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Engagement of people with long term conditions in health and social care research

Barriers and facilitators to capturing the views of seldom-heard populations

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Background

The importance of including socially excluded groups in health and social care research has become increasingly recognised, and is underpinned by recent UK government policy (see, for example, *Inclusion Health*, Cabinet Office, 2010). There is a recognised need for more sophisticated and flexible responses to improve access and quality of services for socially excluded groups. An integral part of this improvement is the inclusion of the views of socially excluded groups in both consultation and research about health and social care. The definition of seldom heard or socially excluded is not straightforward and, at its broadest, can include the long term unemployed, those in severe and persistent poverty, people experiencing domestic violence, care leavers, ethnic minority groups, ex-servicemen and women, people living in remote areas and those who do not meet the necessary eligibility criteria for the provision of statutory provision of care interventions (i.e. self- funders). More commonly, the focus is on those considered to be most vulnerable: homeless people, traveller groups, sex workers, people with intellectual disabilities, refugees, asylum seekers and prisoners or ex-offenders. Those with long-term health conditions (an illness or condition which requires treatment, management or support for the rest of someone's life) may be seldom heard because their long-term condition (such as an intellectual disability, dementia, stroke, mental health condition, etc.) makes participation more difficult. They may even have more than one long-term condition that further impacts on their participation in research and they may also be part of one of the socially excluded groups noted above, which further exacerbates their exclusion from research.

Aims

This rapid review aimed to explore the recent literature about the barriers and facilitators to including seldom heard groups as participants in research related to health and social care.

Three core questions which have relevance to policy and future research practice guided this review:

- What do we know about whose views and experiences are excluded from research and how often such exclusions happen in health and social care research?
- Why are some people's views and experiences not heard?
- What methods are there for facilitating people's views to be heard and are these facilitators population-specific or can they be applied to other groups and guide good research practice more generally?

Methods

An initial scoping exercise was carried out to identify and refine the key search terms. The review covered literature published in peer reviewed journals for the period 2001 – 2011. All papers included were relating to UK studies and had been published in English. The full extraction process incorporated 18 databases and hand-searching of appropriate journals. A total of 2,031 potentially

relevant studies were identified and following screening by title, 537 papers were identified and the abstract (and in some cases, the full paper) reviewed. This resulted in 107 papers being identified for extraction. After application of quality criteria, a further 24 papers were excluded and the remaining 83 studies were extracted into tables, with mapping and narrative synthesis undertaken.

Summary of findings

Of the papers included in the review, just under half related to people with intellectual (learning) disabilities. Although under half of the studies were qualitative studies, a range of research methods were included: e.g. surveys, focus groups, interviews and literature reviews. Most papers described the methods used to conduct research with those who were seldom heard but only eight studies had set out to compare different ways to involve those who were hard-to-reach or hard-to-engage in research.

The narrative synthesis identified the barriers to and the facilitators for involvement of these groups in research. Key findings from this analysis are summarised below under the three questions that guided the research.

What do we know about whose views and experiences are excluded from research and how often this exclusion happens in health and social care research?

- The research reviewed predominantly focused on four groups as being difficult to reach or engage in research – those with intellectual disability; older adults, in particular those with dementia; those with mental health conditions; and those from minority ethnic groups. A very few papers focused on other groups, such as people with physical and sensory disabilities and gay men.

- There were a number of groups on which no research was found, including self-funders, homeless groups, and Gay Lesbian Bisexual Transgender groups.

- Studies which did include, for example, people with intellectual disabilities or older adults did not necessarily consider how representative their sample was in terms of other risk factors for exclusion, such as ethnicity. As such, very little is known about the extent of exclusion of these groups from health and social care research.

Why are some people's views and experiences not represented in some research related to health and social care?

There were many reasons found why the views and experiences of certain groups may not always be represented in research on health and social care of people with long-term conditions. These have been summarised under three broad headings relating to: assumptions in design; definition and recruitment; and population characteristics.

Assumptions in the design phase of the research

- A key barrier to inclusion was the fact that in the process of designing studies researchers sometimes made assumptions which led them to choose methods that excluded particular groups

- In some cases researchers made assumptions about who couldn't be involved from the outset. This was accentuated by the requirements for ethical approval and the complexity in the process of gaining consent.

