

Responding to Requests to Archive Data

Study data should only be archived when there has been thorough consideration of how it should be realised in the design, ethical review and governance of the data collection and explicitly agreed with participants. When publishing a manuscript (and when the study is likely post-consent), the authors may be asked to confirm the availability of their data in a repository. Institutional pressures and a growing critical awareness of the need to offer research data 'open' for future use may leave them inclined to make this possible but we would argue against post-hoc re-negotiation of consent. First, researchers may have offered to do as much as possible within their control to maintain participants' anonymity and confidentiality. Archiving transcripts, audio and video files and other related visual data

¹ <http://timescapes.researchdata.leeds.ac.uk>

² <https://discover.ukdataservice.ac.uk/QualiBank>

³ <https://www.ukdataservice.ac.uk/get-data/key-data/qualitative-and-mixed-methods-data>; the qualitative archive here was previously known as the Economic and Social Data Qualidata

⁴ <http://journals.plos.org/plosone/s/data-availability>

⁵ <http://www.nature.com/openresearch/about-open-access/open-data/>

⁶ <http://olabout.wiley.com/WileyCDA/Section/id-406071.html>

such as photographs and drawings, even when anonymised, raises risks to anonymity and confidentiality, particularly through the innocent collection of details (see for example one of the first Open Access articles in Qualitative Research in Psychology on anonymity in the Internet Age; Saunders et al. 2015). We would argue that data should only be archived with participants' explicit consent, which means giving them time to think about the implications and discuss with those close to them. While there may be circumstances where researchers could return to ethical review and participants to renegotiate consent, it is important to remember that it will take time and preparation. Importantly, unless the researchers have agreed follow-on communication with participants, there is usually an implicit agreement of no further contact. For example, in a video interview study of a rare cancer presented on the award winning healthtalk.org, the researchers agreed with their participants that they would invite them to a study of the 'demo' site and to the public launch (Witty et al. 2014, Branney et al. 2011) and that data could be kept for further analyses (Branney and Witty 2016, Branney et al. 2016, Branney et al. 2014a, Branney et al. 2014b). While the analysis on the website includes audio and visual quotes for some participants and therefore reveals their identity, public archiving of the transcripts was not discussed during data collection. It is possible that many of these participants would, retrospectively, agree to public archiving but we would argue that they have concluded their involvement and the researchers should ask no more than that which was initially agreed. Second, curating data for archiving takes time and skill. If researchers do re-negotiate consent, they will need to spend considerable time anonymising their data and ensuring it is in a format that others can navigate. To illustrate these issues in a relatively small study, a one-day participative event explored treatment choice with fewer than ten participants (Branney et al. 2017). In a focus group, all participants designed an interview schedule, which they subsequently used in participant led interviews. The data therefore includes audio and video files, transcripts, interview schedule, and researcher notes. Assuming all participants consent to archiving all data, the audio and video files and transcripts would need anonymising in parallel for consistency and curated with the interview schedule and researcher notes into a format that explained the role of each file in the study. Given these difficulties, it is important to consider how to decline requests to make data public.

When declining a request to archive data from publishers, we recommend the *define-defend* approach. Murray (2009) explains this rhetorical strategy in her guidance on doctoral viva voce. Before *defending* your approach, it's important to define (or explain) what you did. This is particularly important when responding to someone with little knowledge about your work. Importantly, key terms in data archiving, particularly consent and privacy, have a range of meanings and therefore explaining what you did will help establish their meaning in relation to the data underpinning your manuscript. This means that all involved should have shared meaning of the context in which the defence is situated. For example, you may thank the editor for the opportunity to deposit data in their publisher's repository and explain how you negotiated anonymity and confidentiality with your participants. You could then decline the request to archive data because it would, for example, through the innocent collection of details, as is so often the case in qualitative research, will breach participants' privacy (perhaps referencing the publisher's policy on exceptions to data archiving).

Conclusion

In this article, we have presented a brief background to open access data. In response to requests to archive data when publishing (where you have completed all consent procedures with participants), we recommend using the define-defend approach using the privacy exception in publisher's data policies. Rather than trying to renegotiate consent after the study, we think study data should only be archived after thorough consideration in the design, ethical review and governance, which should include explicit agreement with participants. While this article is far from exhaustive, we hope it piques your interest. We are keen to convey that we are not 'anti-archive', but need confidence that our research practices, in terms of obtaining appropriate consent and appropriate data management, are not overlooked in favour of the rapid expansion of making data 'open'. We hope you will consider archiving data for future studies. We have included some links on anonymising data (also termed data redaction and de-identification) and highlight one for qualitative studies.

Links on Anonymisation

- US National Institutes for Health Data Sharing Policy and Implementation Guidance, particularly 'Human Subjects and Privacy Issues': https://grants.nih.gov/grants/policy/data_sharing/data_sharing_guidance.htm see particularly 'Human Subjects and Privacy Issues'
- Canadian Institutes of Health Research Best Practices for Protecting Privacy in Health Research; <http://www.cihr-irsc.gc.ca/e/29072.html>
- UK Data Archive: Anonymisation Overview; <http://www.data-archive.ac.uk/create-manage/consent-ethics/anonymisation>
 - Note this this includes another page focusing on qualitative data: <http://www.data-archive.ac.uk/create-manage/consent-ethics/anonymisation?index=2>
- Australian National Data Service, Data Sharing Considerations for Research Ethics Committees; http://www.ands.org.au/__data/assets/pdf_file/0009/748737/HREC-Guide.pdf

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