


BMJ Open Quality Person-centred data collection methods to embed the authentic voice of people who experience health challenges

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To cite: Prior SJ, Mather C, Ford K, *et al.* Person-centred data collection methods to embed the authentic voice of people who experience health challenges. *BMJ Open Quality* 2020;**9**:e000912. doi:10.1136/bmjopen-2020-000912

Received 6 January 2020
Revised 23 June 2020
Accepted 3 July 2020

INTRODUCTION

The patient or consumer voice in health-care has evolved from an aspiration to becoming an expectation, which in some developed countries is respected by inclusion in nationally auditable standards (Australian Commission on Safety and Quality in Health-Care).^{1 2} Inclusive and appropriate research about patient perspectives requires skills and resources to ensure that sound quality assurance processes are designed, delivered and evaluated. Understanding the characteristics of the population is key to ensuring appropriate representation of consumers in person-centred or patient involvement research methods. Vulnerable patients, those with ongoing health and literacy challenges, can benefit from advocacy, and often are not used to being valued in terms of their own views, lacking empowerment to present their own opinions. Additionally, traditional methods need to be used more sensitively to ensure that these consumers can be included and participate equitably in the quality assurance process.

Meaningful person-centred engagement is occurring more often in healthcare settings through the process of codesign. Originating from design science, codesign is defined as the engagement of patients and other consumers, to capture their experiences in the design or redesign, of healthcare services and is a central concept of health improvement initiatives.³ Codesign includes core principles of equity, understanding of experience and service improvement and provides an avenue for person-centred participation, recognising that consumer experience and knowledge is increasingly being considered important to complement professional knowledge.⁴ Direct engagement of patients and other consumers in research and health service improvement activities requires careful methodological planning around

desirability and feasibility and the practical implications for the involvement of patients and consumer as participants.⁵

The following examples of person-centred research methods enable the authentic voice of individuals who experience health challenges to be collected. The five approaches provide opportunities for the voice of consumers to be heard. Each of the methods can be used to emphasise active participation by consumers in the design, delivery and evaluation of health services safety and quality systems.

METHODS

A review of person-centred research methods in the literature was undertaken to scope for current techniques to ensure currency of the information. Patients or consumers were not involved in this review of methods as the focus was on different strategies, rather than recruitment of participants in any study.

The search strategy employed a pragmatic approach⁶ as it allowed the research methods to be the focus. The authors initially searched individually for articles using multiple databases including CINAHL, MedLine and Scopus. Articles that described person-centred strategies for the methods within their area of expertise were sought. A further search using references of articles and updates over the time period of development of the manuscript was also undertaken. The research group met monthly over a 12-month period to discuss the research methods, literature and develop the article. The authors included research that specifically related to methods deployed for researching person-centred issues, rather than reports of findings from consumer involvement in research studies.



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INTERVIEWS

Interviews can be used to gather information as part of qualitative and quantitative data collection for research, education or quality assurance purposes. Understanding the characteristics of the group of interest, identifying potential issues with recruitment, ethical concerns such as consent, privacy and confidentiality need to be addressed. The development of the interview schedule usually depends on the methodology. For example, semi-structured questions with prompts may be more valuable for encouraging narratives, whereas a more structured schedule could promote eliciting specific information from participants. A previous study⁷ used face-to-face interviews to engage with immigrant patients and ascertain factors influencing their ability to trust healthcare providers. The findings outlined the complexity in developing rapport and creating trust in intercultural healthcare, a valuable outcome for improving person-centred care and overall quality in healthcare. Additionally, Sandvik and McCormack⁵ highlighted the importance of deploying a person-centred framework that promoted mutuality of understanding between the researcher and interviewee.⁵

Skill in interviewing relies on the interviewer being able to prompt and elicit required information in partnership with participants without creating bias or leading the voice of the participant's opinions, experiences or descriptive accounts. Initially, it is important to develop rapport and ensure the participant understands the purpose of the data collection and willingly consents. The setting of this type of interview may also alter the patient–researcher relationship. Conducting an interview in the patient's home may differ from being carried out in healthcare environments and should be considered when planning. It is also important to ensure that the participant knows there are no right or wrong answers.

Studies have shown telephone or digital technology can be as effective as face-to-face interviews.^{8–10} However, other considerations are needed when telephone interviews are selected as a cost-effective method of data collection. As visual cues are lacking, it is important that patients can hear adequately, that there are no distractions and that there is an understanding of what the interviewer is asking. The participant may divulge information such as using a hearing aid or hands-free telephone that could be useful for ensuring a successful interview. Preparation is important for both parties including confidence in using the technology for interviewing or providing assistance to the participant. A previous study comparing the use of telephone and face-to-face interviews found that there were some advantages to the telephone method.⁹ The authors suggest that participants who agree to be interviewed about sensitive topics may prefer the anonymity; it is easier to reach a wider participant group and that interviewer and participant safety is more easily controlled.

