How to improve diversity in patient and public involvement

Abstract

Patient and public involvement involves ascertaining the opinions of and collaborating with patients and members of the public to holistically improve the quality of research. Patient and public involvement provides patients with a platform to use and share their lived experiences. This allows healthcare professionals to gain a deeper appreciation of the patient's perspective, which enables future research to be more patient centred and tailored to patients' requirements.

Patient and public involvement aims to broadly encapsulate the opinions of the public, so ensuring diversity is recommended. This article provides a practical framework to increase diversity and engage hard-to-reach demographics in patient and public involvement. It highlights some common barriers to participation and methods for overcoming this, describes sampling frameworks and provides examples of how these have been adopted in practice.

Key words: Diversity; Patient and public involvement

Submitted: 14 March 2021; accepted following double-blind peer review: 23 March 2021

Rebecca Golenya[1,2]

George D Chloros[2,3]

Michalis Panteli[2,4,5]

Peter V Giannoudis[3,4,5]

Anthony Howard[4,5,6,7]

Author details can be found at the end of this article

Correspondence to:
Anthony Howard;
anthonyjhoward@leeds.ac.uk

Background

Since 1997, the NHS has striven towards creating a healthcare service that is patient centred, open, accountable and involves service users (Mockford et al, 2012). The National Institute for Health Research established INVOLVE to facilitate engagement of the public and community stakeholders in healthcare research (Domecq et al, 2014; INVOLVE, 2021). INVOLVE defines patient and public involvement as 'research being carried out "with" or "by" members of the public rather than "to", "about" or "for" them' (Hayes et al, 2012).

Patient and public involvement provides a platform for members of the public to collaborate with healthcare professionals to improve future research. Members of the public may have different priorities and opinions to healthcare professionals, so patient and public involvement enables these voices to be heard. The patient expert can provide a unique and invaluable insight which can holistically improve the standard of research (Ocloo and Matthews, 2016; Staniszewska et al, 2018). It has been estimated that 85% of healthcare research expenditure is wasted; common sources of waste include poor prioritisation, study design, methodology, dissemination and implementation (Minogue et al, 2018). Early patient and public involvement can help optimise these categories and reduce waste of healthcare research expenditure (Minogue et al, 2018).

Patient and public involvement activities may include asking members of the public whether the research question and outcome is a priority to patients (eg is the suggested research topic a concern for patients with the condition?) and if the language used in documents intended for the public is understandable to a lay person, as well as whether the methodology of a research project is acceptable to patients (Hayes et al, 2012). Members of the public can also become involved with grant proposal applications and aid more effective dissemination and implementation of the research findings (Tomlinson et al, 2019).

Diversity in the members of the patient and public involvement group is essential to ensure opinions from some communities are not marginalised (Hoddinott et al, 2018). However, patient and public involvement has been criticised for exclusivity and tokenism, with educated middle-class males being overrepresented as participants in medical research (Hussain-Gambles et al, 2004; Martin, 2008; Bonevski et al, 2014; George et al, 2014; National Institute for Health Research, 2015; Staniszewska et al, 2018). A report by the National Institute for Health Research (2015) acknowledged the perception of exclusivity.

How to cite this article:
Golenya R, Chloris GD, Panteli M, Giannoudis PV, Howard A. How to improve diversity in patient and public involvement. Br J Hosp Med. 2021. https://doi.org/10.12968/hmed.2021.0176

The National Institute for Health Research has identified key groups 'often excluded from user involvement, are people with alcohol and drug problems, young people, people who communicate differently, people who use residential services, people with learning difficulties, refugees and asylum seekers, people with complex support needs, older people and people from black and minority ethnic groups' (Beresford, 2013).

These groups can be termed hard-to-reach demographics: they have been described as populations that are physically or socially isolated, vulnerable (eg subject to stigma) or hidden (meaning that there are no sampling parameters or defined limits for the population) (Ellard-Gray et al, 2015). The exclusion of these demographics within patient and public involvement impedes on the generalisability of the results, equity of healthcare, and opportunity for ethnic subgroup analyses (Hussain-Gambles et al, 2004; George et al, 2014).