Defining and recruiting seldom heard groups

- Seldom-heard groups were sometimes hard to define due to individual differences between the members of such groups – e.g. differences between different minority groups might require different strategies for involvement.

- For those who accessed health and social care services, finding relevant participants was easier and barriers usually came later in the research pathway.

- Underuse of services by those from ethnic minorities and those with milder levels of intellectual or physical disabilities living with their families, means that these groups are often harder to identify and contact, as are those who fund their own social care, those who are homeless and those from travelling communities.

- Some potential participants did not see themselves as part of the target group (not disabled or not ill enough to have anything to add to the research) or did not see the benefits of taking part. The timing of the approach to participant could also be a barrier – especially in relation to the illness trajectory. If people were too ill to take part or felt they had recovered then they were less likely to take part.

- Services sometimes act as gatekeepers and make decisions about whether to involve particular people or can, either wittingly or unwittingly, sabotage the recruitment process by not communicating the research to those they represent.

- In the research reviewed a convenience sample was commonly used which meant that some samples were not necessarily representative of the population and that others were being over researched as they were the easiest to contact.

- Lack of trust of the individual or institution conducting the research could also hamper recruitment.

Characteristics of specific populations

- There were three core characteristics which appeared to impact on participation in research whether at recruitment stage, at consent stage or during the data collection stage:

1. Where people had cognitive impairments or difficulties with communication, the challenges to successful recruitment and involvement were substantially greater.

2. Language and cultural differences also had an impact on the success of data collection.

3. The presence of physical or sensory disabilities along with the specific characteristics of particular long-term conditions could play a role in whether or not people with long-term conditions agreed to take part in research but also in whether they remained part of the sample during the data collection phase.

- Failure to adapt materials to the needs of the participants throughout the research pathway from recruitment to data collection often resulted in failure to recruit people or to gain valid data. Failure to provide translation and interpretation services when required, for example, would often result in the exclusion of people from ethnic minority groups at all stages of the research process.

- The use of particular types of research methodology - or even of particular question formats - often excluded people with cognitive impairments, such as intellectual disabilities or dementia, or, at the very least, meant that any data gathered was less valid or reliable as a measure of their views and experiences. Reliance on only one source of data accentuated this issue. Issues, such as response bias (e.g. acquiescence), difficulties with the concept of time, of making comparisons and memory difficulties all had an impact on the ease with which data could be collected and also the reliability and validity of that data in the long run.

- Lack of sufficient time and resources for recruitment and data collection can also result in exclusion of people who needed more support or time to process the information provided before deciding whether to take part and/or to complete questionnaires or interviews. Similarly, limited resources can affect whether researchers can collect data from more than one source - or in different formats - to ensure reliability. Whilst the use of observation was recommended for gaining the experience of people with severe cognitive and communication impairments, this is often very resource intensive and can be considered intrusive especially if researchers are to ensure that observational data is valid and reliable.

- Accessibility of the research environment was an important element, especially for people with physical disabilities or those who were frail due to age or their long term condition. If expenses of getting to the venue were not reimbursed or if there was a lack of accessible transport then there could be an impact on participation.

What methods are there for facilitating people's views to be heard?

A number of strategies arose from the research:

1. Including stakeholders in the design process and in the testing of measures, letters and interview schedules was particularly important for ensuring a research design and data collection process that was as accessible as possible. Involvement of a user reference group can operate as a counter balance to researchers' assumptions which can constrain involvement of seldom heard populations. The review provided little guidance as to the 'best structure' or model of the group and this is an area that warrants further study. Organising such a group in a meaningful way also has time and resource implications which were not discussed in the papers reviewed.

2. Allowing additional time and increased flexibility at each stage of the research process was highlighted in 54 of the 83 papers reviewed. Little specific guidance was provided about time frames but this is not surprising given the range of different populations and methods used as well as the different skill levels of the researchers involved. There was no overt discussion about how researchers could work effectively with research funding or commissioning bodies in setting-up appropriate time-frames around research projects. The majority of commissioned research has a time-limit of between two and three years. Ensuring the inclusion of seldom-heard communities could take a considerable portion of that time.

3. Multiple recruitment strategies, often including face-to-face contact with potential participants to build rapport and trust, were used in some studies to ensure that as many people as possible were recruited. Providing materials in, for example, easy read format or the use of audio or video materials to explain the research, using recorded audio consent rather than written consent, were also all found to be important means by which to involve those with communication difficulties or different language. Accessing members of particular communities, such as those from black or other ethnic minority groups, could be facilitated using community groups and grassroots organisations.

