International Collaboration for Participatory Health Research

Position Paper No. 6

Participatory Health Research with Migrants: Opportunities, Challenges and Way Forwards

Version: September 2021

Editorial Group:

Maria Roura Dr.	School of Public Health, University College Cork	Cork, Ireland
Anne MacFarlane Prof.	School of Medicine and Health Research Institute, University of Limerick	Limerick, Ireland
Sónia Dias Dr.	NOVA National School of Public Health, Public Health Research Center, Universidade NOVA de Lisboa	Lisbon, Portugal
Joseph W. LeMaster Dr.	Kansas University School of Medicine	Kansas City, Kansas, USA

Acknowledgements

CONTENTS

1. ABSTRACT

Context

Migration is one of the most politically pressing issues of the 21st century but migrant health remains an under-researched area. The International Collaboration for Participatory Health Research (ICPHR) working group on migration developed this position statement to address opportunities and challenges in relation to migrant health. This paper is based on the premise that migrants are a heterogenous group with resources, resilience and capabilities to lead or partner Participatory Health Research (PHR) initiatives. PHR about migrant health and with migrants is the same as PHR with other groups and about other topics in many respects. There are, however, some specific issues worth considering, for example, racialized discourse about migration or paying attention to linguistic and cultural dimensions that support partnerships. Thus, this position paper aims to contribute to a shift from a deficit model that sees migrants as passively affected by policies to their reconceptualization as citizens who are engaged in the co-creation of solutions in partnerships that are attuned to specific opportunities and challenges.

Methods

This paper examines the opportunities and challenges posed by the use of PHR with migrants. It draws on a broad literature to provide examples of successful PHR with migrants and highlights critical issues for consideration.

Findings

Successful initiatives illustrate the value of engaging migrants in the definition of the research agenda, the design and implementation of health interventions, the identification of health protective factors, and the operationalization and validation of indicators to monitor progress. Within increasingly *super diverse* contexts, fragmented community landscapes that are not necessarily constructed along ethnicity traits; inadequate structures of representation; local tensions; and operational barriers can hamper meaningful PHR with migrants.

Conclusion

For each research context, it is essential to gauge the "optimal" level and type of participation that is more likely to leverage migrants' empowerment. The development of Monitoring and Evaluation tools, and methodological strategies to manage inter-stakeholder discrepancies and knowledge translation gaps, are steps in this direction.

2. CONTEXT

Migration has become one of the most politically pressing issues of the 21st century. Migration and mobility is a diverse experience, with potential for both positive and negative impacts for individuals and societies as a whole [1].

There is no standardized way to define "who is a migrant" [2]. For the purpose of this paper, we consider as migrant *"any person who is moving or has moved across an international border or within a State away from his/her habitual place of residence, regardless of the person's legal status, whether the movement is voluntary or involuntary, what the causes for the movement are and what the length of the stay is"* [3]. Discourses about migration are highly racialized in many contexts; whereby, the normative nature of people moving away from their habitual places of residence is ignored. Instead, certain kinds of migration (e.g., "irregular migration") and anti-immigrant sentiment toward certain ethno-cultural groups are marked out as problematic, and migrants are designated as "risky" for host societies. This racialization and 'othering' is deeply problematic. It reduces the person who has migrated to a single, social label or identity with no attention to intersectionality, that is, the other layers of identity and experience in the person's life. Further, racialized discourses about migration and 'othering' can lead to stigma and social exclusion of certain types of migrants in host communities. This can exacerbate health inequities that are repeated over and over in different situations and contexts, such as the specific impact of the COVID-19 global pandemic on refugees in crowded camps and low-paid documented and undocumented migrant workers in front-line precarious employment.

The authors of this position paper have combined experience of Participatory Health Research (PHR) partnerships in western Europe, North America and Africa with refugees, asylum seekers, and migrant workers—both documented and undocumented—via local immigration policies.

