Participatory health research with migrants

A COUNTRY IMPLEMENTATION GUIDE
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Abstract

This country implementation guide identifies key issues in regard to migrants' involvement in health research. It offers evidence for adopting a participatory health research approach for meaningful, rather than tokenistic, involvement. By drawing on concrete, diverse examples of research projects, this document offers a how-to guide for those interested in conducting participatory health research with migrant communities, including all phases of the research from agenda setting to data collection to knowledge transfer. The guide also draws attention to some cross-cutting issues, such as power dynamics, language differences and impact in participatory health research, and describes how these can be addressed in research projects. Policy recommendations to support migrants' involvement in health research are summarized in the final section.
Contents

Acknowledgements iv
Abbreviations and acronyms v
Executive summary vi

1. INTRODUCTION 1
  1.1 What is participatory health research? 1
  1.2 Who is a migrant? 5
  1.3 Why PHR with migrants? 6
  1.4 Objectives 8
  1.5 Methodology 9

2. FINDINGS 10
  2.1 How to carry out PHR with migrants: participation throughout the research process 10
    2.1.1 Setting the research agenda and defining research questions 10
    2.1.2 Research process and governance 12
    2.1.3 Recruitment 13
    2.1.4 Research methods 14
    2.1.5 Data analysis and interpretation 17
    2.1.6 Dissemination and knowledge transfer 19
  2.2 How to carry out PHR with migrants: cross-cutting issues 21
    2.2.1 Representation 21
    2.2.2 Power imbalances 22
    2.2.3 Language differences 23
    2.2.4 Reimbursement of peer researchers and community partners 24
    2.2.5 Conflict 25
    2.2.6 Project time frames 28
    2.2.7 Impact 29

3. THE WAY FORWARD: POLICY CONSIDERATIONS 31
  3.1 National policies 31
  3.2 Funding 31
  3.3 Training and skills development 33

4. CONCLUSIONS 34
  4.1 Strengths and limitations 34

References 36
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## Abbreviations and acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ICPHR</td>
<td>International Collaboration for Participatory Health Research</td>
</tr>
<tr>
<td>LGBTIQ</td>
<td>lesbian, gay, bisexual, trans, intersex, queer</td>
</tr>
<tr>
<td>NGO</td>
<td>nongovernmental organization</td>
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<tr>
<td>PHR</td>
<td>participatory health research</td>
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<tr>
<td>PLA</td>
<td>participatory learning and action</td>
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<td>RCT</td>
<td>randomized controlled trial</td>
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Executive summary

Participatory health research (PHR) is a research paradigm that commits to the meaningful involvement of key stakeholders throughout the research process. Unlike traditional research methodologies, PHR conducts “research with” people, rather than “research on” people. Key stakeholders are involved in all stages of the research, including design of the research, framing of questions, fieldwork, data analysis and dissemination. It is important to distinguish this from tokenistic involvement of migrants in health research, where the research itself is conducted, controlled and written up by academic researchers and migrants’ participation is limited to consultations and input at specific times in the research cycle, for example to support recruitment or dissemination.

International policies offer clear imperatives for community involvement in the development and delivery of health services as well as in health research. However, while patient and community groups are increasingly involved in research because of these policies, there is a pattern of exclusion whereby underserved communities are not involved to the same extent. This is the case for migrants, particularly in research, and this underrepresentation has significant negative effects on health policy and practice as well as health outcomes. It leads to policies and practices that are biased towards the dominant population groups and do not reflect the health needs of diverse migrant groups, thereby engendering inequality and discrimination in health-care provision.

Where traditional research may fail to include migrant communities, participatory approaches to research offer avenues for engagement with a wide range of stakeholders and entail a range of significant benefits. As well as the benefits of supporting equitable relationships, there are other benefits including (i) identifying timely and relevant research topics; (ii) ensuring the participation of “hard-to-reach” communities such as undocumented migrants; (iii) generating in-depth, nuanced and locally relevant knowledge; (iv) improving service delivery; and (v) empowering individuals and communities.

PHR is conducted by a group of people affected by or involved in the issue at hand, with the explicit aim of effecting positive social change. Stakeholders can include service users/members of civil society; representatives of health organizations and other civil society groups; health-care professionals; community leaders; policy-makers; and academic researchers.

PHR is not limited to a specific research method. It can involve any method that is deemed appropriate to answer the research question. Qualitative methods and, particularly, arts-based methods, can be especially useful in supporting partnerships and in designing inclusive ways of generating and analysing data. This is because of their flexibility and adaptability to the needs, skills, interests and aims of a specific group of co-researchers. Mixed-methods projects can be powerful levers of change because they combine the in-depth explorations of qualitative research with quantitative methods such as surveys and scales.

By drawing on concrete examples from research projects in the WHO European Region and further afield, this guide explains step by step how to adopt a participatory approach in migrant health research. The coproduction of knowledge is described throughout the research cycle.
Examples explain how to:

• collaboratively set the agenda and define research questions;
• ensure participation throughout the research process and in the governance of the project;
• make use of the participatory design in regard to participant recruitment;
• adapt both quantitative and qualitative research methods to a participatory paradigm;
• collaboratively analyse data; and
• ensure that data dissemination, knowledge transfer and application of the findings are in line with the participatory ethos.

Cross-cutting issues that affect many PHR projects with migrant communities are discussed by drawing on best practice examples, including questions of representation, power imbalances, language differences, reimbursements, conflicts within the project team, project time frames and impact. In the last section, policy recommendations that would support the implementation of PHR with migrants throughout the WHO European Region are discussed. First, it is proposed that national policies relating to migrant populations and/or health care, such as intercultural/migrant health strategies, should incorporate a commitment to PHR, as this is an important lever to increase migrants’ participation in health research. Secondly, PHR differs significantly from traditional forms of research in that it involves a diverse group of stakeholders throughout the research process. Therefore, research funding needs to be made available to build research partnerships and to sustain partnerships over time in order to avoid partnerships being started and stopped by short-term research funding issues. Funding also needs to cover staff resources in projects where policy staff or health-care staff become members of PHR teams. Lastly, training and capacity-building in PHR with migrants is needed so that more health policy-makers, service planners, providers and researchers gain the attitudinal disposition and skills to work in a participatory manner with migrant communities.
1. Introduction

While patient and community groups are increasingly involved in the development and delivery of health services as well as in health research, some underserved communities are not involved to the same extent. This is the case for migrants, particularly in research (1). Underrepresentation can lead to policies and practices that are biased towards dominant population groups and that do not reflect the health needs of such underserved and hard-to-reach groups, thereby engendering inequality and discrimination in health-care provision. Cross-cutting issues that affect many PHR projects with migrant communities include questions of representation, power imbalances, language differences, reimbursements, conflicts within the project team, project time frames and impacts (2).

1.1 What is participatory health research?

The International Collaboration for Participatory Health Research (ICPHR) was established in 2009 in order to promote and develop PHR and its application in policy-making and health service delivery. In its first position paper, it outlines what it considers are the main features of PHR (3). First, it is important to clarify that PHR is a research paradigm rather than a method. A research paradigm refers to the underlying assumptions and values that define “good research”, whereas a method refers to the particular tool chosen to get there. Within the paradigm adopted by PHR, “participation is the defining principle throughout the research process” (3). PHR moves research from “research on” people to “research with” people. It has a central commitment to the development of partnerships between community members and professional stakeholders (academics, service planners, policy-makers or health-care providers). Qualitative methods, and particularly arts-based methods, can be useful for supporting partnerships and for designing inclusive ways of generating and analysing data (4,5). However, any research method (quantitative surveys (6), semi-structured interviews (7,8), randomized controlled trials (RCTs) (9), focus group discussions (10), participatory world cafes
Participatory health research with migrants: a country implementation guide

Participatory learning and action (PLA) research, arts-based methods can be used in a participatory research project if deemed appropriate by the research partnership to answer the research question.

There is a broad, pluralistic and growing family of bottom-up participatory research approaches that all share a focus on the inclusion of local experts in local communities as active participants in research. These approaches include participatory research, participatory action research, emancipatory action research, community-based participatory research and PLA. PHR draws on these interconnected approaches to research and applies the participatory principles to health-related topics.

For more information and references about the various participatory research traditions from different countries and time periods that influence PHR, see the position paper published by the ICPHR entitled What is participatory health research?

As a research paradigm, PHR takes a critical stance towards traditional research approaches because they separate and exclude those whose life or work is the subject of the research from the process of knowledge production. Traditionally, research is conducted with a top-down approach, with little or no involvement of the people under study in the process of defining research questions, gathering and analysing data and disseminating and applying results. To overcome these exclusionary practices, PHR leads us to ask a number of questions.

- Whose ideas are informing the research questions and in whose interests is it taking place?
- Who is controlling the research process?
- Who decides on the outcomes of the research and for whose benefit?

PHR acknowledges participation in knowledge production about issues that affect people’s lives as their human right. As a research paradigm, PHR holds specific assumptions about the world and how it should be studied.

The primary underlying assumption is that participation on the part of those whose lives or work is the subject of the study fundamentally affects all aspects of the research. The engagement of these people in the study is an end in itself and is the hallmark of PHR, recognizing the value of each person’s contribution to the co-creation of knowledge in a process that is not only practical, but also collaborative and empowering... The engagement of others within the research process can also be important, for example, policy makers who can act on the research findings and thus improve the situation of those affected by a health issue.

PHR is rooted in postcolonial scholarship and activism. One of the key people who influenced PHR, and action research more generally, is Paulo Freire. Freire was a Brazilian educator and community activist. His seminal book Pedagogy of the Oppressed continues to inform participatory approaches to research, community work and education. Freire postulated that people need to be an active part of any educational (or research) endeavour for it to have any meaningful effect on improving people’s lives.

