

Giving voice to the voiceless:

how to involve vulnerable migrants in healthcare research

INTRODUCTION

Migration, with the prospect of large numbers of people permanently staying in a country, poses a challenge to society including the healthcare sector. This has been magnified by the large numbers of migrants and refugees that are currently entering Europe. Most of the refugees will stay over the years, some of them without ever getting permission to stay and thus becoming undocumented. In this article we use the term 'migrants' as an overarching term for refugees, undocumented, and other migrants. Primary care plays a key role in the provision of high-quality, affordable care for these groups, who face large health inequities and barriers to accessing health care.^{1,2} European general practice has acknowledged its responsibility to this group.³ However, stating good intentions in its professional approach alone will be insufficient. Even under stable conditions there is a lack of guidance for migrant care, due to insufficient knowledge of morbidity patterns and healthcare needs.¹ This is not unique for migrants, and is also relevant for other marginalised groups. In that respect, primary health care may benefit, in coping with the current challenge of migrants and refugees, from its experience with care for other marginalised groups. At the same time primary care can use this crisis to strengthen its generic approach towards marginalised groups. It is essential to understand the values and expectations attached to health before it is possible to respond to patient needs.⁴ As with other vulnerable groups, research with and for migrants and refugees, 'giving them a voice', is vital to generate the knowledge that informs policy and practice. Under the current politicised conditions,⁵ it is a moral obligation to avoid a 'tokenist' involvement, and to contribute to the quality of migrant health care.⁶

Service users, including migrants, are experts by experience. Although complex, there is a growing understanding of successful engagement of migrants in research, even those who are 'undocumented'.⁷⁻⁹ Although the strategies identified are not significantly different from those advocated for the involvement of other service users in research (for example, INVOLVE [<http://www.invo.org.uk/>]), the language and cultural differences, and migrants' precarious legal position — in particular those without appropriate documents — pose specific challenges.

In this editorial we present practical guidance on how to overcome these challenges, based on our experiences.

Reasons for under-representation

Researchers face practical problems in engaging migrants. There are few representative networks of patient organisations; research methods rely heavily on the language and reading skills of participants; and migrants have concerns about confidentiality and have other priorities in life.^{10,11}

Legal barriers to involving (undocumented) migrants can play a role, as can ethical issues: concerns whether participation is truly voluntary or that migrants may have unrealistic expectations about the benefits for their conditions.⁵

Practical guidance on how to involve migrants in research

In general, recruitment and involvement of migrants takes time. However, this investment of time can lead to rich results.

STUDY DESIGN

Participatory action methods can ensure that the voices of hard-to-reach groups are heard and that research is performed *with them* instead of *on them*.^{9,12,13} Particularly exciting is the possibility of engaging migrants as co-researchers, who share language and cultural background with the study group.¹⁰ This helps to adjust instruments to the needs of the participants, provides deeper understanding of the data, and helps to disseminate the results within the community. Recruiting interviewers from the community increases response rates.¹⁰

A mixed-methods approach combining participatory qualitative and quantitative methods is likely to produce the evidence needed by policymakers and practitioners.¹⁰

Representative sampling is often not possible as the target population is seldom precisely known, given the changeable status of migrants. However, case-control studies are feasible and can provide valuable information on health and use of healthcare facilities, comparing groups of migrants or with native people.¹⁴

Surveys and questionnaires have to be translated and back-translated. 'Translated' is broader than linguistic: it includes checking the cultural meaning, appropriateness, and relevance towards the research population. It

is preferably done jointly with representatives from the research population.

RECRUITMENT

Using multiple recruitment strategies optimises numbers involved and at the same time minimises the risk of selection bias. Snowball tactics, or chain sampling using networks of researchers, practitioners, and volunteers, are often used successfully. Recruitment through GPs usually leads to a high response rate because migrants trust GPs, but it misses those who do not have access to GP care. Migrants may feel obliged to participate, whereas GPs might be over-protective and not invite migrants in difficult personal circumstances.