The PHR projects we have participated in were invited or hybrid spaces of participation, meaning that they were initiated by university, non-governmental, or State agencies for health. They were entirely or primarily developed to respond to issues of social exclusion and health inequities and often had an interest in building capacity and empowering migrants through participatory partnerships. In keeping with PHR, the projects were designed to centralise the resources and build upon the expertise of migrants through partnered research in order to identify effective solutions to identified problems. We learned with and from each other while working on a variety of health issues and topics. PHR initiatives with migrants such as these remain rare in the field of health research, as the health of migrants remains on the margin of policy making in countries at all income levels; and health authorities do not commonly work with civil society and migrant groups to progress migrant health issues.

The migrants in the partnerships were from very diverse backgrounds and some/many individuals in the partnerships had backgrounds in academia and professions such as health, law, and economics. Many of the partners working in university and State

agencies were migrants. At the same time, the authors are aware of the power and privilege in the partnerships that they have experienced.

In this paper, we draw on examples of PHR projects and partnerships in which we have participated, as well as on examples from the published literature. We have endeavoured to draw on examples from around the globe but acknowledge that there will be important examples of good practice and critical insights that are not reflected here.

Migration and Health

The vast majority of migrants in the world are defined as migrant workers, but the numbers of refugees and people displaced by conflict, natural disasters, and climate change are at their highest levels, representing 10% of all migrants who move between countries [4, 5]. Migrant workers, particularly those who are low-skilled from lower-income nations and who work in low paid, precarious employment in host countries are under-researched in the global migrant health literature. The gender dimensions of human rights and health and the vulnerabilities of female migrant workers are also under-researched. The health of internal migrants is often overlooked. Other types of migrants and refugees are heavily researched because of attention from academic researchers to their complex physical and psychological health needs. This underscores the importance of addressing the health of all migrants as a part of the global health-for-all agenda.

There have been important, recent developments to promote integration of migration and mobility into healthcare planning. Acknowledging the essential relationship between good health and successful migration, the World Health Organization (WHO) Member States adopted the 2008 World Health Assembly Resolution on the health of migrants (WHA.61.17), and launched a Strategy and Action Plan for Refugee and Migrant Health in 2016 [6]. In addition, the Colombo Statement, which was endorsed by 19 Ministers and government representatives in 2017, affirmed that migrants should be active stakeholders in program planning and decision-making [7]. Still, as mentioned above, migrant health remains an under-researched area in global health and has received insufficient attention by health system planners.

Migrants are sometimes healthier than the host population on arrival [8, 9] highlighting the resources, capabilities and strengths of migrants. At the same time, there is evidence of health disparities between some migrants and their host populations and a growing awareness that this is linked to the negative impacts of arrival and integration into host countries, due to negative impacts of the broader social determinants of health (SDH) [8, 12, 13]. Like other community or patient groups, negative experiences of accessing and using health care services is a social determinant of health. Healthcare systems that have, for example, not adapted to address cultural and linguistic diversity are a ubiquitous and profound negative social determinant of health. There is also a pattern of exclusion whereby migrants are under-represented in healthcare decision making fora for citizens — [14, 15] even though, just like other community and patient

groups, they have lived experience and expertise to inform a comprehensive evidence base about their health needs.

Appropriate methodological approaches are needed to respond to the challenges associated with contemporary migration, mobility, and health [16]. Participatory Health Research (PHR) is a research paradigm that has potential to address opportunities and challenges in relation to migrant health. The goal of PHR is "to maximize the participation of those whose life or work is the subject of the research in all stages of the research process, including the formulation of the research question and aim, 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"[17]. PHR is guided by ethical principles to reflect its underpinning values including mutual respect, equality, and inclusion [18]. In PHR, relationship building and the value of sustained partnerships throughout a project, from question identification to result dissemination, is of paramount importance [19]. Grounded on the work of Paulo Freire, the ultimate aim of PHR is to catalyse broad societal transformations for a more fair allocation of resources [20, 21]. The entire process of PHR is conceived to leverage joint societal transformation and transcend the scope of the specific objectives of a particular project. The underlying assumption is that engaging research participants as co-producers of new knowledge fosters their ownership over the research outcomes, which can then serve to articulate and legitimate political claims to address the social determinants of health that impact them.

