

NARRATIVE REVIEW

Migrants' involvement in health policy, service development and research in the WHO European Region: A narrative review of policy and practice

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Abstract

OBJECTIVES: The involvement of individuals and communities in health decision-making is enshrined in WHO policies. However, migrant groups are under-represented in health decision-making processes. Our aim was to explore migrants' involvement in health policy, service development and research in the WHO European Region to identify levers for inclusive and meaningful practice.

METHODS: We conducted a narrative review of grey literature and peer-reviewed research on migrants' involvement in health decision-making across the 53 countries in WHO Europe. We searched for articles published in English between 2010 and the present in two electronic databases (PubMed, Scopus), IOM MIPEX Health Strand country reports, the EU SOPHIE project and using a Google advanced search. Findings were analysed descriptively and using Normalisation Process Theory to investigate levers and barriers to implementation of policy into practice.

RESULTS: Of 1,444 articles retrieved, 79 met the inclusion criteria. We identified 20 policies promoting migrants' involvement, but national-level policies were present in only two countries. We identified 59 examples of migrants' involvement in practice from half of the WHO Europe countries ($n = 27$). Our Normalisation Process Theory (NPT) analysis of 14 peer-reviewed empirical papers found that participatory research approaches are a lever to putting policy into practice in a meaningful way.

CONCLUSIONS: Migrants' involvement in health decision-making requires explicit national policies that are implemented evenly across policymaking, service provider and research activities in all countries in the WHO European Region. Participatory approaches to involvement activities are encouraged because they are a lever to perceived barriers to migrants' involvement.

KEYWORDS

health policy, implementation science, migrant health, participatory research

Sustainable Development Goal: Good Health and Well-being, Reduced Inequalities.

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INTRODUCTION

The involvement of individuals and communities in health decision-making is enshrined in World Health Organization (WHO) policies [1–5]. There are models to support such participation in order to shape health *service provision* and health *policy* in several jurisdictions [6–10], and, increasingly, funding agencies have encouraged or mandated the involvement of the public in health *research* [11–14]. There is a plethora of concepts and terminology in this field because it has diverse origins in terms of geography, disciplinary perspectives and objectives [15, 16]. In this paper, we refer to involvement as a process ‘through which individuals formulate meanings and actions that reflect their desired degree of participation in individual and societal decision-making processes’ [17].

Public involvement in health governance is a complex, multifaceted phenomenon based on respect for people as experts about their own health. It represents a commitment to incorporating people’s expertise with that of other stakeholders who are more usually involved in decision-making, for example health professionals, service planners, policy makers and academics [18]. This generates a more comprehensive knowledge base that leads to more responsive policies and healthcare services, improved design of public health interventions that have a better chance of being implemented, improved health outcomes, less research waste and greater health equity [19–21].

Public involvement has been conceptualised as a dynamic process that relies on dialogue and negotiation for the *co-production of knowledge, aiming for democratic decision-making between diverse stakeholders* [16, 17]. There are different levels of involvement [22] and increasing recognition that it is necessary to move from tokenistic consultations to more participatory partnerships that are meaningful and sustained [23–25]. The operationalisation of public involvement remains problematic, with multiple translational challenges [26–29], reliance on a limited number of traditional methods [30] and under-representation of minority and marginalised social groups [31, 32], who are considered ‘hard to reach’ or, as Lightbody argues, ‘easy to ignore’ [33]. This paper focuses on the under-representation of migrants in health decision-making and the policies developed to reverse this trend.

While international agencies provide definitions (see Box 1), there is no universal agreement on the definition of a migrant [34, 35]. Over 96 million international migrants lived in the WHO European Region as of 2019 [36], with the majority being migrant workers [37]. Migrants are a very diverse group with variation in resilience, resources, health status and health outcomes [38]. There are, however, specific sub-groups who experience disadvantage, marginalisation and health inequities due to their transitory journeys, legal status and eligibility for healthcare in destination countries [39–41]. This pattern of inequity is also clear in emerging evidence for new diseases, such as COVID-19 [42].

Box 1 Definitions

Migrant

A person who moves away from his or her place of usual residence, whether within a country or across an international border, temporarily or permanently, and for a variety of reasons.

<https://www.iom.int/who-is-a-migrant>

Refugee

Someone who is unable or unwilling to return to their country of origin owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion.