This review provides a practical guide to improving diversity in patient and public involvement recruitment through:

1. Highlighting traditional recruitment methodologies
2. Addressing individual barriers to recruitment and/or participation
3. Using sampling frameworks when recruiting hard-to-reach demographics.

Traditional recruitment methods

Before recruitment, INVOLVE (2012) recommend creating a timeline, calculating expenses, applying for funding (where required), creating recruitment documents for the public, and considering whether the combined skills of the research team are sufficient for the demands of the project. To promote transparency and co-production throughout the process, the 4Pi National Standards – principles, purpose, presence, process and impact – should be considered (National Involvement Partnership, 2015) (**Table 1**).

Clear, jargon-free recruitment materials should be available in various formats (eg letter, email and online) to promote resource equity (Hayes et al, 2012; National Involvement Partnership, 2015). They should detail the role description, personal specification and background information (INVOLVE, 2012). Advertising materials should be aimed at the appropriate demographic, who have the necessary characteristics, skills or lived experiences. For example, does the patient need to have a certain medical diagnosis (eg motor neurone disease), be involved in a certain community (eg support group for heart failure) or have prior patient and public involvement experience (INVOLVE, 2012; Tomlinson et al, 2019)? It is important to consider the time commitment to the patient and public involvement group and whether it would be feasible for members to attend regular meetings, or whether remote or infrequent meetings would be more appropriate (INVOLVE, 2012).

Methods to distribute recruitment material include social media, local support groups, charities (The Brain Tumour Charity, 2021), existing patient and public involvement groups (within the university or local hospital), or through discussion with a healthcare professional (eg outpatient clinics) (Hayes et al, 2012; Tomlinson et al, 2019). As an example, to recruit patients with a certain cancer diagnosis (eg leukaemia), outpatient services or established support groups may be beneficial. **Figure 1** gives an overview of the recruitment cycle.

Overcoming individual barriers to participation

Addressing the individual barriers to participation with practical solutions will ensure that members of the public feel valued and ensure that involvement is within their remit. Studies into the lack of diversity in research have highlighted that there are several recurring factors preventing individuals from hard-to-reach demographics from participating (Hussain-Gambles et al, 2004; George et al, 2014; Ellard-Gray et al, 2015). Barriers include fear, mistrust, accessibility, costs, consent issues, stigma, sociocultural barriers, poorly designed trials, and lack of information (Hussain-Gambles et al, 2004; George et al, 2014). Reducing barriers to participation will promote diversity in the participants, which promotes health equality, equity and generalisability of results to the general population. This article broadly categorises the individual barriers into mistrust, confidentiality, accessibility and sociocultural barriers.

Table 1. Summary of the 4Pi National Standards*

4Pi standard	Brief explanation of the principles
Principles	Highlighting shared principles and maintaining respect, inclusivity, equality and fairness
	Actively listening to the voices of the public and changing in response to expressed views
	Transparent and clear communication
	Minimising the power differentials between the public and professionals
	Acknowledgement of cultural differences and sensitive topics with adaptation of the language and actions used
Purpose	The purpose of the involvement is clear and agreed by the participants
	Individual roles and activities are acknowledged by the participants
	Informing of the limitations to the process and influence of the group
	Outcomes agreed, with monitoring and evaluation
Presence	Diverse members of the public should be involved at all levels to promote representation of the general population
	Involvement of service users who are directly affected by the topic under investigation
Process	Helping the public to contribute to the best of their ability
	Providing information that is accessible and through various means
	Engaging hard-to-reach demographics
	Providing role descriptions
	Flexible involvement of the public so they can become involved with different opportunities. Flexibility with the process promotes compassion when service users struggle with chronic health problems
	Considering and adjusting meetings to ensure they are patient friendly and acceptable when living with a chronic health problem
	Clear, regular, jargon-free communication
	Providing written documentation well in advance
	Providing feedback
	Supporting training, emotional, and administrative needs of the public
Impact	Impact involves assessing: ■ Were the intended outcomes achieved? ■ How have the public influenced the project? ■ How did the service users public feel about being involved the process? ■ What are the real-world changes that have occurred?

