Addressing migration and health inequity in Europe

Normalising participatory health research approaches in the WHO European region for refugee and migrant health: a paradigm shift

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The Lancet Regional Health - Europe 2024;41: 100837

https://doi.org/10.1016/j.lanepe.2024.100837

Summary

While people's involvement in health research is increasingly the encouraged norm in many countries, the involvement of refugees and migrants in research about their health is rare. Here, we call for a paradigm shift in the field of refugee and migrant health to make participatory health research routine, i.e. normalised. To disrupt 'business as usual', we synthesise evidence about meaningful research partnerships and features of inclusive participatory spaces. We present examples of decolonial, culturally attuned methods that can be used to reimagine and reinvigorate research practice because they encourage critical reflexivity and power-sharing: arts-based research using music and singing, participatory learning and action research, Photovoice and co-design (ideas generation) workshops. We consider the consequences of not making this paradigm shift. We conclude with recommendations for specific structural and policy changes and empirical research questions that are needed to inform the normalisation of participatory health research in this field.

Keywords: **Public health; Migration; Health equity; Community participation; Participatory health research**

Introduction

Migration is a global phenomenon and one of the most pressing public health issues of our time. The International Organization for Migration (IOM) defines a migrant as "someone who has left their habitual place of residence for any reason. This term may include a refugee person, i.e. someone who, owing to a well-founded fear of persecution for several reasons, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country or to return to it".[1] Acknowledging the heterogenity of this population and complexity of definitions in the field,[2] we use the terms "refugee" and "migrant", and employ other terms only if a project or initiative does so.

Mid-2022, there were approximately one billion migrants in the world and almost one million migrants in the WHO European Region.[3] The numbers have grown significantly since the war in Ukraine forced millions of people to flee to other parts of Europe for protection.[4] While migration per se does not necessarily lead to negative health outcomes, structural conditions of oppression beyond the health sector can have a negative impact, examples include unsafe work environments in industries that rely heavily on labour of refugees and migrants or the effects of detention centres on mental health (3). These are intersecting social determinants of health, that can lead to health inequities for some groups.[3,5]

The field of migration health research is growing exponentially with the goal of addressing these

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DOIs of original articles: https://doi.org/10.1016/j.lanepe.2024.100939, https://doi.org/10.1016/j.lanepe.2023.100803, https://doi.org/10.1016/j.lanepe.2023.100804, https://doi.org/10.1016/j.lanepe.2023.100818, https://doi.org/10.1016/j.lanepe.2024.100835, https://doi.org/10.1016/j.lanepe.2023.100805, https://doi.org/10.1016/j.lanepe.2023.100834, https://doi.org/10.1016/j.lanepe.2023.100806

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inequities.[6] However, policy and practice are not always evidence based. This, contributes to persisting inequities.[7] Examples include (1) inadequate screening programmes and health services for ethnic minority and migrant and refugee populations due to structural barriers such as racism, lack of trained interpreters, and lack of culturally sensitive services,[8,9] (2) persistently high rates of HIV infections among migrant sex workers,[10] and (3) the fact that refugees and migrants were disproportionately affected by the COVID-19 pandemic and the related public health responses due to inadequate translation of evidence into culturally attuned practice.[10–12]

We explore one of the reasons for this translational gap—the lack of meaningful participation of refugees and migrants in research.[7] A narrative review of 53 member states in the WHO European Region found that refugees and migrants are rarely involved as partners in the co-production of evidence about their health.[13] As a result, the knowledge and implementation initiatives produced may not reach or benefit those they are intended for because they follow a top-down rather than a bottom-up approach. Responding to these issues, and in line with the recent Global Rabat Declaration,[14] WHO Health and Migration Programme has started building capacity for participatory health research (PHR) to strengthen bottom-up generation of evidence about refugee and migrant health.[15,16]

PHR is a research paradigm with origins in the Global South. It is rooted in postcolonial critiques and emancipatory traditions to promote social justice that can strengthen knowledge translation.[17] For example, to return to some of the aforementioned examples of persisting problems: a project aimed at increasing colorectal cancer screening rates among Chinese migrants in San Francisco, California, modelled participatory partnership structures throughout the process, leading to improved uptake of screening.[18] Sonagachi, a participatory health project in Kolkata, India, resulted in significantly reduced HIV rates among sex workers through leadership from the sex worker community and involvement in all aspects of the project, including project development, implementation, and management.[10] Thus, we come together as a group of academics, community partners, artists, and health policy actors with experience of PHR to stimulate debate about the need for a paradigm shift in the field of refugee and migrant health so that PHR becomes a routine, i.e. normalised, way of conducting research about the health of refugees and migrants. We have combined experience of PHR partnerships in quantitative and qualitative studies in Europe with refugees, asylum seekers, and migrants, both documented and undocumented. Some of us have lived experience of migration (see Positionality Statement, File 1).