3. METHODS

The International Collaboration for Participatory Health Research (ICPHR) working group on migration developed this position statement to address the opportunities and the challenges posed by the use of this research paradigm in migrant health research. It draws on a broad literature to provide examples of successful PHR with migrants and to highlight critical issues for consideration. Members of the ICPHR provided comments on a draft version of this paper which was distributed at the ICPHR 10th Annual Working Meeting at Morgan State University in Baltimore, Maryland, USA (21st-22nd June 2019) and by email in April 2021.

4. FINDINGS

4.1 OPPORTUNITIES

Define the research agenda

Most of the published academic research that has so far been conducted in the field of migrant health represents the perspectives of high-income destination countries and focuses on migrant-specific diseases with a particular emphasis on communicable diseases and the mental health of refugees [4]. This focus on differences between migrants versus the local populations has led researchers to overlook some of the most

common health problems that affect migrants, which are often similar to those affecting the host population [11, 12, 22]. The lack of research on non-communicable diseases among migrants is an example of this pattern and highlights the problematic differentiation of migrant health research from the broader global health research agenda [6].

Concepts of civic responsibility and participation [21, 23-25] emphasize migrants' *right* to shape the research agenda so that research efforts address what migrants perceive as priority needs [26]. Decisive endorsement of the principle of participation is reflected in the increasing requirements by research funders and renewed international commitments to meaningfully involve the public and patients in health research [27-29], including migrants [7]. Still, to date, the research priorities in migrant health have been primarily driven by the interests of academics, policy makers and clinicians [10] with infrequent inclusion of migrants in research prioritization processes [12, 15].

Setting priorities for research is a complex process and there is general consensus that there can be no *best practice*, because of the contextual differences between individual priority setting exercises [30]. PHR, with its focus on incorporating different perspectives to foster mutual learning and deliberation, can be helpful to structure democratic dialogues amongst migrant and other stakeholders and develop a shared vision for research priorities. Previous participatory research initiatives with migrants [31], including use of the *World Café method,* have proved to be effective for research prioritization with migrants in Ireland and the USA [26].

Inform the design and implementation of adequate health interventions

Epidemiological research has shown that some migrants are more affected by communicable diseases, occupational health hazards, injuries, and maternal and child health problems than the local population [11, 32]. Some groups are particularly vulnerable due to the circumstances of their migration experience, including unaccompanied children, victims of trafficking or torture, asylum seekers, and migrants with precarious status or in detention centres [10, 33]. However, migrants are often not granted equitable access to health services, and, as already mentioned, these may not have sufficient capacity to manage their needs in a culturally, linguistically or clinically adequate manner [2, 34]. Widely documented barriers to accessing quality healthcare services include: lack of entitlements; fear of losing employment or residency if affected by certain medical conditions [7, 35]; administrative hurdles; and communication barriers [36]. In addition, certain health interventions [37] may violate individual rights or exacerbate discrimination, for example, when migrants are screened for infectious diseases without adequate referral to treatment when needed [7, 38, 39]. The provision of culturally sensitive services is thus essential to respond adequately to the diverse needs of increasingly heterogeneous populations [10, 37, 40]. However, most interventions and policies are based on data derived from the general population and do not respond to the needs of migrants [41]. Where evidence is lacking, PHR can be a good strategy to fill that gap and pave the way to develop more effective interventions and policies to address the inequities migrants experience.

PHR acknowledges the importance of experiential, practical, emotional and intuitive sources of knowledge. It builds on the *insider* perspectives and direct knowledge acquired by the people living with the health problem under study [42], who are considered *experts by experience* [17]. The multiple ways of knowing that are inherent to PHR can yield the holistic and nuanced understanding that is required to bridge different explanatory models of disease. This has particular significance in PHR for migrant health compared with PHR with groups who are not migrants because the partnership and research processes need to be attuned to culturally and linguistic diversity in order to access and learn from insider ways of knowing. This has potential to prevent ethnocentric biases in the development of health interventions**.**