**The original document expands upon how these principles can be implemented in real world practice. From National Involvement Partnership (2015)*

Mistrust

Mistrust is a well-documented barrier expressed from many demographics (Witte et al, 2004; Syvertsen et al, 2012; George et al, 2014; Ellard-Gray et al, 2015; Condon et al, 2019). Historical unethical conduct (eg the Tuskagee syphilis study) contributes to mistrust and perpetuates the perception that research will ‘benefit Whites or the research institution’ and not their community (George et al, 2014). Mistrust also resonates from those who conduct legally questionable activities (eg drug users and sex workers) because of fear of legal repercussions (Witte et al, 2004; Syvertsen et al, 2012; Ellard-Gray et al, 2015). Patient and public involvement conducted by Morgan et al (2016) demonstrated several methods that can be used to reduce mistrust. This included community gatekeepers facilitating the initial meetings, which were conducted in informal locations with flexible meeting attendance; participants were also reimbursed for their involvement.

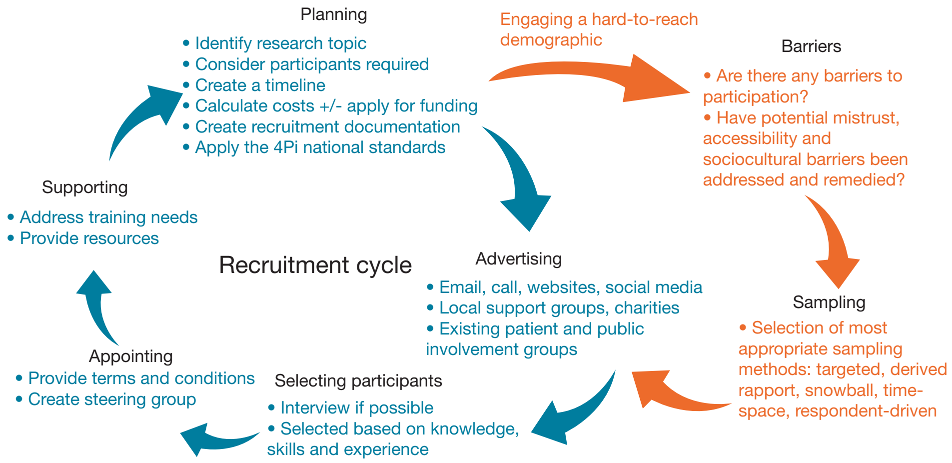

Figure 1. Overview of the steps involved when recruiting for patient and public involvement activities. Traditional methods are highlighted in blue. Additional steps that may be required when engaging hard-to-reach demographics are shown in orange. From Hayes et al (2012); National Involvement Partnership (2015).

Confidentiality

Breaches of confidentiality are another barrier to public participation (Ellard-Gray et al, 2015). Confidentiality is essential throughout patient and public involvement, to ensure discussion can be open and honest (Hayes et al, 2012). Despite its importance, absolute confidentiality can be difficult to maintain because of the typical format of group discussion. INVOLVE recommend providing both the public and researchers with the same confidentiality agreements and providing training to the public (Hayes et al, 2012). Participants should also be offered other opportunities to discuss patient and public involvement topics with the research team, should private discussion be preferable. Limits to confidentiality are imposed when adopting certain sampling techniques for hard-to-reach demographics. For example, in snowball sampling, each participant has been referred so their anonymity has already been compromised (Ellard-Gray et al, 2015). Alternatively, when using time-space sampling, members of the public may observe participation with the research team and infer a characteristic about them (eg that the participant is homosexual) (Stueve et al, 2001). This breaches confidentiality and may result in further unforeseen complications, such as facing stigma or discrimination in the community secondary to this (Stueve et al, 2001). Discretion is therefore urged when conducting interviews in the community and practical solutions to maintain confidentiality should be sought.