Following completion of an interview, it is important to ask the participant whether they would like to add any other information. This opportunity may be where

participants provide vital information in their own words without the constraints of scheduled questions. Similarly, asking participants whether they would like to be sent a copy of the transcript, so they can verify the discussion during the interview is important if the participant has difficulty with expression or other comorbidities, such as deafness or poor digital voice connection that may have hindered understanding during the interview.

FOCUS GROUPS

Focus groups use group discussions, facilitated in a specific manner to gather informal information on a selected topic. In healthcare, focus groups can assist in generating a rich understanding of consumer experiences, beliefs and values, and developing strategic goals aligned with these outcomes. While one-on-one interviews can be suitable to obtain a measure of personal feelings and opinions, which can be beneficial for eliciting the opinions of minority groups, focus groups may be useful for obtaining opinions that are likely to reflect the majority.¹¹ Codesign using focus groups is an opportunity for patients and other consumers to consider and discuss their experiences within healthcare systems and services in a collaborative, participatory setting.⁴ Theis *et al*¹² held focus groups to determine what factors were important to patients during their healthcare journey. This information was then utilised to develop 'report cards' as a strategy for consumer choice in healthcare, commonly used in the USA to compare providers and health plans as well as incentivise quality improvement.¹²

The size of a focus group can determine the progression of discussions and, although sometimes difficult and unpredictable, ensuring optimum number of participants can assist with achieving the desired outcomes. Six to eight people per group are generally recommended, however, focus groups can work with as little as 3 or up to 14 participants.¹³ To encourage respectful and active conversations among all participants, the moderation of focus groups requires a complex set of skills. The moderator needs to be able to guide the discussions without introducing bias such as leading the group or unconsciously providing positive or negative cues. They need to be able to encourage a relaxed and comfortable space for participants to engage.

The composition of focus groups plays an important role in determining the data that will be gained from the discussions. For example, purposive sampling, considering the socioeconomic status of potential participants, has been shown to be beneficial in focus groups with chronically ill participants where it was demonstrated that societal norms are flexible and can be challenged and reformulated during focus group discussions.¹⁴ However, forming a representative focus group does not ensure participants will be equally represented in discussion. Participants with higher education, health literacy and better knowledge of health systems have the potential to dominate conversations because they are better equipped

to do so. Individuals participating in focus groups of this nature often construct their ‘patient view’ by establishing themselves as knowledgeable, or by validating or challenging another’s claims, depending on the dynamics of the group.¹⁵

A further limitation that can hinder focus group participation is poor moderation. Tausch and Menold¹⁶ describe inadequate moderation as a major barrier to successful focus group discussion for a variety of reasons including poor group dynamic, inability to use various communication methods, concentrated attention and poor preparation.

There has been recent interest in the use of online focus groups¹⁷ which due to the COVID-19 and social distancing measures may become more accepted by groups who could be impacted by potential exposure to pathogens by leaving home. Additionally, consumers who are less mobile, lack transport or have difficulty attending a face to face focus group could join remotely to participate in data collection processes. Conversely, the use of online focus groups may also preclude citizens who do not have access, or know how to use digital technology. Additionally, some people with specific health challenges such as hearing loss may not be able to fully participate or prefer to use a traditional face to face approach where visual cues are more easily interpreted.

CITIZEN JURIES

A citizen jury is a participatory action research method that draws on the symbolism of a jury trial.¹⁸ It is a deliberative and inclusive approach for community engagement that is increasingly being used to gain understanding about issues of health concern and policy. Key tenets of citizen juries are inclusivity, deliberation and active citizenship.¹⁹ It is these features that indicate citizen juries can allow representation and give a voice to those who might normally be less visible.

In a citizen jury, evidence and opinions of experts are presented to a representative group (jury) who then deliberate to reach an outcome—for example, a consensus or priority list.¹⁸ Citizen juries are based on the notion that any person, given the opportunity, time, support and resources is capable of decision making about complex technical, health, scientific and ethical issues,^{20 21} including diverse subjects such as population ethical issues; resource allocation; health policy; environmental health and community well-being.¹⁹ Citizens’ juries acknowledge representation is not just for the very literate and advantaged, but is, by intent, inclusive of people who experience wide-ranging disadvantage and inequity. The approach provides a presence or ‘voice’ of marginalised or minority groups so that their interests and perspectives are included.²²

The process is overseen by a steering committee to guide question development, evidence presentation, oversight, stakeholder engagement and dissemination or implementation.²¹ Recruitment occurs by word of mouth;

via community or government organisations; electoral role or random digit dialling or more deliberative.¹⁹ Jury size may be 12–24 citizens who meet for a period of time, usually between 1 and 5 days¹⁹ to ‘hear, question, challenge and clarify expert witness testimony from a range of perspectives’.²⁰ In healthcare, expert witnesses may include clinicians, policy-makers and health consumers who provide testimony about their personal experience of the aspect of healthcare under deliberation.²⁰

A study²³ involved a citizen jury to assess health needs in an area with high levels of social deprivation and social exclusion, including poverty; poor housing; high levels of death, illness and disability; alcohol and drug abuse; poor access to health services and low literacy. Rejecting traditional methods of jury selection, recruitment occurred by way of talking to people at post offices, supermarkets, outside schools and at bus stops to ensure a diverse group reflecting the needs and interests of the community. This example of citizen juries shows how, with careful planning regarding recruitment and support during the period of participation, the method can be inclusive of some of the most marginalised in communities.