In this Personal View, we first elaborate on the rationale for a PHR paradigm and the evidence about *meaningful PHR partnerships*. This is crucial because participation has become a "buzzword". It is "known" but not necessarily fully understood in terms of its origins and the implications of its values for dismantling "business as usual" in existing research practices in favour of more equitable and democratic ones. Moreover, the label "participatory" can be misused to hide and/or exploit, rather than to address, power and social inequities.[19] Second, drawing on best practice and lessons from our own research, we describe the concept of *participatory space*[20,21] to explore how this can support the reimagining and reinvigorating of research partnerships in the field of refugee and migrant health. We present three case studies that elucidate *decolonialising, culturally attuned methods* that can be used to enact research partnerships in more equitable and democratic ways.[22] Third, we consider what happens if we do *not* make this change. We conclude with recommendations to underpin a paradigm shift to normalise participatory health research with refugees and migrants.

Participatory health research as a research paradigm: key values for meaningful partnerships

Participatory health research is a transdisciplinary paradigm rooted in postcolonial critiques and other emancipatory traditions. For decades, postcolonial scholars and activists have criticised traditional "research" as a tool of domination, "inextricably linked to European imperialism and colonialism".[23] This is because the power to make decisions about what is being researched, which methods are used, who is invited to participate, what the data means, and where the findings should be disseminated is traditionally in the hands of academics, not the communities who are affected by the issues at hand. Thus, traditional research can reproduce unequal power dynamics between the Global North and the Global South, as well as between academic researchers and the communities under study in any geographical research setting, e.g. white middle class researchers in high income countries doing research on (rather than with) migrants and refugees.[24] Health research participants, particularly indigenous people and people of colour, have been treated as objects to be measured, observed, questioned, analysed, and exploited. Extractive ways of producing knowledge—where the privileged researcher "mines" people for knowledge that benefits the researcher above all, with little or no benefit for the communities under study, or, indeed, actual harm to communities—are compared to colonial practices of extracting resources from colonised places.[24,25]

PHR strives towards greater equity and social justice.[17,26] and has inspired important conceptual models such as community based participatory research.[18] In PHR, those whose lives or work is the subject of the research are involved in *all stages of the research*, from agenda setting and research design to recruitment, data collection, and analysis to dissemination and knowledge translation.[16] Involvement in priority setting, research governance, and data interpretation and dissemination is considered the minimum requirement for meaningful partnerships.[27]

Participatory methods can be very useful to support this process as they are characterised as collaborative and inclusive, favouring co-design and co-production.[22,28] They are committed to whole-person engagement, and seek to elicit not only cognitive, but also affective and sensorial knowledge.[23] Methods are specifically cultivated to promote the recognition of all knowledge holders, thereby challenging dominant hierarchies and redistributing power. Such counter-hegemonic methods also promote collective, ethically driven responsibility and creativity.[28]

Clearly, PHR is much more than qualitative research designed to elicit in-depth knowledge about migrants' views and perceptions on a given health issue. Further, PHR is much more than involvement in a research project at one point in time, e.g. the recruitment phase, or employing a participatory method in fieldwork *without attention to changes in governance and power sharing*. Thus, a paradigm shift to PHR will require changes in research teams. For example, to achieve actual power-sharing rather than tokenistic involvement, critical (self) reflexivity is important. In practice, this includes reflection on collective explorations of stereotypes, implicit bias, and racist micro-aggressions (particularly in research that involves white academic researchers and communities of colour) or continuous forms of evaluation embedded in the research process to ensure that the project lives up to the expectations of participatory research.