<https://www.unhcr.org/en-ie/what-is-a-refugee.html>

Asylum seeker

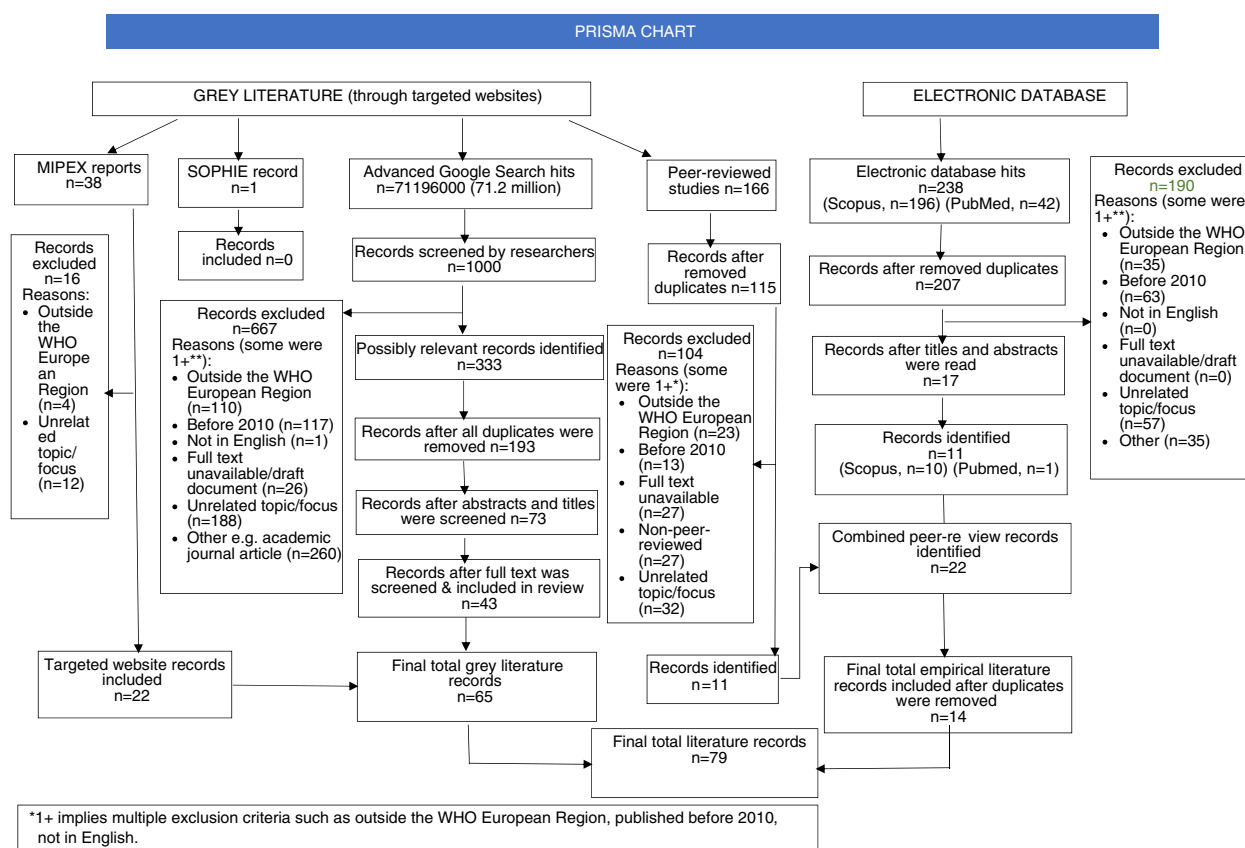
Someone whose request for sanctuary is yet to be processed.

<https://www.unhcr.org/en-ie/asylum-seekers.html#:~:text=%C2%A9%20UNHCR%2FAchilles%20Zavallis,who%20qualifies%20for%20international%20protection.>