The commitment to involving those whose life or work is the subject of the research into the research process – or indeed, ensuring that they take the lead in defining, conducting and
disseminating research – is at the core of critical postcolonial perspectives (18). By focusing on the effects of colonialism and imperialism on people, postcolonial scholarship commits to creating “new and different sorts of knowledge to help decolonize consciousness” (19). Postcolonial perspectives acknowledge that the everyday lives of people in decolonized regions of the world – as well as the lives of those migrating from decolonized regions to the global North – continue to be shaped by colonial ideologies, institutions and practices and the resulting inequalities and inequities; these can be expressed, for example, in institutional and interpersonal racism (20,21) and in exclusionary migration policies (22,23).

Emancipatory movements throughout the global South and postcolonial scholars have criticized traditional research as a tool of domination because of the ways in which it can reproduce unequal power dynamics between the global North and the global South, between (often white middle class western) academic researchers and the communities they study. Extractive ways of producing knowledge – where the privileged researcher mines people for knowledge that benefits the researcher above all, with little or no positive effects for the communities under study – are compared with colonial practices of extracting resources from colonized places (18,24).

Following the motto “nothing about us without us”, participatory approaches take the postcolonial critique of research as a tool of domination into account by explicitly paying attention to this history and power asymmetries, and by co-designing and co-conducting research with the people affected by the issues at hand through the following key principles.

The following guiding principles were adapted from the more extensive list identified by the ICPHR (3).

- **PHR is participatory.** The goal of PHR is to maximize the participation of those whose lives or work is the subject of the research in all stages of the research process, including the formulation of the research question and goal, the development of a research design, the selection of appropriate methods for data collection and analysis, the implementation of the research, the interpretation of the results and the dissemination of the findings.

- **PHR is a collective research process.** PHR is conducted by a group of people affected by or involved in the issue at hand. This can include service users/members of civil society; representatives of health organizations; health-care professionals; policy-makers; and academic researchers. All of these people become partners and “co-researchers” in the PHR project. Unlike traditional research projects, where ownership generally lies with the academic researchers and/or the funder, the goal is for the ownership of PHR projects to lie in the hands of the group conducting the study. Decisions regarding all stages of the study are made collaboratively.

- **PHR promotes critical reflexivity.** PHR projects involve conversations and activities that increase critical consciousness (17) among the research team regarding the ways in which power and powerlessness affect the daily lives and practice of those whose life or work is the focus of the research.
• **PHR is locally situated and produces local, co-created knowledge.** PHR leads to knowledge that is grounded in the reality of daily life and work in a specific place and time, rather than focusing on high-level, abstract and generalized knowledge. This is important for generating workable solutions to existing problems in the local context.

• **PHR aims for transformation through human agency.** The explicit aim of PHR projects is to affect positive social change. PHR can have significant impact in two distinct yet interrelated ways: first, through the dialogic process itself, when the people involved in the research (such as representatives of migrant communities, health professionals, policy-makers or academic researchers) gain new insights that lead to changes in their attitudes, knowledge and practice; and secondly, through specific actions resulting from the research (such as changes in health policies, improved access to health care or improved health outcomes among key populations through public health campaigns) (25,26).

The label participatory has become popular in knowledge production and it is important to be clear that “not all research that is labelled as participatory [is] true to participatory research’s underlying values and principles” (5). For example, some studies involve stakeholders in the design of the research or the interpretation of the results through consultations, but the research itself is conducted, controlled and written up by academic researchers, possibly resulting in a tokenistic version of participatory research (3,27). PHR, when done whole-heartedly, requires “the more powerful to give up power” (5).

There have been many attempts to clarify different levels of participation. For example, Chung and Lounsbury (28) identify four types: (i) compliant participation, referring to mainstream research where participants are recruited into the study and give their consent to take part; (ii) directed consultation where individual members of the communities affected by the issue at hand are asked for advice or input on specific issues (for example via qualitative interviews with experts such as representatives from nongovernmental organizations (NGOs)); (iii) mutual consultation, which involves longer-term engagements such as via research advisory boards that include community members, although control over the research process and decision-making power remains with the academic researchers; and (iv) empowering co-investigation, where academic researchers and community members share decision-making power and governance over the research. Only the last qualifies as participatory research in the sense that the authors are referring to in this document.

Another typology illustrates the continuum of participation throughout the stages of research: (i) framing of the issue; (ii) research design; (iii) data collection; (iv) data analysis and writing up; and (v) dissemination and action. Ideally, the community/stakeholders are full collaborators at all stages of the research (Fig. 1).
Fig. 1. Participation continuum from the traditional researcher to the community members for control of all aspects of the research

![Participation continuum](image)

Source: Burns et al., 2011 (29).

### 1.2 Who is a migrant?

This guidance focuses on PHR with migrants. The International Organization for Migration defines migrants as people who have moved away from their place of usual residence, whether within a country or across an international border, temporarily or permanently and for a variety of reasons (30). This wide definition encompasses many different migration experiences and people from many different backgrounds: a person fleeing war; a person leaving a rural area to work in a city; a person working for an international company being transferred to another country; a spouse coming to live with their partner in a new country; a student living abroad for a year; a person trafficked across borders by an organized crime group for the exploitation of their labour; or someone moving to another country simply because they like it better. All of these people are migrants.

In relation to health, this diversity can be explored through the lens of the social determinants of health. Social determinants of health are nonmedical factors that influence health outcomes, including income, employment status, working conditions, education, housing, social inclusion, structural forms of discrimination and access to health services. The experiences of migrants will vary greatly depending on their social position for these factors: “health and illness follow a social gradient – the lower a person's socioeconomic position, the worse their chances for health” (31). For example, the health experiences and outcomes of an undocumented migrant who is excluded from the formal labour market and faces institutionalized and interpersonal racism and social isolation (32) likely differs significantly from the health experiences and outcomes of a migrant working a well-paid formal job in an industry that relies on migrant labour, such as a health-care professional or an academic. This lens of social determinants of health also draws attention to the fact that there are overlaps between the experiences of (some) migrants with those of other marginalized non-migrant groups, such as low-income communities, local ethnic
minorities (such as Irish travellers) or people living with disabilities. In this guidance, the focus is on migrant communities as a specific group who share certain similarities due to the fact that they have moved across borders, while also acknowledging that some of the issues discussed here may not apply to all migrants, whereas others will also apply to non-migrant groups facing marginalization and exclusion.

Among the social determinants of health that may shape migrants’ experiences of health and well-being, regardless of their social class or economic privilege, are social isolation, lack of access to professional interpreters in health settings, lack of culturally sensitive service provision and the multifaceted health effects of racism and xenophobia. Legal immigration status is one of the factors that significantly impacts migrants’ eligibility and access to health care, illustrating the way in which migration itself is a social determinant of health (33). However, there are other factors that affect migrants’ health experiences and may mitigate against the exclusion faced by lack of legal status, such as social class, education, nationality and race.\(^1\) At the same time, migrants who reside legally in a country may still face significant exclusion from health care due to issues relating to accessibility of social welfare, exclusionary administrative procedures and institutionalized racism, as is the case for many European Roma migrants (35–37).

By focusing on the social determinants of health as they shape each individual’s health experiences, we purposefully move away from categorizing migrant groups with terms such as labour migrants, economic migrants or refugees; first, because we recognize that the reasons for displacement are complex and overlapping for most, and secondly because these categorizations can create unhelpful stereotypes that discretely reinforce discriminatory assumptions such as “what a migrant looks like” (38). Instead, the proposed approach focuses on migrants’ relationship with the society they live in, acknowledging that experiences of exclusion and marginalization are specific to each person within the national and local context in which they find themselves (22).

1.3 Why PHR with migrants?

International policies offer clear imperatives for community involvement in the health decision-making about services, policy and research (39–42). However, while patient and community groups are increasingly involved in health decision-making due to these policies, there is a pattern of exclusion whereby marginalized groups, including migrants, are not involved to the same extent (43,44).

Within the field of health research, migrant communities face underrepresentation. Their experiences and views may be absent or insufficiently addressed in mainstream health research, despite the fact that migrants constitute a significant population within the WHO European Region. In 2019 there were estimated to be over 96 million refugees and migrants in the Region, corresponding to about 35% of the world’s population of refugees and migrants, and about 10% of the total population of the Region (45). Within the heterogeneous category of migrants, different

\(^1\) Race is a social construct and the concept is used to refer to physical differences between groups of people (mainly skin colour, but also facial features, body shape or hair colour and texture) that societies consider to be significant and connected to internal characteristics such as intellectual capacities or typical behaviours. The theory that humans differ from each other in significant biological ways has been disproven by modern genetics. Therefore, race is a social construct imbued with unequal power dynamics and discrimination: certain phenotypic characteristics have meaning because of sociopolitical, not biological, factors (34).
Introduction

Communities face exclusion from health research for different reasons. Traditional research methods such as surveys and interviews rely on language and/or reading skills and may exclude communities that do not speak the dominant language to simplify research design (46,47). People experiencing discrimination and exclusion from mainstream society may have doubts about the relevance of research for their lives. Migrants in the process of seeking international protection, or those threatened by deportation, may be reluctant to take part in research projects that involve one-off interviews or focus groups because of concerns around anonymity and a lack of mutual trust (48,49).

For these reasons, migrant populations are often considered hard to reach or, as Lightbody et al. argued, “easy to ignore” (50). While recent analyses suggest that there are some signs of increased involvement of migrants in health decision-making across the Region (51,52), it is notable that this often refers to participation in service delivery, such as public health initiatives, rather than policy-making or research, and that involvement is spread unevenly across the Region (1). This underrepresentation of migrant communities in health research has significant negative effects on health policy and practice, as well as health outcomes. It leads to policies and practices that are biased towards the dominant population groups and do not reflect the health needs of diverse migrant groups, thereby reproducing inequality and discrimination in health-care provision.

Where traditional research may fail to include migrant communities, participatory approaches to research offer avenues for engagement with a wide range of stakeholders and entail a range of significant benefits, as outlined in a paper published by the ICPHR Working Group on Migration (2).