Previous successful PHR initiatives to involve migrants in the adaptation of health services include: 1) the development and implementation of guidelines to improve communication in cross-cultural consultations in 4 European countries [43]; 2) the co-production of a breast screening video by Asian migrant women in the UK [44]; 3) the co-design of a child obesity intervention in Australia [45]; 4) a diabetes prevention program with Sikh Asian Indians in New York [46]; 5) the development of a mental health intervention with Bangladeshi women in the Bronx, New York [47]; 6) an HIV prevention program with Latinos in the USA [48]; and 7) the development of a computer-assisted safer sex intervention in Europe [49]. These initiatives involved migrants in the design and implementation of the initiative from start to finish, and at multiple levels within healthcare organizations and processes. Against the backdrop of concerns about the challenges of involving migrants in health research because of perceived or actual differences ('othering'), these examples show that migrants *can* be involved effectively in participatory research and decision-making to adapt healthcare services and interventions, so they are relevant, respectful, responsive to their lived experiences, and aligned with their needs [50-52, 53].

Tackle the social determinants of health (SDH)

High-quality care for migrants cannot be addressed by health systems alone. Notwithstanding the resilience and capabilities of migrants who have resourcefully completed transit journeys and navigated resettlement in host countries, some migrants from low to high-income countries are often marginalized [22] and exposed to social, occupational and economic conditions that have detrimental effects on their health [7, 54, 55]. Further, the death of migrants during their migration journey is a tragic illustration of the vulnerabilities that can overcome migrants' resilience and capabilities at different stages of a migration process which often entails unsafe travel, poor nutrition, psychosocial stressors, and harsh living and working conditions [7].

A comprehensive response to the needs of migrants to avoid or minimize health inequities requires health systems to engage with other key sectors such as welfare, housing, education, and legal protection [56, 57]. While the importance of the SDH is widely recognized [7, 11], the role of public policies beyond the health sector continues to be overlooked in migrant health policies [58]. In turn, the SDH agenda has been criticized for adopting a "colour-blind" approach that presumes an improvement of socio-

economic conditions will have a homogeneous impact on the health of different ethnic groups [59]. Indications that migrants do not fully reap the expected health benefits associated with improved material conditions point to gaps in our understanding of how ethnicity and socio-economic status intersect with other SDH issues (e.g. racism) to influence migrants' health [8]. And these indications call for a more explicit acknowledgement of structural and historical factors, as has been highlighted by *critical race* [60] and *intersectionality* scholars [61].

Because it is locally situated in the everyday life of research participants, PHR enables the contextualization of individuals' local knowledge and lived experiences across the different layers of the *social ecology*. This means that besides accounting for the individual and family factors that influence health, a broad range of community level and broader structural/historical factors must also be considered, including neighborhood characteristics and the ethnically patterned unequal distribution of resources and power. McElfish et al. for example, report the use of PHR to engage a displaced Marshallese community in Arkansas USA using a sociological lens to identify organisational, community and policy barriers that constrained self-management efforts by community members affected by Type 2 Diabetes [62].

Participatory research should lead to action and ensure that the benefits of the research are shared with relevant local actors. Enabling diverse stakeholders to learn from each other and plan together can yield fresh ideas about the conditions that are necessary to sustain optimum health at each level of the social ecology, and the policy initiatives that can produce these conditions. Previous work with ethnic minorities suggests that PHR can effectively promote broader level societal change. In Kansas City, Missouri USA, for example, a participatory initiative with Black Americans leveraged positive change in schools, churches, the media and the private sector [63]. In London, the participation of migrant women in a breast screening promotion project was reported to be an empowering experience that challenged the hegemonic narratives of migrant women as homogeneous and powerless victims [44].

Identify health protective factors

Despite the importance of addressing migrants' vulnerabilities using a SDH approach, it can be harmful to assume that the health of migrants is typically poor when compared to the host population [9]. Re-iterating our emphasis on migrants' capabilities and resilience as well as the heterogeneity of 'migrants', the focus on vulnerability can obscure evidence showing migration as a positive experience for many, and the fact that many migrants are young, fit, healthy and/or highly educated [7]. Migrants are, instead, often framed as carriers of disease, difficult healthcare users, poorly compliant [64] and ultimately, a burden to health systems and societies at large [65]. Worryingly, the argument that diseases travel in migrants' blood is recurrently used by anti-migrant political leaders to advance their political agenda [8, 66].