Migrants’ involvement in *individual*-level decision-making about their health care is inhibited by well-documented problems such as lack of access to health care and sub-optimal supports for communication in cross-cultural consultations [43–45]. Policy options to address this have been developed in the WHO European Region [46, 47]. The issue of *societal*-level decision-making has had less attention. This is problematic because migrants, like members of any community or population group, have experiential knowledge and expertise that is a necessary resource for developing policies, planning or adapting services to make the best use of available resources [48, 49]. The WHO Europe Strategy and Action Plan for Refugee and Migrant Health [50] emphasises migrant participation in health care, but few national policies explicitly promote migrants’ involvement in health decision-making, and policies that are in place may not be implemented [51]. There is also a lack of statutory mechanisms for migrants’ involvement [52]. Further, language and cultural differences between migrants and host country stakeholders can limit involvement in health participatory activities. Migrants can experience research fatigue when they do get involved in projects or initiatives because they do not see changes arising from their participation in research; undocumented migrants or those who are in the process of seeking protection may not feel safe being in contact with health or academic agencies [39, 53]. Nonetheless, the MIPEX 2016 project highlighted that there are examples of good practice in some settings and the achievements warrant further investigation [52] because to offer an important opportunity for learning and identifying transferable

TABLE 1 Explanation of NPT constructs

Construct	Analytic question
Sense-making	Does this new way of working make sense to stakeholders and offer a potential advantage over current practice?
Engagement	Are there 'champions' to drive the new way of working and enrol all relevant stakeholders, and do they stay engaged?
Enactment	Have stakeholders the necessary resources, skills, confidence and experiences to put the new way of working into practice and achieve their intended goals?
Appraisal	Can stakeholders see benefits of the new way of working from formal or informal appraisals? Can they make or suggest adjustments to enhance its workability and impact?

**FIGURE 1** PRISMA chart

lessons, particularly about leveraging policies for migrants' involvement in societal health decision-making *into practice*.

The aim of this review is to comprehensively examine the policy context for involving migrants' in societal decision-making processes in the WHO European Region. Specific objectives are to:

1. Identify policies that are in place to support migrants' involvement in decision-making processes for
 - a. Policymaking
 - b. Service development
 - c. Research
2. Identify examples of migrants' involvement *in practice* in these three areas
3. Examine levers and barriers to the migrants' involvement *in practice*.

METHODS

We conducted a narrative review using guidance for assessment of narrative review articles [54] and grey literature searching [52].

We searched the IOM MIPEX Health Strand country reports, the EU SOPHIE project and two electronic databases (PubMed, Scopus), and used Google advanced search, between March and July 2020. The sample of peer-reviewed papers was augmented by references identified during the Google search of grey literature and recommendations by content experts. We liaised with WHO National Focal Points in August–September 2020 to address emergent gaps in literature from countries in the study region.

For all searches, we used combined sets of terms relevant to migrants' involvement in health decision-making

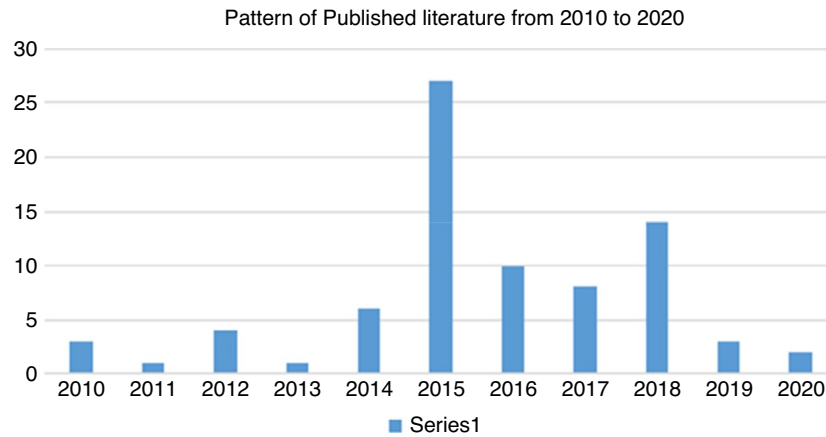


FIGURE 2 Pattern of published literature from 2010 to 2020

(‘migrant’/‘refugee’/‘asylum seeker’, ‘policy’, ‘user involvement’, ‘user participation’, ‘policymaking’, ‘health service development’ and ‘research’): see Table S1.

We included peer-reviewed literature that (i) reported original, empirical research using quantitative, qualitative or mixed methods, (ii) from the WHO European region, (iii) in English, (iv) from 2010 onwards and (v) related to health policies for migrant involvement in health decision-making in our three areas of interest—policy, service development and research. Grey literature was included if it met criteria (ii)–(v).

All empirical studies and 25% of grey literature were examined and agreed independently by two reviewers (Authors 2 and 4). A third reviewer (Author 1) resolved disagreements. We extracted and tabulated data based on the objectives of our review, iteratively developing categories to comprehensively compare and contrast literature from these diverse sources.