There are a number of benefits of PHR with migrants.

• **Identifying timely and relevant research topics.** PHR ensures that migrant communities are involved in setting research agendas and that “research efforts address what migrants perceive as priority needs” (2). If research questions, design and outputs are relevant to the communities affected by the issue (5), we produce less research waste (1), that is, less abstract research that is disconnected from the pressing health issues facing diverse communities. This, in turn, increases the likelihood that (i) people take part in research and (ii) findings have positive impact because they address real-life issues.

• **Ensuring the participation of hard-to-reach communities.** PHR can serve to counteract the bias in mainstream research described above and ensures that the lived experiences of so-called hard-to-reach populations are taken into account.

• **PHR starts with building relationships.** The involvement of migrants as partners and co-researchers throughout the research process can significantly enhance the credibility, validity and relevance of research, which, in turn, facilitates the recruitment of participants (2).

• **Generating in-depth, nuanced knowledge and overcoming research bias.** In traditional research, questions, research and methods reflect the biases of the academic researchers who are setting the agenda; for example by adopting a deficit model of migrant health (that is, assuming that migrants generally have poorer health compared with the non-migrant population) (2). PHR can overcome these limitations by “having a wider set of perspectives to draw on” (5) and building on people’s own accounts of what goes on in their everyday lives (2). It can help to develop a strengths-based approach through a focus on communities’
unique resources, such as knowledge, experiences and social capital. In this way, PHR offers a unique opportunity to co-create new, unexpected knowledge “which cannot be gained by academic researchers who are separate from the lives they are studying” (3).

- **Improving health-care delivery.** Blind spots in mainstream research can result in a one-size-fits-all approach to health-care policy and practice that does not address the lived experiences and needs of all migrant groups, in turn leading to health inequity. Involving migrants in the process of writing policies and designing and implementing health initiatives can ensure that they are “relevant, respectful and responsive” to their lived experiences (2), thereby increasing the acceptability, uptake and sustainability of health interventions and services. Because of its flexible, collaborative approach, PHR “generates a more comprehensive knowledge base that leads to more responsive policies and healthcare services [and] improved design of public health interventions that have a better chance of being implemented” (1).

- **Empowering individuals and communities.** Participatory research can contribute to the empowerment of the individuals taking part as well as the wider communities they are connected to, through reducing social isolation, counteracting the effects of social stigma and discrimination, developing skills, growing social networks and social capital, and enhanced health literacy (1,4,53). In this way, PHR can contribute to tackling the social determinants of health and mitigating the effects of inequality (2). At the same time, PHR also facilitates learning and growth for the academic researchers involved. As communities and co-researchers are empowered to share their knowledge and contribute to the research process, academic researchers are given the opportunity to rethink and unlearn dominant and dominating ways of conducting research through this reciprocal co-learner relationship (8,48). Lastly, PHR with migrants also works towards enhancing the intercultural knowledge and skills of all project partners (including health-care providers) as they learn from each other, with the potential of leading to more culturally sensitive and equitable health policies and practices (54).

### 1.4 Objectives

This document aims to provide concrete step-by-step guidance and research tools to involve migrants in health research. By drawing from international best practices and concrete research projects from both within the WHO European Region and further afield, the guide:

- offers evidence for adopting a PHR approach for meaningful, rather than tokenistic, involvement of migrants;
- describes how to involve migrant communities in all phases of the research, from agenda setting, to data collection, to knowledge transfer;
- offers ways to address cross-cutting issues, such as power dynamics, language differences and impact in PHR with migrants; and
- summarizes policies that increase migrants’ involvement in health research within the WHO European Region.

The target audience for this guide includes those in health policy-making roles at local, national and international levels; international and national organizations representing migrant communities;
international and national organizations working on health planning and provision and/or with migrant communities; and researchers. While this guide specifically addresses the situation in the WHO European Region, the contents, with context-specific adaptations, is also applicable to other countries and regions.

1.5 Methodology

This guidance draws on the following sources:

• position papers published by the ICPHR and associated publications;
• a narrative review of migrants’ involvement in health decision-making in the WHO European Region; and
• case studies selected from peer-reviewed literature.

This ensures that the guidance is fundamentally grounded in the participatory paradigm – all of these sources represent participatory forums and draw on real-life participatory research collaborations.

Specifically, information was drawn from the following ICPHR position papers and related publications.

• ICPHR (2013). Position paper 1: what is participatory health research? (3). This publication describes the plurality of approaches that come together under the umbrella of PHR and synthesizes key values, characteristics and ethics of PHR.
• Abma et al. (2019). Participatory research for health and social well-being (5). This handbook, published by members of the ICPHR, offers concrete practical step-by-step guidance on how to conduct PHR.
• ICPHR (2020). Position paper 3: impact in participatory health research (26). This publication summarizes what impact means in the context of PHR and how it can be captured and documented.
• Roura et al. (2021). Participatory health research with migrants (2). This publication was written by the ICPHR Working Group on Migration and outlines the opportunities and challenges of PHR with migrant communities, drawing on international research.

The guidance also draws on the literature review by MacFarlane et al. (1). This is a narrative review of migrants’ involvement in health policy, service development and research in the WHO European Region, and served as the foundation for the policy recommendations in section 3 of this guide. It demonstrated that migrant groups continue to be underrepresented in health decision-making processes and that national policies are required to ensure participation across policy-making, service provision and research activities in all countries in the WHO European Region.

Case studies of PHR with migrants were also drawn from the international peer-reviewed literature. Case studies were chosen based on the detailed, thorough information they could provide on concrete aspects of PHR with migrant communities and in order to represent a wide range of research topics, populations and locations.
2. Findings

2.1 How to carry out PHR with migrants: participation throughout the research process

As highlighted in the Introduction, PHR is defined as research that involves key stakeholders in all aspects of the research process in a meaningful way and where governance and decision-making power is shared between project partners. The following findings provide some guidance on how to adopt a participatory approach throughout the various phases of research based on examples from successful research projects. The projects reflect a range of topics, populations and locations throughout the world, with a focus on case studies from the WHO European Region.

2.1.1 Setting the research agenda and defining research questions

There are several different ways a PHR project with migrants may start, including (i) initiation of the project by a large organization such as a government department or an international/national NGO seeking to examine and improve a health issue; (ii) initiation by a migrant group or organization that identifies a need for research on a specific area; or (iii) initiation by an academic researcher or student interested in a topic/research question. Ideally, the specific research topic/questions would be co-designed after connections have been created between the different project partners.

A guide developed by Care Alliance Ireland as part of a public and patient involvement capacity-building initiative (55) offers some examples of tokenistic involvement of community partners that would not meet the standards of PHR as outlined in section 1. These problematic examples include:

- last-minute request for involvement in a funding bid – “all we need is your signature”;
- expectation of involvement in research with no specific budget for the community partners;
- research questions already fully formed – no room/time for meaningful debate; and
- the researcher just wanted the community partners to help with participant recruitment or to facilitate access to respondents (known as being a gatekeeper).

From a PHR perspective, deciding what the focus of the research should be constitutes a crucial opportunity to counteract unequal power dynamics and ensure that the topic under study is relevant to the communities affected by it. In this way, PHR differs from traditional migration research where “research priorities … have been primarily driven by the interests of academics, policymakers and clinicians with infrequent inclusion of migrants in research prioritization processes” (2). Boxes 2.1 and 2.2 illustrate ways in which migrants have been included in research development.
Findings

Box 2.1. **The Irish World Music Café: using arts-based methods to identify research priorities**

A team of academic music researchers, academic health researchers and an NGO focused on advocacy and human rights for migrants co-designed a research project to involve migrants in the development of a set of research priorities for Ireland. The project built on an existing creative method called the Irish World Music Café, which was developed to welcome Syrian refugees to the mid-west region and to promote social inclusion of new communities with the local communities (56). The Irish World Music Café involves musical icebreakers and cultural sharing such as people teaching each other songs from different parts of the world.

The research team adapted the Irish World Music Café concept to create an arts-based research space. They integrated focus group discussions about health issues and research priorities with the Café’s musical elements, along with some other arts-based methods (drawing, poetry and song-writing). Participants for the research prioritization project included representatives of migrant support groups, health-care providers, and health and music academics working in the area of migrant research. The cafés were held online during the COVID-19 pandemic, once a week for two hours over the course of six weeks. The discussions from the focus groups resulted in a collective identification of three actionable themes: holistic health, language and culture, and mental health. Working groups were established to take actions in each of these areas forward upon completion of the World Café sessions.

Evaluation of the project found that the use of music to create a research space stimulated the process and helped to facilitate open conversations about research priorities: it served to equalize power differences between participants and brought a deep human dimension to the interactions.

Box 2.2. **Answering local questions: a participatory research project with Eritrean migrants**

This study in Israel was initiated by two local activists and social entrepreneurs and four Eritrean asylum-seekers who shared English and Hebrew as common languages (6). The team wanted to find out more about the health needs of the Eritrean refugee community, with a specific question regarding their willingness to pay for health insurance. This initiative was intended to act as a step towards community organizing and jointly advocating access to Israel’s public health-care system. The academic partner – a public health nurse with a background in PRH – was invited into the team during the conceptualization phase. Her expertise was used by the team to develop a mixed-methods survey and was also an asset in regard to quantitative data analysis. In this way, the project was able to combine their expertise in order to answer research questions that were deemed relevant by community members, serving the collective aim of improving access to health care for Eritrean migrants in Israel.
2.1.2 Research process and governance

At the outset of a project, it is crucial to co-create a working agreement – whether in writing or any other appropriate form (5). Because of the involvement of a diverse group of people, it is necessary to spend time discussing expectations, aims and objectives of the research; agreeing on guidelines for communication, including handling of difficulties and conflict; management of the research process including reimbursements; storing of data and confidentiality; training requirements; and agreements regarding frequency, format and duration of meetings. This may need to be discussed before applying for research funding (for an in-depth consideration of funding for PHR with migrants, see section 3.2).