4. Flexibility was also of key importance in the selection of methods used and the application of different techniques. For example, there was a clear consensus that self-completion structured questionnaires were inappropriate for some seldom heard groups. Alternative methods and sometimes multiple methods, such as interviews, focus groups or observation, may be necessary. A combination of different types of communication aids and stimuli to promote participation, such as using drawings, photos and objects -not just verbal questions and show-cards -, were important to promoting responsiveness and validity of responses.

5. Finally, one method that had received much attention in the research reviewed was the use of proxy respondents to ensure that the experiences of people with cognitive or communication disabilities were included. Views on the effectiveness of this approach

varied but there appeared to be some existing scales that showed good concordance between proxies and participants. Using proxy respondents was more successful when they were asked about how they perceived the quality of life of the participant, rather than how they thought the patient perceived their own quality of life, and when the respondent had regular contact with the individual. However, overall there was very little research which tested when proxies should be involved, the best way to involve them in terms of how questions should be worded, and who was best placed to act as a proxy in which situations.

Recommendations

Although the research reviewed was limited to the UK, was related primarily to just a small number of seldom-heard groups and included some research that was not as robust as it could have been, the findings from this review are consistent with those from research conducted in other countries and there are a number of recommendations which can be drawn from the review. These relate specifically to the findings described above but also include recommendations for further research to fill the gaps identified in the review. Some of the key recommendations include:

1. Researchers should involve user reference groups or individual user consultants in designing the study, including deciding on recruitment strategies, on the methods of data collection and on the adaptations needed to measures in order to involve as many people as possible.
2. When working with people from seldom heard groups, more time and resources should be allowed in order to recruit people to studies using more than one recruitment strategy where needed. More time, flexibility and adapted materials and procedures are also required in order to maximise involvement, responsiveness and reliability of responses during data collection. However this has implications for funders and commissioners of research or service evaluation with these groups of people.
3. Information materials should be clear and accessible to the target population.
4. Researchers and others involved in gathering data need the skills and knowledge to interview or conduct focus groups with those some seldom heard groups, especially those with cognitive, communication or cultural differences. Training in alternative forms of communication or cultural sensitivities may be needed.
5. Triangulation of data collection methods is often needed especially where it isn't possible to get a self-report measure or the reliability of people's self-report might be in question due to cognitive or communication impairments.
6. It is sometimes also necessary to use different ways of obtaining the same information across different groups of people. For example, surveys often have to be simplified and combined with pictures or other media to allow those with communication or cognitive impairments to understand them. When different versions are used, however, researchers should make the effort to map across the measures to establish reliability. For example, how closely related are the results from self-report measures, observation, proxy measures, etc.

7. Researchers should report more about the characteristics of people who participate so that it is possible to know whether those from seldom heard populations are included and then to consider how representative their sample is in terms of the whole population studied.
8. Although there is currently a lack of research on different groups and the issues for research participation, it is clear that, when working with people from ethnic minority groups, it is important not to just group people together as one (e.g. BME group) as the diversity between different ethnic groups is substantial and can affect the success of recruitment and involvement.
9. Ethical approval processes need to recognise the need for flexibility to respond to the individual needs of people taking part, while at the same time balancing the need to protect the interests of participants.
10. Further research is needed on:
    a. the use of proxy respondents. In particular, research that focuses on who are suitable respondents, what type of questions they can reliably respond to, in what type of situations they should be used and how these responses map across to alternative methods, such as observation
    b. whether, and how, to adapt existing measures for particular groups e.g. EQ5D and the Adult Social Care Outcome Toolkit (ASCOT) measure, which are included in the national outcomes frameworks.
    c. the best alternative techniques for eliciting responses for different groups – e.g. photo elicitation or Talking Mats etc.
    d. other seldom heard populations currently missing in the research. In particular, those who are homeless or from travelling communities, and those from a range of different minority ethnic groups.
    e. the role and attitudes of professionals who sometimes act as gatekeepers, such as GPs, other primary care staff, social care staff, etc.
    f. the comparative cost implications and effectiveness of recruitment and data collection methods which promote more inclusive research.
    g. the characteristics of people who do not respond to survey and the reasons why people drop out of research studies or chose not to take part in the first place.

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