Meaningful participation also relies on iterative action research cycles that promote *co-learning* whereby community members with "insider" experience and "outsiders" (e.g. researchers, NGOs, local governments) share and respect each other's knowledge in order to create new understanding and work together to form action plans.[29] Meaningful participation also aims for *collective action* whereby the communities affected by the issues at hand set their own agenda and are mobilised to carry out research in the absence of outside initiators and facilitators.[29] Thus, it is a collective endeavour where participation is a central rather than an instrumental goal.[17,30]

Finally, PHR explicitly aims for transformation and social change in two distinct yet interrelated ways. First, through the transformative process of taking part in this kind of research: by engaging in critical (self) reflexivity and collaborative ways of working together, the people involved in the research (including, of course, the academic researchers) inevitably change and can benefit from new knowledge, skills, and networks, with evidence of ripple effects beyond the primary and anticipated objectives.[31,32] Second, PHR can improve the chance of actions impacting on health policies or service delivery, resulting in improved access to health care or improved health outcomes.[26,33] Dissemination and feedback loops to the communities involved are essential so that research impacts (or lack thereof) are discussed and understood.

We are very aware that using PHR is not a panacea.[28,34] It has limits particularly in the face of aforementioned structural conditions of oppression. There are also specific challenges for its use with migrant and refugee communities.[35] Apart from the extended time commitment and the related struggle to receive long-term research funding,[36] challenges include but are not limited to: addressing representativeness ("who speaks for whom?") and attending to the complexity of defining "community"[37]; managing intra- and inter-group power dynamics in research and community settings[28,38]; decolonising research relationships and unlearning hierarchical ways of doing research[39–41]; supporting language and literacy needs in diverse teams[42]; making decisions about distribution of funds, including financial reimbursements for peer researchers[43]; and engaging with traditional university ethics procedures, which may not align with participatory research processes.[44] Nevertheless, we advocate that it is important to address these challenges in order to harness the opportunities that PHR offers. These include the opportunity to strengthen research prioritisation, understanding of social determinants of health, development of health indicators, interpretation of results, design and implementation of tailored/fit-for-purpose health interventions, and dissemination of findings to diverse audiences.[15,35,45,46]

While the notion of a paradigm shift can seem enormous, the rich tradition of participatory health research offers umbrella concepts and resources to guide this change, weaving together theoretical knowledge but also "experiential, practical, emotional, and intuitive ways of knowing".[17] In the following section, we introduce *participatory space* as a particularly valuable interpretive concept to concretely guide research practice.

Participatory spaces: reimagining and reinvigorating research practice

Participatory space emphasises that spaces have physical dimensions but are also shaped by temporal and social dimensions.[20,21] A defining feature of their social dynamics relates to the question: who opens the space? Participatory spaces may be initiated and controlled by public institutions (invited spaces), initiated and commanded by communities (taken spaces[47]), or sponsored by public institutions that maintain a direct connection with a local community or service user movement (hybrid spaces[32]). The concept of participatory space can also be used as a heuristic tool to explore spaces in action, examining, for example, decision-making processes between people from different backgrounds. This concept draws particular attention to power dynamics and sociocultural norms that shape interactions in spaces as well as the strategies and tactics that people employ to have a voice within, and across, intersecting spaces.[48]

Using participatory space as a heuristic lens to analyse findings from the aforementioned narrative review of refugees' and migrants' involvement in health research in the WHO European Region, currently, research in the field of refugee and migrant health generally takes place through *invited spaces*. There was no example in the literature of a *taken space*. A small number of *hybrid spaces* were identified. While rare, these spaces show important promise for more meaningful involvement of refugees and migrants in three ways. First, they can strengthen the mobilisation of refugees and migrants who are described as hard to reach because of fears of engaging with state agencies for research.[32] Second, they can incorporate material practices, i.e. participatory methods, tools, and techniques to *concretely* create more research space[22] where there is active attention to power asymmetries in inter-cultural interactions, facilitated through dialogues that migrants describe as safe and enjoyable, sustaining their engagement in research over time.[49,50] Third, hybrid spaces can support dialogues in research between migrants and statutory service providers and planners that foster co-learning, creativity, and collective action leading to sustained impact in various settings (e.g. clinical).[31,51]

Below, we present three case studies of hybrid spaces to elucidate inclusive and innovative participatory spaces across the research cycle. The first is about the use of the arts in a research prioritisation project. The second describes the way a steering group decided to work differently together by incorporating participatory methods into their meetings. The third focuses on a project that combined a peer research model and participatory methods for inclusive fieldwork.