At the outset of the collaboration, honest conversations about who does what, when and why are crucial. This includes sharing expectations regarding the aims and limitations of people’s involvement in the research. When working with migrants with an insecure legal status, questions around how the research may or may not support their asylum claim or legalization process may need to be discussed, as well as questions relating to health, such as the role of the research team in supporting individuals in accessing health care.

The following questions were adapted from the Care Alliance Ireland’s guide for community organizations (55). They can serve as a template for what may need to be discussed in the process of setting up governance structures and writing research agreements.

- At which stages of the research process will the community partners be involved (framing the research question, research design, fieldwork, analysis, dissemination or implementation)?
- How will the involvement of the community partners be supported?
- What training will be available to the research team, including community co-researchers and academic researchers?
- Where did the inspiration for this research come from?
- What other community groups or organizations are involved?
- What is a realistic time commitment per week/month for community involvement in the project?
- If community partners have difficulties with the project team, who can they approach within the university/research institute?
- What is planned for compensating community participants for items such as their time, travel, loss of income as part of their work on the project?
- Will childcare be provided or childcare costs covered?
- How will the community partners be involved as coauthors on publications from the project?
- Is there an open access publishing policy?
- How will community partners be involved in the dissemination of the results and recommendations, such as through presentations or public engagement activities?
- How will the outcomes and outputs of the research be shared with people who took part?
- How will the outcomes and outputs of the research benefit the people who took part or a wider community, in the short or long term?
PHR with migrants often involves a collaboration between people from different backgrounds, with different social status and power. In order to avoid tokenism and a reproduction of inequalities, the structures for dialogue and making decisions about the project need to reflect a strong commitment to addressing and overcoming power inequalities (Box 2.3). This means considering the ways in which the research collaborators need to work together in order to ensure meaningful engagement and dialogue: “The challenge is not to subsume differences of opinion and knowledge, but to enable stakeholders to deal positively with differences and to seek mutually acceptable outcomes” (12).

Box 2.3. Collaborative governance: creating a community committee to guide the research process

The development of a logic model for a youth mental health promotion intervention used a participatory approach in a Palestinian refugee camp in Beirut, Lebanon (57). In order to facilitate the collaborative governance of the project, a Community Youth Committee was created: a grass roots coalition composed of 17 NGOs that work with young people in the camp, funders of projects in the camp, representatives of the United Nations Relief and Works Agency, community residents, academics from the American University of Beirut and, most importantly, young Palestinian people living in the camp. Participation was sustained throughout the project, indicating high levels of commitment and involvement.

At the outset of the project, the Committee discussed, agreed and recorded rules regarding the governance of the project, including membership, attendance, voting and decision-making. Generally, decisions were arrived at through consensus, allowing for extensive dialogue to reach the consensus. When divergent viewpoints were strong, a vote was taken and a majority rule applied. In the early stages of the coalition, each organization had one vote, including the university team. As trust built, the decision was made to allow each individual to have a vote. Meeting frequency and length varied throughout the project, based on the requirements for each phase, ranging from weekly shorter meetings during the conceptualization phase to bimonthly, day-long meetings when the team were preparing the mental health interventions.

2.1.3 Recruitment

It can be difficult to recruit research participants into a health research study (46,47) when working with marginalized populations such as:

- people for whom engaging with the State and public institutions may be risky (such as undocumented migrants, asylum seekers, migrant sex workers, ethnic minorities facing racism), who may, therefore, want to avoid being involved in academic research or may simply be difficult to find;
- people who speak a language other than the national language(s);
• people who are weary of “being researched” due to past experiences of extractive research without positive effects on their lives; and
• people who do not engage with health and social services, for example because they do not know how to access those institutions, do not feel welcome or do not want to use them.

PHR offers two important solutions to this problem: (i) co-ownership over the research process through collaborative agenda-setting, which can help to reduce research fatigue by ensuring that the research questions are relevant to community stakeholders (see section 2.1.1) and (ii) involvement of peer researchers. Peer researchers are people who share aspects of the lived experience and the cultural and linguistic background of the research participants. They are recruited, trained and paid as collaborators to facilitate the research process. They can help to decide the best strategy for approaching and recruiting potential participants (where, when, how and who), as well as to collaborate as recruiters themselves. One issue might be that cold-calling potential participants via the telephone may not result in many responses, as people may not answer if they do not know who is calling; other forms of communication such as WhatsApp may be widely used but pose issues for academic researchers because of data protection concerns. Peer researchers can help to solve these problems within the specific local context (Box 2.4).

Box 2.4. Recruitment of hard-to-reach groups via peer researchers

The Service User PeResearcher project was a participatory study in the west of Ireland (58). The aim was to produce a guideline integrating service users’ and service providers’ perspectives concerning strategies to support cross-cultural communication between general practitioners/clinicians and migrants. The academics formed a partnership with seven community interpreters, representing the dominant languages and places of origin in the study region. This meant that language and cultural differences between the research team and the migrant communities could be overcome. The community interpreters were hired as peer researchers and received a total of 40 hours of training before commencing fieldwork. One of their key responsibilities was the recruitment of study participants from their own language and cultural groups; this included the co-design, translation and dissemination of recruitment leaflets and direct engagement with potential study participants to answer questions and concerns about the study. They successfully recruited 51 migrant service users into the study, most of whom had very limited English, some being undocumented migrants or asylum seekers.

2.1.4 Research methods

PHR does not have to be qualitative – it is a research paradigm that does not rely on one specific method (see section 1.1). It can involve any method (including quantitative methods) deemed appropriate by the research team to answer the research question. Qualitative methods, and particularly arts-based methods, lend themselves to the co-production of knowledge because
of their flexibility and adaptability to the needs, skills, interests and aims of a specific group of co-researchers. Quantitative methods (either as stand-alone projects or in mixed-methods studies) may be appropriate if statistical evidence is needed to answer research questions and to develop impactful recommendations. Standardized instruments may need to be pilot tested to ensure they are understandable and acceptable for the target population, and consideration needs to be given to how surveys or questionnaires will be distributed (for example, are online surveys accessible to the potential participants?).

The following diverse examples show how different research methods can be successfully employed in PHR with migrants (Boxes 2.5–2.8).

**Box 2.5. Community researchers using in-depth interviews to investigate social determinants of sexual and gender-based violence**

A study in Flanders in Belgium and the Randstad Region in the Netherlands used a community-based participatory research approach with qualitative in-depth interviews to examine the social determinants of sexual and gender-based violence as experienced by refugees, asylum seekers and undocumented migrants (7). The research team included a diverse group of 22 refugees and asylum seekers with Afghan, Iranian, Iraqi, Kurdish, Roma, Somali, and former Soviet Union backgrounds. They were trained as peer researchers, including skills in conducting in-depth interviews in an empathic and ethically sound way. The peer researchers each interviewed 12–14 people. The questionnaire for the interviews was developed jointly with the peer researchers to ensure that the content and language reflected the lived experiences of the communities involved. It was translated into the languages of the respondents by the peer researchers and collectively coanalysed, as well as co-presented to academia, civil society and policy-makers in a large interdisciplinary seminar. The peer-led interviews resulted in nuanced findings on this sensitive topic, identifying specific vulnerabilities that differed significantly from those of Belgian and Dutch nationals.

**Box 2.6. Using quantitative and qualitative methods in a participatory study on ethnic equality monitoring**

The Ethnic Minority Health in Ireland – Co-Creating Knowledge study was a participatory research project that aimed to analyse how ethnic identifiers are introduced, embedded and used in the Irish health-care system (10). Ethnic equality monitoring in health care is a way of identifying and responding to health inequities related to ethnicity. The study co-constructed research between researchers, community members and the decision-makers who apply research findings. A steering group, including representatives of migrant and ethnic minority communities, was established to ensure participation of key stakeholders throughout the research process.

The mixed-methods study included a secondary quantitative analysis of data from a national longitudinal study, as well as a qualitative component exploring the implementation of
ethnic identifiers in selected primary care settings. Participation of stakeholders was ensured in different ways in each of these work packages, demonstrating that there is no one-size-fits-all approach to participation: different methods may require different approaches.

The statistical analysis of existing quantitative data was conducted by members of the academic research team and presented to the steering group. The role of the steering group was to contribute to data interpretation and the development of recommendations. For the qualitative component, participation of key stakeholders was ensured in the following ways. The steering group was involved in selecting primary care sites for the case studies and deciding on the qualitative methods to be used to gather data (including focus group discussions and interviews). Furthermore, community researchers co-facilitated fieldwork using PLA methods with academic research and reported back to the steering group about the data and emerging findings.

**Box 2.7. The benefits and challenges of conducting a community-based participatory RCT**

A collaborative research team developed an RCT to test the effectiveness of a community-based mental health intervention among low-income Afghan, African and Iraqi refugee adults in the United States of America (9). The project was grounded in 10 years of collaboration between the academic partner and a community advisory council of Hmong refugee women. The team co-created the mental health intervention and it was trialled and run successfully in multiple locations.

The team decided to design and conduct an RCT in order both to grow the evidence base for their mental health intervention and to secure funding, in acknowledgement of the fact that RCTs are still considered the gold standard of evidence by many funding agencies. The team found the following challenges with conducting a community-based RCT: (i) ethical issues around refusing/offering assistance and support to participants in the control group; (ii) diffusion of intervention resources throughout the small refugee community, where it was difficult – and possibly counterproductive – to avoid that the benefits of the mental health initiatives affected relatives and friends; and (iii) staff and community concerns about the RCT design and questions regarding the necessity of proving the value of the intervention via an RCT when it had already been found to be effective based on the experience of the team members and the community, particularly in light of the requirement to exclude the participants of the control group from the intervention.