A better understanding of factors promoting resilience and positive health among migrants could contribute to breaking down harmful stereotypes [8] and provide

valuable clues about how to preserve the health of migrants and host populations as a whole. Whereas conventional research tends to focus on the deficits of vulnerable people, PHR builds on their *strengths* [17] and their own accounts of *what goes on* in their everyday life. This familiarity with the environment can potentially unveil how health-protective assets and resilience are acquired and maintained over time, and what the contextual conditions that enable or constrain this are. PHR about migrant health could help specifically to unravel how psychological resources (e.g., positive identity, confidence, optimism, connectedness) are embedded within social structures (e.g., social hierarchies at work, at home, in public spaces). This would further our understanding of the contingent conditions that foster/hinder health for different people in different contexts, broadening the current focus on individuals' behaviour and psychological skills by placing individuals' choices in context.

Operationalise and validate indicators to monitor progress

The evidence base and action to address health inequities affecting migrants cannot be furthered without robust monitoring frameworks grounded on reliable measures, and the definition of concrete indicators against which actionable goals and targets can be set. These indicators should transcend disease-based surveillance approaches to also include the broader social determinants of health [67], and adequately capture the constructs that they are intended to measure (i.e., be valid and reliable). International recommendations advise national governments to review existing monitoring mechanisms across the health and development sectors for the purpose of incorporating migrant health-related variables and engaging in target-setting processes [7]. Ideally, a common set of internationally comparable indicators should be employed. However, there is no standardization/harmonization and the validity of some of the most commonly employed indicators in migrant health research has been questioned. A long tradition of *acculturation r*esearch for example, has extensively employed one-dimensional definitions of *ethnicity* that fail to recognize that identities are diverse and neither stable nor unconfounded [68]. Similarly, subjective measures of self-rated health are often used as an indicator of health status [69] although the meaning of *excellent*, *good, fair* or *poor* health differs across populations [70, 71]. Finally, the indicators of socio-economic status that are employed in most SDH studies (e.g., occupational class, income, education) do not measure accurately the economic status of migrants, whose personal income often fluctuates due to SDH factors that do not impact other marginalized populations [68]. These indicators also miss less tangible dimensions of subjective social status [72] (e.g., participation, prestige, integration in social networks) that predict health outcomes independently of traditional indicators of socio-economic status [73].

PHR can account for the subjective, dynamic, multifaceted, and contextual nature of the indicators that are commonly used in migrant health research, helping to unpack their social significance. Previous research on ethnic and migrant health in Ireland illustrates the potential of PHR to operationalize key constructs in relation to health information systems [74]. The co-creation of a new instrument to measure mental health with Bangladeshi women in the Bronx, New York [75], and the operationalization of the

concept of *wellbeing* by Moroccan migrants in Spain [76], show that PHR can broaden and deepen our understanding of how to measure multifaceted concepts in epidemiological research, while building collaborative capacity to ensure adequate design and usage of monitoring instruments. This is essential to track health systems performance and the impact of diverse policies on migrant health.

Having presented successful examples of PHR in migrant health, we next consider key challenges and potential strategies to overcome them.

4.2 CHALLENGES

Power dynamics

Conducting PHR with any group, including migrants, is not exempt of challenges. Frequently reported barriers in PHR that can equally or similarly impact PHR with migrants include conflicts amongst participants, often because of issues related to sharing power and the distribution of resources amongst stakeholders [17]. The "fall back into dichotomies of power" or "tyranny of participation" whereby the nature of power dynamics within and amongst stakeholder groups—including researchers—is overlooked, and only the narrow spectrum of interests of the most powerful/vocal is considered, is another frequently highlighted challenge of participatory research [17, 77].