Refugees and undocumented migrants can often be reached through churches and mosques, NGOs supporting these groups, shelters for refugees or for the homeless, and budget stores.

INFORMED CONSENT

Obtaining informed consent is particularly delicate when involving vulnerable groups. Personal verbal explanation, emphasising confidentiality, can reassure migrants to sign the consent form, which has to be designed in a user-friendly format: written in simple, short sentences and without references to legal issues. Sometimes ethical committees have to be convinced of the necessity to use these instead of the regular ones.

User-friendly procedures are best adjusted to the occasion when an opportunity for contact arises and it is possible 'to make hay while the sun shines'. Participants should be informed about the study in a single process and, when willing to join, should fill in the consent form (Box 1). This 'opt in' method depends heavily on the ethical conduct of the researcher, who will have to be convinced that participation is voluntary and deliberate.

CONTACTING PARTICIPANTS

Many migrants, in particular undocumented ones and refugees, do not have a permanent living place and do not answer their phone to an unknown caller's number. Instead, researchers may need to use their own mobile phone and make their numbers known in advance.

DATA COLLECTION

Logistics

Location. Ensure the location for research

Box 1. Example of recruitment procedure for undocumented migrant women⁷

1. The researcher and research assistant visit a shelter for undocumented women and provide group education on reproductive health issues. Various informal interpreters are present to translate where necessary into different languages.
2. At the end of the meeting, the researcher explains the aim and design of the study on health and health needs of undocumented women and what participants can expect, and answers any questions.
3. All women receive an information leaflet written in plain, simple Dutch and an informed consent form. The researcher and research assistant leave the room for about 15 minutes.
4. In those 15 minutes all women read the information, where necessary receive translation into their language by the interpreters, and decide to participate or not.
5. Those who want to participate, sign the form and leave it on a pile in the room. The meeting is over.
6. When the women have left the room, the researcher and assistant re-enter, gather the informed consent forms, and approach the women who have indicated their willingness to participate.
7. With those women they schedule time-slots and interpreters for the interview (3 hours per woman, including medical assessment and information on health care).
8. Before the start of the interview the research assistant explains the procedure and content of the participation again, and assesses if this is well understood by the woman, and if she is still willing to participate. If so, the woman is included and the interview can start.

meetings is safe and discreet, and used by many people throughout the day, like a health centre or community building. The location should be easily accessible by public transport and not in the vicinity of a police station. If women are participating, make sure there is a room for children, as many are single, without babysitting facilities.

Money. Travel costs will have to be reimbursed and a fair fee for participation given, taking into account that most migrants are short of money. Food and drinks or small gifts are also good rewards. When migrants can only be paid in cash, creative solutions have to be found to justify these costs to the financial department of the research institution.

Translation. Migrants often do not speak the native language, nor commonly-used languages like English. Translation will be needed. Professional interpreters are costly and cannot always be trusted; sometimes friends or family can be used, but not when discussing sensitive topics like mental health issues. Here the value of migrants as co-researchers is highlighted because they speak the migrants' language and are trusted.

'Giving back'

Research has the potential to foster a bond with migrants, with positive effects in ensuring health care too. In this way, migrant-participants can be given something back in return for their contribution to the research. For example, migrants were provided with information on the (Dutch) healthcare system and received support to be 'registered' in a general practice.⁷

CONCLUSION

Using elements of this guidance will help to involve vulnerable migrants in healthcare

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research and give them a voice. This can provide an empirical basis from which to engage with policymakers and professionals for essential improvements in health care for migrants and refugees.

At the same time the urgency of the situation around migrants and refugees may provide an opportunity for primary health care to further strengthen research methodology to engage marginalised individuals and communities in the design of their care.

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Provenance

Freely submitted; externally peer reviewed.

DOI:10.3399/bjgp16X685321

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