The team’s reflections on the RCT process highlighted, on the one hand, the feasibility of conducting a community-based RCT, while on the other also raised questions regarding the ethics and practicalities of projects that attempt to fit participatory action research into the frame of medical research standards.
This case study highlights the importance of flexibility throughout the research process, including changing the selected research methods in order to respond in meaningful ways to the needs and preferences of the community collaborators.

An exploratory narrative study focused on the impact of a participatory music-making project, the Scattered People, on social determinants of health and well-being for refugees in Brisbane, Australia (59). The research had originally been planned to expend time on a life histories approach to guide data generation, involving in-depth recorded interviews about participants' lives. In their conversations with participants and community partners, however, it became evident that this was an inappropriate approach for this particular group of people. The participants did not feel comfortable using interpreters for the interviews, and the researchers did not speak the languages required. Without a common language that everyone could speak fluently, in-depth life history interviews would not be possible. Furthermore, participants expressed concerns about the recording of interviews and the level of detailed personal information being recorded, particularly for those who did not have secure legal status.

In response to these concerns, the team decided to conduct informal conversations with the participants instead, focusing on the participants' views on the health and well-being benefits of the Scattered People music programme. The researcher wrote notes and used Clandinin and Conelley’s narrative enquiry method to write a story based on each of these conversations (60). These stories were then shared with the participants and the supporting Scattered People facilitator for verification and approval.

### 2.1.5 Data analysis and interpretation

It may seem a difficult task to involve peer researchers and other community stakeholders in the analysis of data, often leading academic researchers to take responsibility for this phase of research. There are, however, significant benefits to collectively analysing and interpreting data: it may add valuable alternative perspectives on what some of the findings mean and contribute to thinking about problems and solutions (3), and it can be part of the skills development of research team members. It does; however, usually require more time, training and creative thinking about inclusive processes. As data analysis occurs in different stages, it is also possible to assign certain tasks to academically trained researchers (such as the statistical analysis of quantitative data via data analysis programmes), while ensuring higher levels of participation of non-academic partners in other aspects of the data analysis process (such as deciding which variables to use for data analysis, which questions to ask of the data and interpreting the meaning of the findings). The following two examples demonstrate these blended ways of analysing data, ensuring a high level of stakeholder participation while also making use of the skill set of the academic partners (Boxes 2.9 and 2.10).
Box 2.9  

Stakeholder input guides statistical analysis: an HIV prevention project in Portugal

A research project was initiated by a collaboration between Grupo de Ativistas em Tratamentos and NOVA University of Lisbon that brought together a group of diverse stakeholders, including NGOs, community members, health professionals and academics, to promote sexual health and reduce the transmission of HIV among migrant and non-migrant sex workers in Portugal. A participatory survey was conducted to understand sex workers’ HIV knowledge, attitudes and practices and access to health services \(^{5,61}\).

The team decided that academic researchers would carry out the statistical analysis of the survey data but, in line with the participatory ethos of the project, all team members would be involved in deciding the data analysis plan. This included the identification of the variables for statistical analysis, the interpretation of what the findings meant and further questions that needed to be answered as the results were presented. The input from community partners helped the team to determine, for example, different patterns of condom use within the context of sex work, such as the influence of type of sexual partner (regular vs occasional vs concurrent) and the sex work setting (outdoor vs indoor). This exemplifies how stakeholder involvement can improve data analysis: asking the right questions of the data and connecting variables meaningfully are crucial and rely on an in-depth understanding of the lived experiences of the research participants.

Box 2.10  

Using PLA techniques for coanalysis: identifying the most useful guidelines for cross-cultural consultations

The RESTORE project was a PHR study exploring communication in cross-cultural primary care consultations in Austria, England (United Kingdom), Greece, Ireland and the Netherlands \(^{62}\). The research identified existing guidelines and training initiatives that are available to support communication in cross-cultural consultations with a view to implementing some of these within real-world primary care settings. The project actively included stakeholders in the implementation process: migrant service users, general practitioners/family physicians, primary care nurses, practice managers and administrative staff, interpreters and cultural mediators, service planners and policy-makers.

These stakeholders were actively involved in analysing the data through the use of PLA techniques. The guidelines and training initiatives identified in the first phase of the RESTORE project were summarized and presented to the stakeholders. In order to determine which guidelines and training initiatives were considered most useful and practical by the people involved in cross-cultural consultation, the academic researchers facilitated a two-staged PLA process: a commentary chart and a direct ranking exercise. In the commentary chart, stakeholders recorded key points for each of the guidelines and training initiatives as they emerged from the discussion. The direct ranking exercise then asked stakeholders to code each of the key points in one of three categories: (i) positive aspects of the guideline/training initiative being discussed; (ii) negative aspects of the guideline/training initiatives being discussed and (iii) questions to be checked out. The direct ranking exercise allowed stakeholders to indicate priorities or preferences: each guideline and training initiative was
visualized on paper and the stakeholders were invited to add paper-clips to the visuals they considered most useful, leading to a ranking of guidelines and training initiatives. This technique is one way of overcoming power differences in diverse groups and ensuring that decision-making processes are transparent and give an equal voice and vote to all stakeholders.

This coanalysis resulted in the recommendations made by the RESTORE project regarding which guidelines and training initiatives should be implemented in each primary care setting. The role of the PLA-trained academic researchers was to facilitate the discussions and to highlight and address differential views within the stakeholder group until a democratic decision was made. Furthermore, the analysis of the implementation process involved a theoretical component. Normalization process theory can then be used to alert stakeholders to levers and barriers to the implementation of a guideline/training initiative in a real-world clinical setting. In RESTORE, the academic researchers used normalization process theory to monitor and support the stakeholders’ implementation of their selected guidelines and training initiatives, thereby adding a theoretical layer of analysis to the findings.

### 2.1.6 Dissemination and knowledge transfer

In PHR, the process of disseminating research findings needs to ensure that all involved perceive the outputs of sessions and activities as meaningful. In some cases, this results in coauthored academic papers (such as that from the Service User PEEResearchers project (49)), but often, a participatory approach to dissemination explores avenues beyond academic publications. This may result in a combination of different outputs, drawing on the skills of different team members and addressing different audiences. While the outputs of conventional research often target the academic community as an audience, PHR explicitly aims to change the lives of those affected by the issue at hand for the better and, therefore, needs to reach the people who can contribute to that change, such as health-care providers, community members, NGOs and local policymakers. Written texts may not always be the most effective way of disseminating findings and affecting change, and creative approaches to sharing research findings may be appropriate in PHR. In some cases, the creative outputs (such as theatre or music performances, films or visual art) may be produced after the completion of the project, as a dissemination output, whereas in other projects creative methods are employed throughout the data collection process and collated or edited into outputs during dissemination.

Of course, one of the key strengths of PHR is that all key stakeholders should be involved throughout the process, not only members of migrant communities, but in many cases also policy-makers, health-care professionals and other stakeholders, such as members of the lesbian, gay, bisexual, trans, intersex, queer community (LGBTIQ; Box 2.11). Specific issues can also be examined, such as issues of mental health stigma and discrimination and related social determinants (Box 2.12). Because of their involvement throughout, these stakeholders can play a crucial role in the supporting knowledge transfer, that is, the application of research findings in policy and practice.
Queer Crossings was part of the MoVE (methods: visual: explore) project approach utilized by the Migration out of Poverty Consortium, which explored the lived experience of migrants in South Africa (63). The project focused on the experiences of 11 LGBTIQ asylum seekers and migrants in South Africa and resulted in a public exhibition and an open-access e-book that featured the creative work of the participants. The project exemplifies how creative activities can be used both as a data generation method and as a dissemination strategy.

Queer Crossings was a collaboration between academic researchers and the community organization GALA (Gay and Lesbian Memory in Action). The aim was to increase public awareness regarding the violence, discrimination and exclusion faced by LGBTIQ migrants in Johannesburg. The project centred around two creative workshops: a seven-day workshop where a professional writer helped in the facilitation using visual methods such as body-maps (life-sized self-portraits) and non-fiction story writing. This was followed up a year later by a participatory poetry workshop.

The participants decided which images and texts they wanted to share publicly in the exhibition and the e-book. In this way, the project ensured that the decisions regarding the outputs were shared. The participants also worked together – supported by the facilitators – to edit and revise their stories with a view of sharing them with a broad audience, thereby integrating the process of dissemination into the research itself.

The Sanctuary Programme, an action research project in Scotland (United Kingdom), brought together national, regional and local partners with the aim of understanding mental health problems among asylum seekers and refugees in Glasgow; identifying patterns of stigma and discrimination; and exploring solutions (64). The project clearly identified social determinants of (mental) health and the connections between mental health and the living conditions and socioeconomic circumstances of asylum seekers and refugees. Among the actions that arose from the research project were:

- a national campaign and policy advocacy for better provision for asylum seekers and refugees, addressing the social determinants of (mental) health;
- submission to the new Mental Health Strategy for Scotland 2012–2015 that argued for the provision of better mental health and support and services for asylum seekers and refugees;
- participation in the Scottish Refugee Integration Forum, allowing the group to raise issues such as destitution and unemployment; and
- development of peer-led mental health awareness workshops entitled community conversations and delivered to over 300 people.

An evaluation of the workshops found them to be effective in reducing mental health-related stigma, increased optimism in relation to recovery of people with mental health problems and increased confidence about supporting peers with mental health problems.
2.2 How to carry out PHR with migrants: cross-cutting issues

This section is based on Roura et al., 2021 (2) and offers guidance on some of the cross-cutting issues that affect PHR projects, using examples from real-life research projects to demonstrate how these issues can be approached.

2.2.1 Representation

In many research projects with migrants, regardless of which type, there is a significant power imbalance between the people initiating the research (often academic researchers) and the research participants. While the academic researchers may well be migrants themselves, they may still hold a significant amount of privilege, for example based on race, social class, economic means, nationality and/or legal status. Furthermore, the question of representation – who speaks for whom – is particularly pronounced in PHR with migrants. When deciding who to work with and who to include in the research team, it is essential to note and reflect on issues of (in)visibility (which migrant groups are more present in the collective consciousness), “othering” processes (assumptions about those perceived as other and how these can be founded on stereotypes) and power dynamics within migrant communities (who represents whom). In deciding who to approach about a potential research partnership, researchers could consider the following questions.