Accessibility

Accessibility can take various forms, from physical accessibility to access to supporting material. Using a variety of recruitment methods helps to ensure that the recruitment process is accessible, for example only recruiting in outpatient clinics will only recruit patients who are involved in their healthcare and thus opinions are likely to be polarised. Accessibility to meetings should be considered, taking into account the requirement for translators, establishments that have appropriate facilities for disabled patients, offering overnight provisions if there is a travel burden, feasible and/or flexible meeting times, and reimbursed expenses (Hayes et al, 2012). Alternatively, online meetings can be a convenient method to engage participants who are physically isolated. Provisions to supply technology and training to those who are technology deprived should be sought though local voluntary sectors or via grant applications.

Sociocultural barriers

Sociocultural barriers are insidious factors that can prevent public participation, with stigma being a common barrier (Hussain-Gambles et al, 2004; George et al, 2014; Ellard-Gray et al, 2015). The use of culturally appropriate labels that members of the community identify with, and do not feel have negative connotations, helps to reduce stigma (Hussain-Gambles et al, 2004; George et al, 2014; Ellard-Gray et al, 2015). A study recruiting homosexual immigrants found greater participant uptake when a variety of terminology was used to describe sexual behaviour and attraction, instead of just ‘gay’ and ‘lesbian’ (Ellard-Gray et al, 2015; Fournier et al, 2018).

Language barriers can be detrimental when conducting research. Presence of a language barrier impedes on discourse competence, which is where one can easily have a conversation without interruptions to pause and look up words or phrases. As well as the loss of common phrases, it can impede body language interpretation, which can further increase the possibility of miscommunication (Squires et al, 2020). Use of interpreters can help to alleviate these issues, although translation of specific vocabulary used for health or research terms may prove problematic.

Sampling frameworks

The traditional recruitment methods previously described may not be successful when recruiting certain hard-to-reach demographics. Sampling frameworks outline methodologies that can be adapted to reach the target demographic. Finding the most suitable sampling method is an iterative process that needs to be tailored to the target demographic: a successful method will take into account the characteristics of the target demographic and work alongside them (Shaghaghi et al, 2011; Ellard-Gray et al, 2015; Valerio et al, 2016).

Targeted sampling

Targeted sampling involves ethnographically mapping the target population then observing them (Watters and Biernacki, 1989; Kral et al, 2010; Ellard-Gray et al, 2015). To aid ethnographical mapping, data from existing services can be used to identify areas frequented by the target population (Watters and Biernacki, 1989; Syvertsen et al, 2012). At these locations, preliminary characteristic data (eg gender, race) are collected through observation (Watters and Biernacki, 1989; Kral et al, 2010; Ellard-Gray et al, 2015). Once areas and subgroups have been identified, the target population can be recruited from these locations with proportionate sampling quotas (Peterson et al, 2008; Shaghaghi et al, 2011). Achieving success with this sampling method is heavily dependent on the data collected through initial observations; obtaining high-quality observations can be time consuming (Peterson et al, 2008; Shaghaghi et al, 2011). Syvertsen et al (2012) used targeted sampling to recruit female sex workers in locations identified by street-based outreach workers as areas where female sex workers populate.

Derived rapport sampling

This involves community gatekeepers facilitating rapport building between the target demographic and research team. This method is particularly useful when access to the target population is unethical (eg children) or is closed to outsiders (eg the travelling community) (Ellard-Gray et al, 2015; Condon et al, 2019). The use of gatekeepers can help bridge barriers such as language and culture, which can improve communication and help reduce fear and mistrust of the research team (Ellard-Gray et al, 2015; Condon et al, 2019). This sampling method introduces selection bias as participants involved with their community are more likely to be sampled (Ellard-Gray et al, 2015). Another issue is that gatekeepers can be protective of their community and the process is slowed if they are obstructive (Ellard-Gray et al, 2015; Morgan et al, 2016). Condon et al (2019) used community gatekeepers to aid initial introductions and engage Gypsy, Roma and Traveller communities in patient and public involvement.