Case study 1: using arts-based methods to involve refugees, migrants, academics, artists, and health sector colleagues to co-design a set of research priorities for refugee and migrant health in Ireland

Research prioritisation in the field of refugee and migrant health is characterised by top-down imperatives.[15] This project explored the use of arts-based methods research using music and singing to develop an innovative inclusive, social, and creative participatory space for bottom-up research prioritisation between refugees, migrants, academics, artists, and health sector colleagues.

This project was co-designed by members of an NGO focused on advocacy for refugees and migrants and academics, some of whom had a longstanding partnership. Following collaboration on the grant application, a project co-ordination group was established including academics with backgrounds in arts practice and primary health care (n = 3) and migrants working in NGOs (n = 2). In line with PHR principles, funding for NGOs' staff time ensured that the community partner's voice was included in this group's regular meetings to share decisions about project planning from start to finish. Meetings were held online due to COVID-19 restrictions.

The project employed the Irish World Music Café[52] as an arts-based method for research prioritisation. This was on the basis of evidence that music and singing can foster intercultural sensitivity, empathy, and social bonding in a diverse social and cultural group faster than other methods can.[53,54] There is also evidence that music and singing as material practices in participatory spaces have the potential to invert power asymmetries between migrants and professionals through a central focus on showing migrants' capacities as leaders and knowledge holders, enabling them to express their cultural identities, stories, and contexts in a detailed and transformative way.[23,54,55]

Following principles of purposeful and snowball sampling, 23 refugees, migrants, primary care providers, national health service planners, artists, and academics working in the field of migrant health were recruited for six 1.5 hour online music cafés.[56] 11 participants identified themselves as Irish born, nine identified as international migrants and three participants did not disclose their migrant background. An outline of the music café schedule (Box 1) shows the integration of music, singing, song composition, and creative writing with more traditional focus group discussions in breakout rooms.

One activity involved migrants who were musicians. They taught songs from their culture to café participants. One Polish-born musician reflected that "Teaching cultural songs is always stressful for me initially, as I feel I am exposing something very personal. However, I feel that this vulnerability creates better connections with participants. I am also proud of exposing my heritage to different nations. The impact for others is educational by exploring different cultures first-hand."

The emergent research priorities were compared with priorities in the WHO Strategy and Action Plan for Refugee and Migrant Health 2019–2023.[58] There was strong resonance between the top-down and bottom-up priorities, particularly in relation to the need for healthcare adaptation and inter-sectoral action to bring about change. However, a finding about the specific importance of cultural identity and cultural expression for health and well-being among refugees and migrants was only documented via the music café method. This illustrates the ways in which arts-based whole-person methodologies can offer new "ways of knowing" and generate new insights.[59,60]

A qualitative evaluation found that participants from all backgrounds valued the distinctive feel of the music cafés compared to other meeting spaces. They reported that it offered something important in terms of equalising power differences between them and that it helped to bring a deep human dimension to the interactions between participants from different sectors.[57]

Box 1.

Research prioritisation in migrant health: towards a participatory, arts-based paradigm.[57]

Sample schedule of activities in an online Irish World Music Café for research prioritisation

- Opening with recorded music using co-created café playlist
- Musical ice-breakers led by musicians in the café co-ordinating team including e.g. breathing exercises, humming, musical movement, rhythmic games, and interactive melodic and harmonic singing
- Migrant-led song exchange led by musicians who are migrants in the café co-ordinating team, e.g. teaching of simple songs in different languages from different parts of the world to highlight migrants' cultural heritage and role as knowledge holders
- Research activity based on focus group discussions in virtual break-out groups led by café co-ordinating team about research prioritisation, e.g. what is our vision for excellent refugee and migrant health in Ireland; what health issues do we need more information about to achieve that vision?
- Cultural sharing opportunity for café participants to volunteer and share through a performance or playing a video of e.g. songs/poetry from their culture to foster reciprocity
- Song composition to convey key vision, e.g. use of creative writing and drawing activities to synthesise learning and reflections to inform lyrics and rhythm of a café song entitled *Change needed now*
- Café closing song

Case study 2: using participatory learning and action research in a steering committee for a mixed-methods study about implementing ethnic identifiers in Ireland: building trust through transparent shared decision-making

Despite international and national policy imperatives, there is no routine collection of ethnicity data in Irish primary care. This participatory health research project investigated the implementation of an ethnic identifier in Irish primary care.[61] It was based on a new partnership between migrants, academics, and health service planners that was developed with the specific purpose of collaborating on a grant application on this topic.