• Is this group/organization based on self-representation (is it led by migrants) rather than being an organization run by non-migrants for migrants?
• Who does this person/this organization represent?
• How diverse is the representation, for example in regards to ethnic groups, gender, class, sexuality, ability, age and legal immigration status?

Related to the issue of representation is the question whether or not a specific project needs to be specific to migrants or if a better, more-inclusive, approach would be to focus on a specific topic and involve various different people/groups in the project, including migrants (Boxes 2.13 and 2.14).

Box 2.13. Shifting the focus: researching poverty instead of migration

You Do Not See It is a participatory study with mothers living in poverty in the Netherlands (65). It is an example of a PHR project that did not exclusively focus on migrants but rather included migrant women into the project, based on another marker of their multifaceted identity, namely living in poverty. The study included a long-term collaboration with a group of mothers from different national and ethnic backgrounds. It was initiated by a charity working with families in the area with the aim of including the service users more in the development of the services provided by the organization. Mothers living in the area were invited to take part in the project in order to formulate their own (research) aims and questions and to jointly design the project. The women received financial compensation for their time and travel expenses for meeting. The women who responded to the invitation came from a range of different backgrounds, including migrant women.
Box 2.14. Relying on gatekeepers: benefits and disadvantages

Egid et al. (66) conducted a study that explored how participatory health researchers perceive and experience power and how it is discussed and addressed within the context of research partnerships. They conducted online workshops with 59 participants from 24 countries, all of whom had either conducted participatory research or were in the process of doing so. Among the themes explored by the researchers who took part in the study was the question of whether or not to collaborate with gatekeepers, such as community leaders or NGO representatives. They explained that working with gatekeepers has practical benefits – it only requires creating a relationship with one person or organization that can then support the process of participant recruitment – and it may also be a diplomatic requirement, as a way of ensuring support from powerful individuals and/or organizations in the study context and avoiding conflict. However, researchers also highlighted that working with gatekeepers may marginalize certain groups or people within the community, reinforce unequal power dynamics by silencing certain voices and merely “empowering the already empowered” (66).

2.2.2 Power imbalances

Closely connected to the theme of representation is the question of power imbalances within the project team and throughout the research project. It requires empathic facilitation and solid conflict-resolution mechanisms to attend to power imbalances that can lead to the amplification of some voices and the silencing of others. This includes the often unavoidable power imbalance between professional/academic researchers and participants/peer researchers, but also power imbalances within migrant communities (such as those related to age, gender and social class) (2) or power imbalances between different project stakeholders (such as medical doctors vs service users).

In relation to power imbalances between academic researchers and community members, it is important to note, however, that this cannot simply be fixed by avoiding any input from the academic researchers. This may, first of all, obscure the power dynamics, avoiding critical reflexivity and open communication; secondly, it may lead to an undervaluing of what academic researchers can contribute (3).

PHR, and participatory research more generally, is often misunderstood as being a consensus-oriented process in which the perspective of academic researchers should have little influence. We see the strength in PHR lying in the ability to uncover and examine different points of view, which may mean presenting a variety of perspectives throughout a study. Academic researchers involved in PHR are encouraged to bring their knowledge on health issues, research theory and research methods to the dialogue: their role needs to be reflected critically, however, to avoid undue influence on the process, particularly if they are in the facilitating role.

Box 2.15 describes the use of art to facilitate collaboration.
Box 2.15. **Arts-based methods as a way of facilitating collaborative research processes and overcoming power imbalances**

The Mwangaza Mama project in South Africa was another initiative by the MoVE project (see also Box 2.11) and focused on the lives of a group of asylum-seeking women from Angola, Burundi, Rwanda and the Democratic Republic of the Congo, addressing their experiences of trauma and violence as well as their resilience (67). Arts-based methods were used as the primary tool of engagement. A group of women were invited into the project via a local psychosocial support organization. In bi-weekly workshops, the academic researchers offered a range of activities, including multimedia collaging, painting, drawing, creative writing, body-mapping and creating a textile quilt. While creating artwork, the women engaged in conversations about their lives, their well-being and what mattered to them. The themes represented in the final output of the project emerged from these conversations, with sporadic input in the form of questions from the academic researchers. The regular workshops and the use of creative activities allowed for findings to emerge organically and for knowledge about the lives and struggles of the women to be co-produced in a slow, open-minded manner.

Arts-based methods were the key to this collaborative process. Traditional ways of facilitating research collaborations, such as group discussions, run the risk of silencing those who are less familiar and comfortable with expressing their thoughts in a space that is imbued with unequal power dynamics, which in the case of Mwangaza Mama involved white middle class academic researchers and working class black refugee participants. Arts-based methods, by comparison, create space for silence and allow for conversations to emerge as people spend time together doing something. The trust and familiarity built over 18 months of regular creative workshops was the crucial foundation for governance of the research process: decisions about the themes, outputs and aims of the project were made collectively during the workshops.

### 2.2.3 Language differences

Language differences is one of the reasons why certain groups of migrants may be excluded from research. Researchers may feel that working with migrants who do not speak the dominant language is too cumbersome and, therefore, focus on communities and individuals who do not require translation and interpretation. For obvious reasons, this leads to research bias and a pattern of exclusion (2,43). PHR approaches offer solutions because they rely on a team of researchers from different backgrounds working together, often including peer researchers, who can be invited specifically because they have the required language skills and are capable of working as community liaisons ( Boxes 2.4, 2.5 and 2.12 are examples of working with peer researchers). Involving peer researchers can help to ensure that migrants who do not speak the dominant language are offered the opportunity to take part in the research, speaking their preferred language (Box 2.16).
Box 2.16. The role of bilingual community health educators in a participatory video project

The C4H (communication for health) project exemplifies how participatory approaches can facilitate the engagement of migrants who do not speak the dominant language (13). In this participatory video project, four ethnic/language groups – Bangladeshi (Bengali/Sylheti), Chinese (Cantonese), Chinese (Mandarin) and Pakistani (Urdu/Mirpuri/Punjabi) – were involved in the production of a breast-screening video, funded by the National Health Service Cancer Screening Programmes in the United Kingdom. The project was grounded in a long-standing collaboration between the researcher and bi/multilingual community health educators from different ethnic backgrounds. It involved consultation meetings, video production skills workshops, filming and post-production working sessions with the aim of producing a public video promoting breast cancer screening.

Community health educators were crucial for the research and film production process. They mobilized community participation, recruited migrant/ethnic minority participants into the project and scheduled and organized transport for the project participants. During the consultation and video production workshops, they served as interpreters, ensuring that the monolingual participants were included in the discussions and could feature in the final video output.

2.2.4 Reimbursement of peer researchers and community partners

Most PHR projects will involve paying the peer researchers and/or the community organizations involved as partners and, in some cases, also research participants. This is an important ethical issue, particularly when the work requires contributions from marginalized people who may have few other opportunities to generate income, such as asylum seekers, undocumented migrants or migrant sex workers.

There is potential for conflict when it comes to decisions about resource allocations. As with other aspects of participatory projects, ensuring that decisions are made collectively and transparently is crucial for the success of the project. Different groups of stakeholders may hold different expectations regarding their payment and it may be important to address expectations openly during the conceptualization phase of the project. Furthermore, if different project partners receive different payments (for example, an academic researcher is generally expected to be paid more than a peer researcher, and different organizations may have different policies regarding their reimbursement for involvement in research), this needs to be transparent and satisfactory to all involved in order to avoid conflict. These decisions may need to be made before funding applications are submitted. The stakeholder agreement written at the outset of the project can document these arrangements.

In regard to peer researchers, there is no specific rule as to what or how they should be paid. Expectations may vary between groups and locations. Peer researchers can either be paid a regular salary throughout a project or an hourly rate based on their work on the project or based on their outputs (such as numbers of participants recruited) (Box 2.17). Each of
these has advantages and disadvantages: peer researchers may be involved more or less at different times rather than daily, possibly rendering salaries inappropriate. Payments per output may put pressure on the peer researchers to recruit in unethical ways in order to ensure that they get paid. Payments per hour worked may be cumbersome to process. What is appropriate and practical depends on the specific circumstances. There may be issues with these kinds of payment, such as whether people can have additional earnings if they receive welfare payments or if people cannot open a bank account due to legal status. In some cases, in-kind payments may be the most useful, such as daily necessities or groceries. Vouchers for local shops may also be an option. These decisions need to be made in conversation with the communities involved to ensure that they are viewed as acceptable and fair. Further, what is possible may be enabled or constrained by financial systems in universities for part-time work and/or payments or vouchers to people who are not on the official payroll. This highlights the wider organizational influences on this important issue.

Box 2.17. Payments for peer researchers conducting a cross-sectional survey on HIV

A research team conducted a cross-sectional survey in six German cities investigating the knowledge, attitude, behaviour and practices of migrants from sub-Saharan Africa regarding HIV and other sexually transmitted diseases (68). The study was co-designed by a diverse team including peer researchers (members of African migrant communities); stakeholders in HIV prevention, counselling and testing; and researchers in the fields of HIV. The study was piloted and then rolled out across six locations. In each location, a partner organization (such as a migrant support organization, HIV prevention centre) was responsible for recruiting 10–25 peer researchers, who underwent a two-day training. The peer researchers recruited participants and ensured the completion of the survey.

Peer researchers were paid €20 per recruited participant if at least 60% of the questions were answered. The team decided to pay per participant rather than per hour worked as this facilitated budgeting and administration. In addition, peer researchers were paid for taking part in the training, evaluation meetings and focus group discussions for the purpose of data analysis and the preparation of recommendations based on the study findings.