Snowball sampling

Snowball sampling involves study participants helping to recruit further participants. Although this method can be successful for recruiting, it has been criticised for its use of convenience sampling (Heckathorn, 2011). As friends recruit one another, they are more likely to have certain characteristics, resulting in selection bias (Heckathorn, 2011). This results in a potentially homogenous study sample, which reduces the generalisability of the study (Valerio et al, 2016). Syvertsen et al (2012) adopted this method to recruit female sex workers and their non-commercial partner. Female sex workers were screened for eligibility then encouraged via a financial incentive to return with their partner (Syvertsen et al, 2012).

Time–space sampling

Time-space sampling involves three stages (Stueve et al, 2001). The first stage involves ethnographically mapping the target population (Watters and Biernacki, 1989; Kral et al, 2010; Ellard-Gray et al, 2015). Once ethnological data have been collected, appropriate venues are randomly selected and visited by the research team at random times and dates. At the venue, researchers systematically approach members of the target population (Stueve et al, 2001). One drawback to this sampling method is that the venues identified need to be popular and frequented by the target population (Stueve et al, 2001; Shaghaghi et al, 2011). A caveat to this is that members of the target population may be too embroiled in the activities of the venue, or feel that their confidentiality cannot be maintained while in the venue, so they may decide to not to engage (Stueve et al, 2001; Shaghaghi et al, 2011). If appropriate venues are not selected, recruitment will be poor and the sampling method will be biased. A further issue is that members of the target demographic who do not attend such venues, or are isolated, will be under-represented (Stueve et al, 2001; Shaghaghi et al, 2011). Stueve et al (2001) used time-space sampling to ethnographically map homosexual males, which enabled the identification of locations where young Latino homosexual men could be recruited.

Respondent-driven sampling

This is a similar technique to snowball sampling, but respondent-driven sampling is less biased and is representative of the target population (McKnight et al, 2006; Heckathorn, 2011). Respondent-driven sampling involves waves of peer recruitment, where the original participants (seeds) recruit a specified number of further participants to create waves (Ellard-Gray et al, 2015). This sampling method has three core features to aid recruitment: the use of financial incentives, maintenance of confidentiality as participants contact the research team, and recruiting a specified number of participants per participant (Shaghaghi et al, 2011). The negatives of this method are that seeds with larger social networks are more likely to recruit more participants, so there is an element of selection bias (Johnston and Sabin, 2010). Furthermore, isolated members of the target population will not be sampled (Johnston and Sabin, 2010). McKnight et al (2006) used respondent-driven sampling to recruit 608 participants who inject drugs, in New York City. Eight seeds were given coupons with a unique code and the location of the research team. Participants were given a financial incentive for participating and for recruiting further participants (McKnight et al, 2006).

Conclusions

Patient and public involvement is a fundamental part of research and there should be a move away from tokenism towards co-production. Current patient and public involvement recruitment methods are narrow, which has resulted in a lack of diversity. This is detrimental to the individual, medical research, and ultimately the progression of better healthcare. Furthermore, it prevents individuals who are passionate or experts by experience in their condition from empowerment through directing change. Inclusive patient and public involvement models promote diversity, resulting in more patient focused and holistic care. While recruiting participants, identification of potential individual barriers and the implementation of sampling techniques can be used to promote diversity.

Author details

[1]Department of Medicine, St James Hospital, Leeds, UK

[2]School of Medicine, University of Leeds, Leeds, UK

[3]Academic Department of Trauma and Orthopaedics, Leeds, UK

[4]Leeds Institute of Rheumatic and Musculoskeletal Medicine, Leeds University, Leeds, UK

[5]Leeds Orthopaedic Trauma Sciences, Leeds University, Leeds, UK

[6]Department of Trauma and Orthopaedics, Leeds General Infirmary, Leeds, UK

[7]Nuffield Department of Orthopaedics, Rheumatology and Musculoskeletal Sciences, Oxford University, Oxford, UK

Key points

- Current methods for recruitment into patient and public involvement groups are narrow, which has resulted in a lack of diversity.
- Individual barriers can prevent participation in patient and public involvement. Common barriers include mistrust, confidentiality, accessibility and sociocultural barriers.
- Using sampling frameworks in the recruitment methods can aid recruitment of hard-to-reach demographics.