The steering group comprised the applicants and newly hired project staff: academics with backgrounds in social and political science, primary healthcare, and biostatistics (n = 5), migrants working in NGOs (n = 2), an Irish NGO staff member (n = 1), and a policy maker (n = 1). All were Irish born apart from two academics born in Chile and Spain and two NGO staff born in Burundi and Armenia.

While the steering group meetings were held in the university, there were other considerations to create an equitable space: there was budget allocation to pay community partners to prepare for and attend the meetings; for the first six months, meetings were held monthly to build rapport and trust; and meetings were two to 3 h in duration to enable time for further relationship building and detailed discussions about how the team would work together and how they could progress the study work packages.

In addition, the members decided to do things differently to standard steering group meetings by incorporating participatory methods into meetings—they used Participatory Learning and Action (PLA) research as material practices to support shared decision-making. PLA is a practical, adaptive research strategy, underscored by the values of co-learning and collective action, which enables people from diverse backgrounds to focus on issues of joint concern.[62] It offers a range of material practices that facilitate visual and verbal generation of data by diverse groups for co-learning and co-analysis[50,51] (see Table 1). While PLA has been used in fieldwork for research about refugee and migrant health before,[31] it had not been used to restructure dialogues and support transparent decision-making between steering group members who had different levels of social power.

In this study, PLA provided concrete material practices to enable the steering group members to work together and co-design criteria for selecting clinical sites for a qualitative case study.[64] Using PLA meant that they combined their respective knowledges about clinical sites, the ethnic, linguistic, and cultural diversity of the local populations they served, and the scope to build trust in those populations to support recruitment and retention in the study fieldwork. An Irish-born steering group member from the NGO sector reflected: *"the use of PLA worked really well to collect information and as a group we could easily see and discuss all input and come to decisions"*. The outcome was deep insight into the pros and cons of potential sites, transparent decision-making, and, subsequently, effective recruitment of 62 participants from ethnically and linguistically diverse backgrounds for the qualitative fieldwork.[63] This included refugees/migrants from European, African and Asian backgrounds.

Case study 3: a co-creation health literacy project using photovoice and ideas generation workshops to improve health and equity in support of prevention of non-communicable diseases among migrants in Portugal

A health literacy development approach is firmly rooted in the person's lived experience of their contexts and social practices. Yet research still struggles to meaningfully engage individuals, families, and communities

Flexible brainstorming	Fast and creative approach of using materials, such as pictures or objects, to generate information and ideas about a topic.
Card sort	An interactive method for facilitating and recording brainstorming around a topic into thematic areas using 'on the spot' co-analysis.
Card ranking	A collaborative process to examine findings from a card sort and indicate individual priorities or preferences using a voting system to transparently arrive at a democratic outcome.
Traffic-light exercise	A visual ranking exercise using 'red–orange–green' colour coding for individuals to indicate the strength of their agreement/understanding of a given option for group discussion.

***Table 1:* Participatory learning and action research tools and techniques (adapted from Roura et al.[63])**

who are disproportionally affected by health challenges arising from their socioeconomic circumstances.[65]

This participatory health literacy research project aims to conduct a collaborative assessment of strengths, needs, and action ideas in support of prevention of non-communicable diseases among migrants, to inform policies and interventions that improve health equity.[66]

For this purpose, the project created equitable and participatory spaces in the communities to give voice to people's perceived needs and strengths and, building on local knowledge and wisdom, to co-design and implement health literacy actions that are accessible, sustainable, and useful for the people who need them.

A Community Board (CB), set out at the start of the project, engaged migrants (n = 7, one each from Angola, Bangladesh, Brazil, China, Guinea-Bissau, India, Nepal), a multidisciplinary team of researchers (n = 10, three from Brazil, one from Cuba, one from Nepal, four from Portugal, one from Syria), health and social care professionals (n = 6, born in Portugal), and health managers and policymakers (n = 4, born in Portugal) as co-researchers in the research process. Generally, decisions were arrived at through dialogue and consensus.

In this study, the Optimising Health Literacy and Access (Ophelia) process[67] provided concrete tools to enable the CB to jointly frame a timely and relevant research question, participate in the research design (e.g. survey in seven languages, contextually congruent tools for data collection, appropriate strategies to enrol participants), and carry out Photovoice and ideas generation workshops. The involvement of peer/community researchers from Angola, Bangladesh, Brazil, Cape Verde, China, Guinea-Bissau, India, Nepal, Pakistan, Syria and Ukraine in the fieldwork, trained and paid as collaborators, facilitated the research process in recruiting seldom-heard groups.