2.2.5 Conflict

In a project involving a diverse group of stakeholders working on issues that directly affect people’s professional or personal lives, conflict or disagreement is nearly unavoidable. People may disagree, for example on the aim of the project, the meaning of data or the best course of action. Communication styles may differ and people’s understanding of what it means to take part in a PHR process may diverge. The partnership agreements described above (section 2.2.4) can attend to some of these issues by obtaining a consensus on how
to deal with disagreements before problems arise. However, not all disagreements can be pre-empted or avoided. PHR is, by definition, unpredictable to an extent: “the process of meaning making [in participatory research] may take us down an unexpected track, a route less travelled or even never travelled, but engaging in participatory research involves being open to the unexpected, the new and the different” (5). Conflict can be an opportunity to delve deeper, to explore diverse experiences and opinions, as well as to learn better ways of working together across differences (Boxes 2.18 and 2.19). Embedding participatory techniques such as PLA (see above) into the process of working together can be helpful, as are intermittent evaluations and opportunities to collectively and critically reflect on the research process. External support or training may be needed to ensure the project facilitators are equipped to work towards open communication and productive conflict resolution.

**Box 2.18. Group dynamics: when people do not get along**

In the You Do Not See It project with mothers living in unfortunate circumstances in the Netherlands (Box 2.13), difficult dynamics arose between the people involved in the study (65). The project involved bi-weekly meetings where people shared their experiences and co-developed the research project, which focused on the structural causes of unhealthy lifestyles. While the group successfully co-developed a project and engaged with service providers to make their voices heard, conflicts arose during the group meetings. Some of the women expressed annoyance with others’ contributions and judged others’ views in non-verbal and subtle ways, inhibiting inclusive and collaborative communication. Tensions mostly occurred between a mother with a refugee background and two women born and raised in the Netherlands. One woman showed contempt for the less-than-perfect Dutch language skills of one of the participants and another mother, who had fled her country of origin during a civil war, expressed annoyance and judged the stories of poverty shared by Dutch-born women as less painful.

The researchers reflected on these issues via individual self-enquiry (first person), using one-on-one conversations with group members (second person) and using input from colleagues and the literature on participatory methods (third person). These forms of reflection increased empathy and understanding and fed into the facilitation of the group sessions. The researchers also found that arts-based methods, including a photo voice project, were helpful tools to shift group dynamics and focus on the shared issues relating to poverty and (ill)health (65), concluding “conflicts are not technical problems caused by using ‘wrong’ methods or by the researcher’s inadequate navigation in the field…. Reflections on conflict and its complexity are unavoidable and a condition for the production of social scientific knowledge.”
The PaKoMi (Participatory Development of HIV Prevention with Migrants) study was a PHR project in Germany aimed towards HIV prevention. It included collaborators from immigrant communities (including members of African, Bulgarian, Russian and Turkish immigrant communities) as well as service providers (staff from AIDS service organizations) and researchers in four German cities. The evaluation of the project used the stage model to assess people’s level of participation (Fig. 2.1).

All project partners were asked to use the stage model to describe their own and other project partners’ level of participation. The evaluation revealed that the project partners perceived their level of participation differently. While some of the migrant community members in one location felt that the initial phase of the project was at the stage of non-participation, where they were told what to do rather than being involved in the decision-making process, the professional NGO representatives involved described the decision-making process as collaborative. The evaluation resulted in an open discussion about decision-making and led to a deeper understanding of how participatory processes work; particularly if the people involved know each other but have not worked together in a collaborative way before (that is, if they are used to the more hierarchical relationship between a service provider and a service user). The researcher who served as a facilitator played a key role in enabling respectful controversy around these issues. The group’s reflection led to a collaborative decision on how to handle things differently in the future.

**Fig. 2.1.** Stage model to assess people’s level of participation

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<th></th>
<th>Instrumentalization</th>
<th>Instruction</th>
<th>Information</th>
<th>Consultation</th>
<th>Inclusion</th>
<th>Partial delegation of decision-making authority</th>
<th>Decision-making authority</th>
<th>Self-organization</th>
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2.2.6 Project time frames

Inevitably, PHR requires a significant amount of time, resources and a strong commitment to inclusive processes. Training and skills development need to be factored in. Collaborative decision-making in diverse groups takes more time than topdown decisions in a traditional research project. As discussed in section 2.2.5, conflicts or disagreements may be more likely in a larger and more diverse team and will need to be addressed and resolved (3): “The occurrence of messiness in this sense is a fundamental characteristic of PHR, [resulting] in a research process which is nonlinear and multi-focused and in research outcomes which cannot be characterized prior to the study”.

The cyclical, iterative and messy nature of PHR (where messy means difficult rather than careless) may not fit into the tight requirements of funding proposals or project timelines. This means, very simply put, that a participatory approach may not always be feasible: it may be better to conduct a sound, traditional research project than to attempt a participatory project and fail. Ideally, however, these aspects of PHR would be factored into the process by health funding agencies, allowing for some flexibility within the time frame, the research process and the outcomes of the research (Box 2.20).

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**Box 2.20. Good participatory research takes time: the MisSA study in Germany**

The MisSA study in Germany involved a quantitative cross-sectional survey on knowledge, attitudes, behaviour and practices regarding HIV and sexually transmitted infections among migrants from sub-Saharan Africa living in six German cities and utilized a PHR approach (70). The study was funded by the German Ministry of Health and coordinated by the Robert Koch Institute; the national public health institute with a mandate for infectious disease surveillance and related research. The researchers adopted the participatory design involving peer researchers (members of African communities in the study locations) as a way of addressing the issue that surveys on knowledge, attitudes, behaviours and practices regarding HIV and sexually transmitted infections for the general population often do not sufficiently include migrants from sub-Saharan Africa. Recruiting participants via peer researchers led to an inclusion of marginalized subgroups such as migrants without health insurance and/or without legal immigration status. In each study location, the team collaborated with a local partner organization (such as a migrant support organization) that was responsible for recruiting a local study coordinator and peer researchers, as well as coordinating the research process meetings.

The project team succeeded in recruiting a heterogeneous sample of migrants from sub-Saharan Africa through iterative rounds of opportunistic and targeted sampling. However, this required weekly reflection and communication between the study coordinators, peer researchers and the researchers from the Robert Koch Institute, and constant adjustments to the recruitment procedure. It was important for the overall success of the project that the funding body was involved from the very beginning of the study planning. This resulted in support for the participatory approach adopted by the team and prepared the funder to take the unique nature of PHR into consideration.
The project was conducted in stages, allowing time to build a diverse coalition across multiple locations and time to build mutual trust. However, some of the unanticipated aspects of the research findings did not receive as much attention due to fact that there was a fixed end date for the project, which limited the development of local, sustainable actions. The researchers concluded that for a multicentre PHR project with diverse migrant populations, “time is the most important prerequisite” (68).

2.2.7 Impact

As described in the Introduction (section 1), PHR can affect change in two significant ways. First, the participatory research process itself can have profound transformative effects on all those involved – academic researchers and community stakeholders – resulting in changes in their fields of influence (9). Secondly, concrete collaborative actions connected to and resulting from the research can lead to change. These spheres of impact and legacy are interconnected through cycles of action and reflection (71). In PHR, “change does not happen at ‘the end’ – it happens throughout” (26). Some of the impact of PHR is going to be subtle and relational, as power dynamics, social hierarchies and norms are challenged and changed through the participatory way of working together: “learning together both produces impact and is an impact in itself” (26).

It is beneficial to consider at an early point in the research project as to how the impact of a project will be evaluated. This may involve evaluation activities at the beginning, throughout and/or at the end of the project, as well as well after the project has been completed to assess long-term impact. In line with the participatory ethos of the research, the evaluation, including the questions and methods used, should be designed collaboratively with the relevant stakeholders. Dimensions that could be taken into account when assessing impact are (i) the local and national contexts that inform and shape PHR project(s); (ii) the type and extent of participatory practices and how well they actually worked (or did not work); (iii) the impacts of participation on the research and knowledge creation process; and (iv) the range of outcomes and impacts of the project on individuals (such as creating greater confidence, new skills or new networks) as well as on wider social structures (such as policy changes).

In order to document more subtle forms of impact that may not be captured by traditional forms of measuring milestones and outcomes, it is useful to incorporate a way of collecting evidence of individual and collective change throughout the research process. Forms of evidence that may indicate impact include (26):

• changes made to research protocols;
• minutes of meetings documenting how experience and knowledge have been used;
• external indicators and indicators devised collectively through the research process;
• narratives of the project journey;
• stories of how people have made individual changes as a result of involvement;
• narratives of surprise and explorations of the unexpected; and
• reports accounting the changes made in thinking and acting across all those involved (and the ripple effect) as a result of engaging in PHR.
In order to make change sustainable, a broad coalition of stakeholders can be useful to ensure the actions developed in the project are taken up in practice. Furthermore, skills training and capacity-building components allow “local people to carry on the initiatives launched during the research once the project is completed” (3).

It is crucial to be as clear as possible, considering the unpredictable nature of all research and PHR in particular, about the possible impact of the research to avoid unrealistically high expectations and disappointments (Box 2.21); this is especially important when working with marginalized groups who experience significant injustices and inequalities on a daily basis and where long-term changes may be perceived as too little, too late. Participatory approaches to research, however, play an important role in ensuring that (i) the research approach and aims make sense to and are supported by all stakeholders and (ii) the research process is transparent and grounded in the needs and views of all stakeholders and can be adjusted throughout if necessary.

**Box 2.21. Ripple effects: how PHR can achieve lasting change**

The RESTORE project (Box 2.10) implemented guidelines and training on cross-cultural communication in five primary care sites in Europe, using PLA methods as part of the participatory design (62). A follow-up study was conducted four years after the completion of the project in England (United Kingdom), Greece, Ireland and the Netherlands to evaluate if the positive impacts on knowledge, skills and clinical routines were sustained beyond the duration of the project (25). The study found that RESTORE had led to lasting changes in the primary care settings, including a more migrant-friendly attitude and awareness about migrants’ needs as well as improved patient-centred communication. Participants felt that their direct involvement in co-creating the training and the participatory nature of the training sessions (compared with a top-down approach to training) contributed to its sustainable effects.