PHOTO ELICITATION

Photo elicitation interview (PEI) refers to the use of photographs to trigger dialogue in the context of research interview.²⁴ In PEI, interview is stimulated and guided by images. These images can be chosen from archives or magazines, or created by the researcher or the participant. When photographs are taken by the participant, the method is referred to as native, reflexive or autodriver PEI.²⁵ Autodriver PEI shifts the balance of control over generation of data from the researcher to the participant. The increased control autodriver PEI gives participants makes it a person-centred data collection method.²⁶

Images change the focus and energy of conversation²⁷ and can lead to information and understandings that traditional oral interviews may not. Language processing uses different areas of the brain compared with processing visual information, so the use of image-based research methods enables ways of creatively expressing thoughts, concepts and experiences. In doing so the methods can present a different way of telling as well as a different way of knowing.²⁷ Participatory interview activities can be more engaging and can facilitate a more relaxed atmosphere, reduces the power imbalance that can exist between participant and researcher.

This participatory method is an effective way of achieving partnerships with patients and consumers within health services²⁸ and provides a way for inclusion of those less visible and lacking representation. This was demonstrated in a study²⁹ where children took photos to explain things that were important to them, thereby facilitating children’s control over the data.

When photos taken by patients form part of the data there are specific ethical considerations as participants are more visible, including, but not limited to, their physical



appearance and representation. Details of their lives are revealed making them much more identifiable than they might be in traditional research.³⁰ Robust approaches and clear guidance are required about the taking of and use of photographs and specific consent obtained around the use of images in papers, conferences and other forms of dissemination.²⁹

VIDEO-REFLEXIVE ETHNOGRAPHY

Video-reflexive ethnography (VRE) is a participatory research method that regards consumer and clinician participants as experts and encourages their involvement in the research process.³¹ VRE studies tend to start with participant observation and interviews³² to build relationships with participants. The method involves video recording episodes of clinical care, conducted in healthcare settings in real time, known as video ethnography and showing these video recordings back to participants, known as video-reflexivity to elicit their responses and collectively identify practice change.³³

VRE is a strength-based method and is about opening up or exnovating healthcare and recognising what works well in practice.²⁹ Exnovation is more than visualising a clinical episode of care, as its impact is evident in the video-reflexive sessions where clinical care is made explicit.³¹ Wyer *et al*³⁴ used VRE to explore how patients nursed in isolation identify infection risks. Wyer *et al* showed the patient a video recording of an episode of their care, and the video recording produced of the video-reflexive session was then shown to clinicians. Video-reflexivity can act as a catalyst as clinicians become privy to how the patient experienced their care, triggering clinicians to identify strategies to change their practice to improve health service provision. This type of active patient involvement is vital for ensuring quality, person-centred healthcare initiatives.

DISCUSSION

Australian Standards suggest that health service organisations must develop, implement and maintain systems to partner with consumers.² Capturing the consumer voice and experience is an important part of quality assurance across many facets of healthcare. The five methods described highlight a variety of useful tools for engagement with individuals who experience health challenges. The research method chosen to involve and represent consumers depends on the type of data that is necessary to guide maintenance of safety and quality assurance processes. Collaborative management, including patient involvement in design, delivery and evaluation of health services has been shown to drive quality improvement as well as improve health economics and satisfy the legal and moral rights to person-centred care and autonomy in health.³⁵

Patients need to know they are a valuable part of the healthcare team and that their experiences matter. Person-centred research methodologies capture the

patient. Interview methods such as semistructured interviews or the use of interview charts are supported for participants with health challenges as they can be a flexible and personal way of eliciting information for validation or as an experiential account. Similarly, focus groups can provide a level of social cohesiveness and support while building relationships with participants to allow them to share their experiences. The use of citizen juries has capacity to involve the wider community in decision-making, regardless of their status, while PEI and VRE methods provide alternative participatory approaches enabling improved communication in healthcare.

CONCLUSIONS

Patient or consumer involvement can take multiple forms in healthcare and there is no single strategy that can be considered to reflect best practice. Improving the health status and promoting the quality of life for individuals with ongoing health challenges necessitates cultural change at an individual, organisation and systems level. Incorporating a variety of person-centred approaches in routine quality assurance activities provides a means of capturing the experiences of representative consumer groups for the benefit of all stakeholders to ensure high safety and quality in healthcare is maintained.

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Contributors All Authors were involved in the conception of this paper. Each author led one section. A final draft of the paper was prepared by SJP and CM. All authors provided feedback for revisions of the paper and a final edited copy was prepared by SJP and CM.

Funding The authors have not declared a specific grant for this research from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests None declared.

Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement All data relevant to the study are included in the article.

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