Conflicts of interest

The authors declare that they have no conflicts of interest.

References

Beresford P. Beyond the usual suspects, towards inclusive user involvement. 2013. http://www.shapingourlives.org.uk/documents/BTUSReport.pdf (accessed 28 May 2021)

Bonevski B, Randell M, Paul C et al. Reaching the hard-to-reach: a systematic review of strategies for improving health and medical research with socially disadvantaged groups. BMC Med Res Methodol. 2014;14:42. https://doi.org/10.1186/1471-2288-14-42

Condon L, Bedford H, Ireland L et al. Engaging gypsy, roma, and traveller communities in research: maximizing opportunities and overcoming challenges. Qual Health Res. 2019;29(9):1324–1333. https://doi.org/10.1177/1049732318813558

Domecq JP, Prutsky G, Elraiyah T et al. Patient engagement in research: a systematic review. BMC Health Serv Res. 2014;14:89. https://doi.org/10.1186/1472-6963-14-89

Ellard-Gray A, Jeffrey NK, Choubak M, Crann SE. Finding the hidden participant: solutions for recruiting hidden, hard-to-reach, and vulnerable populations. Int J Qual Methods. 2015;14(5):160940691562142. https://doi.org/10.1177/1609406915621420

Fournier C, Brabant LH, Dupéré S, Chamberland L. Lesbian and gay immigrants' post-migration experiences: an integrative literature review. J Immigr Refug Stud. 2018;16(3):331–350. https://doi.org/10.1080/15562948.2017.1299269

George S, Duran N, Norris K. A systematic review of barriers and facilitators to minority research participation among African Americans, Latinos, Asian Americans, and Pacific Islanders. Am J Public Health. 2014;104(2):e16–e31. https://doi.org/10.2105/AJPH.2013.301706

Hayes H, Buckland S, Tarpey M. Briefing notes for researchers: public involvement in NHS, public health and social care research. 2012. https://www.invo.org.uk/wp-content/uploads/2014/11/9938_INVOLVE_Briefing_Notes_WEB.pdf (accessed 2 June 2021)

Heckathorn DD. Snowball versus respondent-driven sampling. Soc Methodol. 2011;41(1):355–366. https://doi.org/10.1111/j.1467-9531.2011.01244.x

Hoddinott P, Pollock A, O'Cathain A et al. How to incorporate patient and public perspectives into the design and conduct of research. F1000Res. 2018;7:752., https://doi.org/10.12688/f1000research.15162.1

Hussain-Gambles M, Atkin K, Leese B. Why ethnic minority groups are under-represented in clinical trials: a review of the literature. Health Soc Care Commun. 2004;12(5):382–388. https://doi.org/10.1111/j.1365-2524.2004.00507.x

INVOLVE. Tips sheet: Recruiting members of the public to get involved in research funding and commissioning processes. 2012. https://www.invo.org.uk/posttypepublication/tips-sheet-recruiting-members-of-the-public-to-get-involved-in-research-funding-and-commissioning-processes/ (accessed 2 June 2021)

INVOLVE. About INVOLVE. 2021. https://www.invo.org.uk/about-involve/ (accessed 28 May 2021)

Johnston LG, Sabin K. Sampling hard-to-reach populations with respondent driven sampling. Methodol Innov Online. 2010;5:38–48. https://doi.org/10.4256/mio.2010.0017

Kral AH, Malekinejad M, Vaudrey J et al. Comparing respondent-driven sampling and targeted sampling methods of recruiting injection drug users in San Francisco. J Urban Health. 2010;87(5):839–850. https://doi.org/10.1007/s11524-010-9486-9

Martin GP. Representativeness, legitimacy and power in public involvement in health-service management. Soc Sci Med. 2008;67(11):1757–1765. https://doi.org/10.1016/j.socscimed.2008.09.024