Photovoice, as a participatory qualitative approach where participants take photographs and produce and discuss narratives to guide the chosen images, proved to be useful to identify and reflect upon issues of importance to them. The Photovoice methodology provided safe, creative, and enjoyable participatory spaces for migrants; for example, one migrant from Nepal reflected *"I was reluctant ... I just arrived in the country, not speaking Portuguese, and with elementary school. But I felt comfortable expressing my view the way I know."* Ultimately, through reflection, collaboration, and power sharing, it contributed to minimising the disconnect between what people need and what is developed to improve health and equity.

Co-design of "ideas generation" workshops, implemented with end-users and health and social care practitioners and led by trained migrants, allowed for rapid brainstorming, and generation and sharing of ideas based on vignettes (short narratives) of typical community members that clearly uncover their health literacy strengths, needs, and preferences. The migrants took the initiative to plan and conduct some of the workshops. The workshops allowed identification and prioritisation of fit-for-purpose actions for health literacy development, especially among groups that are regarded as disadvantaged, and to determine, from their perspective, their needs, their preferences, and how they desired to be engaged.

The action ideas that were generated (e.g. citizen hubs in the primary health care services) and will be implemented in the next phase of the project may result in a roadmap that will serve as a proof-of-concept case study with the potential to extend and scale-up experiences at the national/international level.

Consequences of not making a change to participatory health research

Progressing migration health research without a paradigm shift to PHR means that the existing pattern of exclusion and tokenistic practice in research spaces is likely to continue. "Business as usual" reinforces inequities and social injustice in the following ways, as postcolonial and indigenous scholars and activists have long pointed out.[68]

First, because migrant and refugee communities are excluded from the research process (or tokenistic forms of "inclusion" are adopted), the knowledge produced is likely biased and/or limited, failing to fully take the lived experiences and knowledge of those affected by the issues at hand into account. Consequently, knowledge transfer initiatives will continue to be ineffective in addressing the complexities of health inequity within a concrete local context, leading to avoidable illness and death.[69]

Second, being denied a voice in the processes that affect people's lives, including knowledge production and knowledge transfer, is a form of epistemic injustice.[70] Excluding people from research that concerns them perpetuates social exclusion. Similar to other forms of structural violence that limit people's access to social resources and social influence,[71] exclusion from knowledge production can be viewed as indirectly contributing to health inequalities such as higher rates of diabetes and other chronic illness in communities regarded as vulnerable or disadvantaged.[72]

Third, this continuation of exclusionary research furthers distrust and "research fatigue", whereby refugee and migrant communities are withdrawing from research spaces because they are experienced as exclusionary, hierarchical, and lacking impact on the concrete material circumstances of people's lives.[24] This contributes to structural biases in the evidence base for refugee and migrant health.[15]

Search strategy and selection criteria

The impetus for this Personal View came from findings of a narrative review of migrants' involvement in health decision-making The search strategy and selection criteria for that review were identified through searches of PubMed, Scopus and grey literature sources with the search terms 'migrant'/'refugee'/'asylum seeker', 'policy', 'user involvement', 'user participation', 'policymaking', 'health service development', and 'research' from 2010 onwards. Articles were also identified through consultation with WHO focal points in the WHO Euro Region. Only papers published in English were reviewed. The narrative review concluded that (i) migrants' involvement in research is rare and (ii) that participatory health research approaches were valuable for supporting their meaningful involvement. Our Personal View takes this discussion forward by drawing on our combined experience and knowledge. In addition, as mentioned, we present case studies that illustrate feasibility and implementation of these approaches. The final reference list for our Personal View was generated on the basis of originality and relevance to the broad scope of our submission.