Other concerns are the modest impact of participatory research in terms of specific actions bringing about societal change [78], mostly because of constraints upon PHR participants' influence over key political decisions [79]. The assumption that participants will have the necessary time available to contribute to PHR; the criteria used to economically compensate some contributors but not others; the amount of the economic rewards provided; the mismatch of expectations; accountability issues; different communication styles; different perceptions of time; and the limitations posed on researchers' autonomy are other challenges that have been highlighted [78, 80, 81]. Ethical concerns may arise in relation to multiple (and at times conflicting) roles assumed by researchers and organizational stakeholders (e.g., as fundraisers and resource allocators) [82, 83].

Finally, the uneasy confrontation of lay researchers with managerial procedures and fixed timelines may place additional strain over the smooth implementation of PHR [84]. Nonetheless, it is valuable to reflect on some specific features of PHR focused on migrant health.

Definition of 'migrant communities'

Amidst the conceptual and practical difficulty of defining who is a 'migrant', it is also difficult to define 'migrant communities' and their 'representatives'. Social scientists have long contested idealized notions of 'communities' [85]. The assumption that these

are constructed primarily around ethnicity is hotly critiqued by ethnicity scholars as inadequately linked to pre-conceived ideas of homogeneity and identity [86]. The over-culturalization of the concept – it is argued – leads to a "collective image of communion premised on a shared culture" that fails to capture the actual context of real-world settings. The loose use of the concept as a "black box" [87] is problematic because "the community becomes too easily an explanation, as opposed to something to be explained" [87, 88].

On a more practical side, migrant populations are often very mobile, with frequent re-location to other countries, regions, or neighbourhoods. Migrant communities are often dispersed in transnational networks and materialized "online" or virtually, as opposed to being based in a physical location. Of course, mobility such as this is a feature across communities but the nature of dispersal policies for asylum seekers, seasonal employment opportunities and forced trafficking are examples of how this plays out specifically among migrant communities. These examples highlight the stark lack of choice that asylum seekers, low-paid migrant workers, as well as other migrants. This transient situation hampers the establishment of settled "communities" with relatively durable boundaries within which to conduct research. This is especially the case in countries that are unwilling to support the formation and maintenance of civil society structures or where governments and philanthropists favour financially supporting local charities focused on providing basic services to vulnerable migrants, as opposed to strengthening the rights of migrants within the core infrastructure of civil society. As a result of these socio-political factors, the associational landscape of migrant organisations can be thin and fragmented.

Representativity

The absence of formal, physically bounded migrant communities often leads to research partnerships being established with organisations that provide services to migrants, as a proxy for migrants themselves [89]. This is not unique to PHR with migrants. Early calls from development scholars warned that non-participatory, 'top-down' assumptions made by international development programs during the 20th century could be repeated in the health field [23]. As a matter of fact, an individual's role as "community representative" may confer him (or her) an increased control over how resources are used/distributed and serve to reinforce the power of community-based elites [84, 90]. This is particularly worrying in contexts where assimilationist policies or cultures prevail, and where the fundamental principles underlying PHR are not necessarily endorsed by migrant "representatives." A charity worker performing as a "community representative," for example, may not endorse ideas around migrant empowerment but rather see migrants as passive recipients of charity who should "adapt" to the host society, as opposed to being active contributors who enrich a multi-cultural society.

Given the heterogeneity of the migrant population, we cannot assume that community representatives or actors will always represent the interests of the community they purport to serve in a given context or more widely, even where "migrant communities" exist in the form of established migrant organizations or associations.

As noted by Wright, PHR is not universally nor categorically "better" than other forms of research [17]. Understanding the migrant associations' landscape, their role and functions, and — importantly — their linkages with the broader communities and the State, is crucial to decide the type and level of participation that suits each specific research setting. Key questions to ask since the outset include: "What type of community organizations exist?"; "What type of activities do they conduct?"; "Who participates in them and why?" [23]. This should be useful to assess the extent to which particular groups of migrants (e.g., newcomers, irregular migrants, asylum seekers, trafficked persons) are represented, and what should be done to ensure their views are also taken into account.