McKnight C, Des Jarlais D, Bramson H et al. Respondent-driven sampling in a study of drug users in New York City: notes from the field. J Urban Health. 2006;83(S1):54–59. https://doi.org/10.1007/s11524-006-9102-1

Minogue V, Cooke M, Donskoy A-L, Vicary P, Wells B. Patient and public involvement in reducing health and care research waste. Res Involv Engagem. 2018;4:5. https://doi.org/10.1186/s40900-018-0087-1

Mockford C, Staniszewska S, Griffiths F, Herron-Marx S. The impact of patient and public involvement on UK NHS health care: a systematic review. Int J Qual Health Care. 2012;24(1):28–38. https://doi.org/10.1093/intqhc/mzr066

Morgan H, Thomson G, Crossland N et al. Combining PPI with qualitative research to engage 'harder-to-reach' populations: service user groups as co-applicants on a platform study for a trial. Res Involv Engagem. 2016;2:7. https://doi.org/10.1186/s40900-016-0023-1

National Institute for Health Research. Going the extra mile: Improving the nation's health and wellbeing through public involvement in research. 2015. https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/Going-the-Extra-Mile.pdf (accessed 2 June 2021)

National Involvement Partnership. Involvement for influence. 2015. https://www.nsun.org.uk/wp-content/uploads/2021/05/4PiNationalInvolvementStandardsFullReport20152.pdf (accessed 2 June 2021)

Ocloo J, Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. BMJ Qual Saf. 2016;25(8):626–632. https://doi.org/10.1136/bmjqs-2015-004839

Peterson JA, Reisinger HS, Schwartz RP et al. Targeted sampling in drug abuse research: a review and case study. Field Methods. 2008;20(2):155–170. https://doi.org/10.1177/1525822X08314988

Shaghaghi A, Bhopal RS, Sheikh A. Approaches to recruiting 'hard-to-reach' populations into research: a review of the literature. Health Promot Perspect. 2011;1(2):86-94. https://doi.org/10.5681/hpp.2011.009

Squires A, Sadarangani T, Jones S. Strategies for overcoming language barriers in research. J Adv Nurs. 2020;76(2):706–714. https://doi.org/10.1111/jan.14007

Staniszewska S, Denegri S, Matthews R, Minogue V. Reviewing progress in public involvement in NIHR research: developing and implementing a new vision for the future. BMJ Open. 2018;8(7):e017124. https://doi.org/10.1136/bmjopen-2017-017124

Stueve A, O'Donnell LN, Duran R, San Doval A, Blome J. Time-space sampling in minority communities: results with young Latino men who have sex with men. Am J Public Health. 2001;91:922–926. https://doi.org/10.2105/ajph.91.6.922

Syvertsen JL, Robertson AM, Abramovitz D et al. Study protocol for the recruitment of female sex workers and their non-commercial partners into couple-based HIV research. BMC Public Health. 2012;12(1):136. https://doi.org/10.1186/1471-2458-12-136

The Brain Tumour Charity. Involving patients and carers in research. 2021. https://www.thebraintumourcharity.org/funding-for-brain-tumour-researchers/patient-public-involvement/ (accessed 28 May 2021)

Tomlinson J, Medlinskiene K, Cheong V-L, Khan S, Fylan B. Patient and public involvement in designing and conducting doctoral research: the whys and the hows. Res Involv Engagem. 2019;5:23. https://doi.org/10.1186/s40900-019-0155-1

Valerio MA, Rodriguez N, Winkler P et al. Comparing two sampling methods to engage hard-to-reach communities in research priority setting. BMC Med Res Methodol. 2016;16:146. https://doi.org/10.1186/s12874-016-0242-z

Watters JK, Biernacki P. Targeted sampling: options for the study of hidden populations. Soc Probl. 1989;36(4):416–430. https://doi.org/10.2307/800824

Witte SS, El-Bassel N, Gilbert L et al. Recruitment of minority women and their main sexual partners in an HIV/STI prevention trial. J Womens Health. 2004;13(10):1137–1147. https://doi.org/10.1089/jwh.2004.13.1137