Conclusions

Normalising PHR with migrant and refugee communities is an enormous but essential endeavour that requires nothing less than a paradigm shift, including significant changes to the health research ecosystem in terms of funding, research processes, and research governance. Fundamentally, the enactment of collaborative research about refugee and migrant health must be reimagined and reinvigorated. Explicit, critical attention must be given to: "Whose voices are we hearing, who's left out, who's not even at the table? [...] Who'd we forget because of our particular blinders?"[73] Traditional ways of doing research must change, with academics being prepared to relinquish power because, if no one actually gives up power, nothing changes.[24,74]

Three specific changes on a structural or policy level towards achieving the normalisation of PHR are: incorporating a commitment to PHR in all national policies outlining priorities in research; developing funding streams that take the cyclic and complex nature of PHR into account, for example by financially supporting the participatory *development* of research agendas, and by ensuring sustainable, long-term ways of funding PHR that avoid "one-off" initiatives and start-and-stop research; and investing in PHR training and skills development to support the paradigm shift and ensure that participation is implemented throughout the research process and tokenism is avoided. Such capacity building will occur in the context of a major imbalance of resources to invest in research on refugee and migrant health between academic institutions of the Global North versus academic institutions of the Global South. For this reason, the WHO Health and Migration Programme, within the frame of the Global Research Agenda, is organising a network of academic institutions to facilitate North–South cooperation and capacity building in this area of research. PHR capacity building could be integrated into this network and evaluated to monitor progress and impact on the field of refugee and migrant health research.

In regard to research practice, empirical studies are needed including examination of: how representativeness of refugees and migrants in research partnerships can be addressed given the heterogeneity and diversity of identities and experiences; lessons learned from COVID-19,[19] the ways in which digital technologies may expand the reach of participatory methods and tools in intercultural research settings that are historically used face to face (e.g. PLA focus groups); and evidence about culturally attuned material practices for partnership and research goals that can radically reinvigorate research, e.g. under-researched methods such as music and singing as arts-based research.[57] Research is also needed about the limits and challenges of PHR including critical analysis of good intentions versus truly equitable participatory practices.[75] These studies will have value for the broader goal of a systematised analysis of processes and impacts of PHR in its different complex dimensions.

We have identified these as some initial steps towards changing research practice based on our collective experiences and interests. We encourage others to also co-produce policy and research actions for the normalisation of PHR. The overall goal is that PHR is no longer rare in the field of refugee and migrant health: there need to be more and more research teams "walking the walk", role-modelling equitable, intercultural collaborations that centralise refugees' and migrants' agency, resilience, and capabilities as experts of their own lives with equal or leadership roles in research teams.

Contributors

AMacF, SH, BK and SD conceived and conceptualized the idea for this manuscript; AMacF, MJM, AG, WK, AH, AP, HP and SD organised resources and data curation (country case studies); AMacF and SH wrote the original draft; All authors reviewed and edited drafts and had final responsibility for the decision to submit for publication.

Declaration of interests

All authors declare no competing interest.

Acknowledgements

In addition to academic and health service colleagues involved in case studies 1, 2 and 3, we wish to acknowledge the following organisations and (with permission) the following individuals: Community organisation that collaborated in case study 1- Doras, Limerick, Ireland; Funder case study 1= Irish Research Council, New Foundations Award; Quote case study 1- Ewa Zak-Dyndal; Community organisations that collaborated in case study 2–Intercultural Diversity Education Centre, Ireland and Shannon Family Resource Centre; Funder case study 2–Health Research Board, Dublin, Ireland (HRA-PHR-2015-1344); Quote case study 2–Colette Bradley; Community organizations that collaborated in case study 3–AD SUMUS–Associação de Imigrantes de Almada; AJPAS–Associação de Intervenção Comunitária; Alto Comissariado para as Migrações; ALCC–Associação Lusofonia Cultura e Cidadania; Associação Casa-da-Índia; Associação de Imigrantes Mundo Feliz; Associação Islâmica da Tapada das Mercês e Mem Martins; Associação Lusofonia Cultura e Cidadania; Associação Unidos de Cabo Verde; Casa do Brasil; Centro Porta Amiga de Almada–AMI; Cruz Vermelha Portuguesa–Delegação de Braga; InPulsar- Associação para o Desenvolvimento Comunitário; NIALP–Intercultural Association Lisboa; Prosaudesc–Associação de Promotores de Saúde Ambiente e Desenvolvimento Sócio Cultural; Solidariedade Imigrante–Associação para a Defesa dos Direitos dos Imigrantes; UAI–Associação Cultural Luso-brasileira de Apoio à Integração em Portugal; Funder case study 3 Fundo para o Asilo, Migração e Integração (Ref.PT/2021/FAMI/693). AG is supported by FCT - Fundação para a Ciência e Tecnologia, I.P. (Reference CEECINST/00042/2021/CP1773/CT0001 and DOI identifier 10.54499/CEECINST/00042/2021/CP1773/CT0001).

Appendix A. Supplementary data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.lanepe.2024.100837.

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