Local tensions

Assuming the existence of any group willing to work together for a common goal is questionable [85]. The assumed existence of "migrant communities" willing to work together for a common goal is challenged in increasingly *super diverse* contexts [91, 92] in which different migrant groups may not necessarily share the same interests, or maybe share some, but compete for others. Here, power dynamics are layered with politicised and racialized complexities: The high rate of *Brexit* voters among long established migrant communities in the UK is an illustrative example that challenges the assumption that all migrants share a common goal [93]. Because the more recently arrived migrants often lack structures for effective representation, their views are less likely to be accounted for, and these views do not necessarily fall under the umbrella of "migrant" interests, as voiced by the most organised groups [85]. The coexistence of shared and competing interests is also prevalent among migrants "belonging" to the same ethnic group, because "identity and interest are not insoluble" [94], and, following intersectionality, different sub-groups are likely to hold — at least some — diverging interest and views (e.g., youth, women). In contrast with the ideal of cohesive communities, the everyday spaces of neighbourhoods are in fact often characterised by tensions, fragmentation, competition, and conflict. Idealised notions of "community" can thus serve to actually mask and even reinforce wider structural inequities, which is clearly at odds with the principles underlying PHR. It is thus essential to reconceptualise the concept of migrant communities in more fluid terms (e.g., not necessarily constructed along ethnicity traits), acknowledge the existence of conflict, as well as the potential inadequacy of organised structures of representation that may exist. The potential rise of conflict of interests needs to be expected, assessed, monitored, and disclosed.

In this context, it becomes crucial to adopt a balanced approach that eschews the "idyll of community" critiqued by ethnicity scholars [95], but also an exclusive focus on conflict and local tensions. This will help to demystify the role played by communities and their representatives while at the same time help PHR partners to reflexively work together to identify potential niches of shared interests and aspirations around which common efforts can be articulated [96].

Formative research following the principles of PHR can be useful to assess whether and how heterogeneous populations and stakeholders may cooperate successfully, by

putting aside differences and working towards a common goal that may actually produce a shared "sense of community." Where this is unlikely to be the case, it will be crucial to acknowledge that less or a different kind of participation may – in fact – be the "optimal" level or type of participation for a particular research context.

Operational barriers

At programmatic and implementation levels, there are commonly reported challenges that need to be addressed that do not arise in PHR with other populations. Regarding the issue of language barriers, it is well established that these frequently lead to the exclusion of migrants who do not speak the host society language(s) placing them amongst the most socially excluded. This has major implications in terms of equity. The use of visual and culturally adaptable Participatory Learning and Action research techniques [12, 52] with the collaboration of trained interpreters and peer researchers can be an effective way to respond to linguistic diversity in migrant health research [50, 97]. However, the involvement of peer researchers in any PHR can lead to blurred personal and project boundaries and requires an ethical and reflective approach [98]. This should be taken into account by partners who are using a peer research model in migrant health projects.

Other ethical issues related to PHR with migrants include negative consequences from taking part in research that could put migrant populations at risk of marginalisation into even greater peril. For example, the specific concerns of undocumented migrants about engaging with projects initiated by universities and State agencies, and thereby having their legal status exposed, is noteworthy [42]. Ensuring that informed consent procedures truly inform migrants of both the benefits and potential risks of participation becomes essential here. This may be hard to achieve when the invitation to participate comes from organisations that provide social services to prospective research participants. Careful decisions need to be taken over the most adequate compensation and other types of support to be provided to participants, considering the characteristics and risks of each particular context. Asylum seekers living in countries that do not permit them to have paid employment means that compensation and support for involvement have to be administered in specific ways that do not jeopardize their State allowances**.** A number of resources are available to guide such decisions in accordance with the ethical principles of PHR [18].

Another common challenge is related to other PHR stakeholders' priorities. For example, academics are often committed to traditional (non-PHR) methods and may feel pressured to quickly publish the evidence in high-impact scientific journals. Policy makers or industry stakeholders may be resistant to research findings that challenge their assumptions, values, attitudes, or practices, or lack the commitment (or power) to respond to the specific concerns expressed by migrants [81]. Divergence and controversy arise while achieving meaningful consensus, which implies negotiation between conflicting interests. Ideally, such a process should help actors to reorient and expand how they define the 'problem' under discussion, considering their multiple perspectives of analysis of the project and different interpretations of its successes/failures. However, in practice, this is not always the case, and inequalities

between negotiating actors may end up favouring those who are most powerful [99, 100].