Apart from these direct forms of impact, the researchers found that the use of a PHR methodology had had more subtle ripple effects. Migrant community members who were part of the RESTORE project reported that it had increased their confidence when dealing with more powerful actors such as doctors and policy-makers, had raised their reputation as change-makers in their location and had led to a sense of empowerment. The stakeholder collaboration led to lasting coalitions and networks in some locations, leading to new projects and initiatives. Additionally, collaborating researchers who had not previously experienced participatory ways of working were inspired by RESTORE to use participatory approaches in their work.
3. The way forward: policy considerations

3.1 National policies

A recent review within the WHO European Region showed a dearth of national policies that aim to increase the involvement of migrants in health decision-making, that is, in policy development, service delivery and research (1). Rare exceptions were found in Wales (United Kingdom) and Ireland: the Welsh Government’s Policy Implementation Guidance on the health and well-being of refugees and asylum seekers (72) provides direction for regional health boards to develop consistent local protocols, policy and practice to improve services. The Guidance incorporates a commitment to the principle of co-production, in line with the national Social Services and Well-being (Wales) Act 2014. In Ireland, the National Traveller and Roma Inclusion Strategy (73) and the National Intercultural Health Strategy (74) involved migrant advocacy organizations in the development of their strategies. The Strategies emphasize meaningful participation and partnerships in decision-making as key principles for implementation.

Incorporating a commitment to participatory health decision-making in national policies could become an important lever to increase migrants’ participation in health research. In addition, it would be beneficial if migrant communities were directly involved – through participatory designs – in the production of these policies. Intersectoral partnerships to develop new policies can create a strong foundation for continuous, sustainable involvement of migrants in all aspects of health decision-making.

3.2 Funding

As described throughout this guide, PHR differs significantly from traditional forms of research in that it involves a diverse group of stakeholders throughout the research process. This participatory process “makes [PHR] more organic, more time-consuming and less predictable than the usual health research” (75). This is true for all PHR, but particularly so for research with migrant communities. As a consequence, special funding mechanisms and resource allocation are required to support successful collaborations that have a lasting impact for the communities involved.

In order to encourage PHR, funding needs to be made available to build research partnerships and to sustain partnerships over time in order to avoid partnerships being started and stopped by short-term research funding (78). This may require specific funding streams that take into account that PHR requires additional resources before the commencement of the actual research, for example seed funding to build the research team and set the research agenda in a participatory way. Funding PHR projects with migrants may also require longer project frames and/or access to continued funding streams for follow-up work. To sustain a participatory approach throughout the research, “staging multi-phase calls with separate funding-phases for partnering, the research phase and the dissemination of results has already proven successful” (75). Funding is also needed to support the continuation of research partnerships between specific funded projects. There is often a gap between the
completion of one project and more funding for a follow-up, which can lead to valuable collaborations falling apart. This kind of continued funding is also necessary to ensure that migrant collaborators are actively involved in developing future projects and follow-ups. Last but not least, there is a need for funding to support the evaluation of PHR – in order to assess and systematize the processes and impacts of PHR with migrant communities.

A higher degree of flexibility regarding project times frames, budget allocation, methodologies and project milestones may be required to account for the organic, collaborative and, therefore, somewhat unpredictable nature of PHR. This flexibility is an investment in the unique potential of PHR, particularly with marginalized groups, to gain unique knowledge that leads to impactful actions, which expand beyond what can be produced using traditional non-participatory methods.

Another key aspect that needs to be taken into account by funding agencies is the crucial role of peer researchers in PHR with migrants. Funding applications need to reflect the diversity of research team members and facilitate the inclusion of co-researchers who may, for example, not have academic curriculum vitae that match the requirements of traditional funding application forms or may not be able to register for work due to their precarious legal status. University regulations around hiring research staff can create obstacles for hiring and paying peer researchers or community organizations, which can make it impossible to follow the principles of PHR. Researchers and organizations working in those conditions face structural disadvantages regarding PHR implementation compared with colleagues working in institutions or countries with more favourable research policies and infrastructures. Therefore, to encourage and facilitate PHR across the WHO European Region, it would be important to tackle these structural barriers, for example by promoting cross-fertilization of PHR-friendly research policies between countries and institutions.

In line with the principle of power-sharing and equity in PHR, funding should also be made available to community organizations to lead on research projects, not only to academic institutions (75). Furthermore, the promotion of PHR with migrants requires a commitment from national funding bodies to resource the involvement of policy-makers and health-care professionals to be part of research teams, for example through allocated staff hours for participatory research (1). This is crucial for the development and sustained engagement of relationships with migrant communities and to allow a growing understanding of community issues and commitment to implementing findings.

A commitment to PHR approaches within national funding bodies can be a mechanism to support the creation of sustainable research collaborations with migrant communities and would explicitly value these projects for their contribution to equality and equity. An example of this is the PPI Ignite Network (Promoting excellence & inspiring innovation), a public and patient involvement initiative in Ireland (77). With funding from national funding agencies (the Irish Research Council and the Health Research Board), the initiative has led to the development of public and patient involvement centres in various universities across the country. This is an example of a national funder devoting resources to building capacity for academia–community partnerships in general, including but not limited to collaborations focusing on participatory migrant health research.
3.3 Training and skills development

As emphasized throughout this guide, PHR with migrant communities holds significant potential to co-create for impactful, relevant knowledge in local contexts. However, participatory approaches differ significantly from traditional ways of conducting research. Training and skills development are crucial to ensure that the principle of participation is implemented throughout the research process and tokenism is avoided. Training and capacity-building should be offered to health policy-makers, service planners, health-care providers, researchers and members of migrant communities to develop the skills to work in a participatory manner. Training can be integrated into a specific project or offered to a broader audience of people interested in learning tools for PHR.

Considering that PHR with migrants is complex and requires a significant amount of time, skills and commitment to change from the old ways of conducting research on people, it is ideal if training has an experiential component and crucial that training and skills development are ongoing processes, rather than a one-off event. It would be beneficial to create networking opportunities that would allow countries/stakeholders with more experience to share their knowledge with others.

A starting point could be the resources established by the ICPHR, in particular the subgroup on migrant health. The ICPHR has developed a range of online resources for PHR in general, including position papers on the principles of PHR (3), ethics in PHR (78), impact in PHR (26), funding PHR (75) and specifically on migrant health research (2), as well as resources such as a quality checklist for PHR projects (79). Furthermore, the ICPHR has successfully coordinated online and in-person training courses for health practitioners, academic researchers, citizens involved in research for social change and postgraduate students, run by collaborating universities in Australia, Canada, Germany, Portugal and the United Kingdom, as well as online courses on public and patient involvement in research (80). Another starting point for training and capacity-building is the online guide to researcher and knowledge-user collaboration in health research created by Participatory Research at McGill University, Canada (81), which offers a step-by-step guide on how to plan, conduct and disseminate PHR.

None of these resources; however, is specifically focused on working with migrant communities. The WHO Regional Office for Europe is in the process of developing training specifically for PHR with migrant communities, which will be made available across the Region.
4. Conclusions

This guidance highlights the benefits of adopting a participatory approach to health research with migrant communities, including (i) the potential to overcome hierarchical power structures and a rebalancing of unequal participation in knowledge production; (ii) the involvement of key stakeholders as partners in the research, thereby increasing its relevance, applicability and impact; (iii) the production of locally grounded, specific knowledge leading to workable solutions and sustainable implementation; and (iv) positive social change both through the personal and interpersonal effects of the dialogical, participatory research process itself and through specific actions resulting from the research.

This guidance outlines how PHR with migrant communities can be operationalized throughout the research process, from the conceptualization and framing of the research question to the dissemination and application of research findings. We have also addressed cross-cutting issues that may arise in PHR projects with migrants and offered potential solutions to common queries.

In order to reap the full benefits of PHR with migrant communities, we have proposed policy changes within national contexts, relating to:

- the development of national policies that aim to increase the involvement of migrants in health decision-making, that is, in policy development, service delivery and research;
- the availability of national research funding that acknowledges the specific requirements of PHR with migrant communities, such as in relation to team building and project time frames; and
- the development of specific training within local and national contexts to ensure that all stakeholders involved are equipped with the necessary skills to contribute to a PHR project beyond mere tokenism.

4.1 Strengths and limitations

A strength of this guidance is the emphasis on high-quality examples from real-world PHR projects, with case studies from 11 countries and with a specific focus on those within the WHO European Region (Austria, Belgium, Greece, Ireland, Israel, the Netherlands, Portugal and the United Kingdom). The case studies drew on projects involving many different communities, including refugees, asylum seekers and undocumented migrants, and from different places of origin, such as sub-Saharan Africa, eastern Europe and the Middle East. A wide range of methods have been described to ensure that the guidance is applicable to different research topics, questions and interests, including quantitative as well as qualitative methods. By drawing on innovative methodologies such as arts-based methods and PLA, the guidance offers concrete suggestions on how to develop valuable, participatory approaches and tools for sustainable partnership building.

A limitation is that the guidance was not informed by direct empirical investigation; it is a compilation of sources. At the same time, this approach has merit for the purpose of the guidance, which is to provide a high-level overview of knowledge in the field about best practice. This
was considered as an appropriate approach given the richness of the available literature, the consensus across the literature about key strengths and challenges and the value of taking what we know rather than generating new studies that may add to research fatigue. Another limitation is that there was no mechanism for migrants’ involvement in the development of the guidance. WHO is currently developing processes for this and these will be important for future technical guidance and related initiatives.
References


The WHO Regional Office for Europe

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Europe is one of six regional offices throughout the world, each with its own programme geared to the particular health conditions of the countries it serves.

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