

Appendix 1

Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

	Page/line no(s).
Title and abstract	Page 1
Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Page 1
Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Page 1
Introduction	
Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	Pages 2-3
Purpose or research question - Purpose of the study and specific objectives or questions	Page 3
Methods	
Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale**	Pages 3-4
Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	Page 4
Context - Setting/site and salient contextual factors; rationale**	Pages 3-4
Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**	Page 3
Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	Page 4
Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**	Pages 3-4
Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Pages 3-4
Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Page 3
Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Page 4
Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Page 4
Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Page 4
Results/findings	
Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Page 4
Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Pages 4-9

Continued

Discussion	Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Pages 9–10
	Limitations - Trustworthiness and limitations of findings	Page 10
Other	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Page 11
	Funding – Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Page 11
	*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.	
	**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.	
	<u>Reference:</u> O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Academic Medicine, Vol. 89, No. 9 / Sept 2014 DOI: 10.1097/ACM.0000000000000388	



Appendix 2

Warm-up discussion (providing background to interviewees involvement in the community)

1. How long how have you been living in the area?
How long have you lived in the UK? (if migrant)
2. Could you tell me if and how are you involved in your community?
Are you a member of any local charity or groups?

Data collection & usage

Provide a description of what big data is.

3. How you ever been interested in how your medical data is being (re)used?
How do you fell about how it is used?
4. What kind of medical data do you feel researchers should have access?
How long should the data be accessible?
Where should it be stored?
5. Who should have access to your medical data?
Medical professionals, researchers, private companies, government, transfer abroad?

Public involvement

6. How do you think researchers should involve communities in the design and governance of research?
Anything particular within your Polish/South Asian communities?
Where should researchers recruit people?
Who should get involved? How to make sure they are involved?

7. What are the challenges or things helping you to involve your community in the design and governance of research?

What are their causes?

How can these barriers be overcome? Who is responsible for it?

Public engagement

8. How much are you interested in learning about how your medical data is used for research?
Would you like to know what changes and new solutions for medicine these offers?
Is it important to do it?
9. How do you feel researchers should share and promote research projects?
Anything particular within your Polish/South Asian communities?
What is the best medium to share this information? Tv, newspapers, NHS leaflets or social media?
What about the language barrier?
Have you been exposed to any campaigns around benefits of big data research? E.g. #DataSavesLives

Conclusions

10. What do you feel should happen because of this research?
How could it be shared among researchers and seldom-heard communities?
11. These were all questions from me. Would you like to add anything else to what we discussed?