Taken together, the general challenge with PHR and the ones that are more specific to PHR with migrants illustrate the importance of maintaining a high standard of quality in terms of process and building the empirical evidence about the value of PHR. In doing this, it is important to avoid tokenizing approaches where participatory claims are used as a strategy to implement already designed policies, rather than to provide spaces for populations to advocate for transformative initiatives. Participatory processes should be described in a transparent and self-critical manner with a comprehensive account of the achievements but also the challenges and limitations faced [101]. Several points should be considered to advance in this direction.

- First, regular monitoring and evaluation (M&E) exercises within PHR partnerships should gather stakeholders' perspectives of how things are progressing, and when and how adjustments are needed. Robust M&E frameworks are urgently needed to guide these processes, with particular attention to power dynamics that may hinder transformative participation dynamics [100]. In a decisive step in this direction, an M&E working group established within the ICPHR is currently drawing from various conceptual frameworks and the views of global PHR practitioners to identify relevant domains, indicators, and questions to be asked [102].

- Second, guidance is needed on what kind of specific strategies and resources (e.g., peer researchers to attend to linguistic and cultural dynamics) may be helpful to recruit, engage and create fruitful inter-stakeholder alliances in this particular field of research. A prerequisite to shared decision making is that partnerships and coalitions are established with inter-sectoral stakeholders [17, 103]. The many different kinds of potential interactive spaces for participation should be considered [104], including those established by the State, academics, or by migrant populations themselves. In addition, innovative methodological strategies are needed to identify and address conflicting priorities among different actors within the broader contexts in which research takes place [101]. The use of arts is an interesting avenue to explore in this direction [105].

- Finally, in all PHR it is important to manage expectations and make it clear at the outset of projects that societal change may not be achieved because of external constraints. In PHR with migrants, and given the politicised nature of the field, this is, of course, also true. While the commitment is *toward* action rather than *guaranteeing* action, explicit and proactive steps should be taken to foster the involvement of migrant partners in collaborative knowledge translation activities to reduce the knowledge-to-practice gap. Bi-directional mentoring between academic and underrepresented groups, for example, is a promising approach that has already been successfully applied with ethnic minorities [105]. All these actions shall be helpful to prevent tokenism and co-optation in this field of research.

5. CONCLUSION

Overall, PHR presents an opportunity to contribute to generating new knowledge about migrants and their health, by bringing together stakeholders who do not usually meet each other in partnerships for research and policymaking. It can potentially contribute to a paradigm shift, from a pathogenic *deficit model* that sees migrants as passively affected by policies to their "re-conceptualization as creative, inspiring, and actively engaged citizens in search of solutions" [8]. This is important to counter the toxic discourse that migrants are a burden to local societies and can help to break down stereotypes by highlighting their positive contribution to social and economic prosperity [1, 5, 11].

This paper has emphasised the relevance of PHR in the field of migrant health research, providing an alternative approach to address the current challenges in health research and tackle health inequities. However, PHR is not a panacea given that there are specific challenges present in enacting meaningful and impactful projects in this field. The ultimate distinctiveness and added value of PHR rests in its potential to catalyse real-world action for greater social justice. Supportive policy environments are essential for this potential to be realised. A genuine progress of PHR with migrants calls for meaningful engagement of inter-sectoral and 'whole' governmental policymakers. In this process, it becomes particularly crucial to grasp — for each particular research context — what is the "optimal" level and type of participation that is more likely to leverage migrants' empowerment so they can better advocate for their voices to be heard, and their rights to be addressed.

At a time where the case for participatory research is gaining momentum, it becomes crucial to encourage and support critical scholarship and reflective, ethical practice [18], not only in the application of PHR with migrants, but also in better understanding the nuances of the approach, so that PHR can truly live up to its potential. The development of monitoring and evaluation frameworks and methodological strategies to manage inter-stakeholder discrepancies and knowledge translation gaps are important steps in this direction.

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