For objectives 1 and 2, we conducted a retrospective analysis of the policy environment. Following Buse et al. 2005 [55], we defined policy as a broad statement of goals, objectives and means that create the framework for activity. We considered that policy is expressed in a variety of instruments and is formulated by international and national actors from state agencies and civil society (e.g. NGOs, pressure/interest groups) with the ultimate goal of enabling statements of intent to convert into practice [56].

For objective 3, we focused on the sample of peer-reviewed empirical studies only because they (i) provided more detail for analysis about the processes of involvement than the grey literature references and (ii) had been through a critical peer-review process. We used Normalisation Process Theory (NPT) [57] to conceptualise levers and barriers. NPT has four constructs that can be useful as a heuristic device to ‘think through’ the data to understand the work that stakeholders have to do to implement a new healthcare initiative (Table 1) [58, 59]. Our NPT coding frame (Table S2) was developed iteratively by reading the references and conducting

an independent coding exercise (AMF and CdF) to determine the coding rules.

RESULTS

Description of included papers

In total, 1444 references (grey literature $n = 1039$; peer-reviewed $n = 405$) were generated and 79 met the inclusion criteria (Figure 1) [4, 25, 32, 53, 60–134]. There is a sizeable grey literature about the policy and practice of migrants’ involvement in health decision-making ($n = 65$), but the peer-reviewed empirical evidence base about migrants’ involvement in practice is scarce ($n = 14$).

We identified references from 30/53 countries in the WHO European region: Austria, Belgium, Bosnia and Herzegovina, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Kyrgyzstan, Latvia, Lithuania, Macedonia, Malta, Netherlands, Norway, Portugal, Romania, Slovakia, Slovenia, Spain, Sweden, Switzerland, Ukraine, United Kingdom of Great Britain and Northern Ireland.

We identified grey literature from 2010 onwards and peer-reviewed literature from 2012 onwards (Figure 2). The references were most commonly focused on migrants’ involvement in *health services development* ($n = 62$) [25, 32, 60, 63, 64, 67–86, 88, 91, 93, 95, 96, 99, 102–115, 117–129, 131–134], followed by *health research* ($n = 41$) [25, 32, 53, 61–67, 71–73, 80–82, 84, 88, 90, 91, 93, 96, 102, 108–110, 113, 114, 117, 119, 124–134] and *health policy development* ($n = 41$) [4, 32, 60, 66, 67, 69–72, 82, 84, 87, 91–94, 97–99, 101, 104, 106–116, 118, 119, 126–130, 132, 134]. Twenty references involved migrants in all three areas [32, 67, 71, 72, 82, 84, 91, 93, 107, 109, 110, 113, 114, 119, 126–129, 132, 134].

In many cases, the references referred to several types of migrants ($n = 33$) [4, 25, 32, 53, 60, 68, 69, 71, 74, 76–78, 80, 106, 108–113, 115, 116, 118–120, 124, 126–129, 132–134]

or related to entire health settings ($n = 31$) [4, 60–62, 66, 67, 70–72, 74–76, 78–80, 82, 84, 105–113, 115, 116, 119, 121, 126].

Policies promoting migrants' involvement in health decision-making

We identified 20 policies that explicitly promoted migrants' involvement in health decision-making (Table 2). They comprised international frameworks and action plans [4, 106, 110–113, 115, 121, 122], international and national guidelines or recommendations for specific migrants' groups or health topics (e.g. health promotion, mental health, sexual violence) [108, 114, 117, 118, 120] or broader public health and social determinants of health [116, 119].

Finally, national-level policies were identified ($n = 3$) from two countries—Ireland and Wales. The Welsh Government policy implementation guidance on the health and well-being of refugees and asylum seekers [105] provides direction for regional health boards to develop consistent local protocols, policy and practice to improve services. It stipulates that care for refugees and asylum seekers will be provided in line with one of the main principles of the national Social Services and Well-being (Wales) Act 2014, which is co-production. In Ireland, the National Traveller and Roma Inclusion Strategy [107] and the National Intercultural Health Strategy [109] involved migrants in the development of their strategies and emphasise meaningful participation and partnerships in decision-making as key principles for strategy implementation.

Examples of migrants' involvement in health decision-making in practice by country

Fifty-nine references reported examples of migrants' involvement in practice from 27 countries, including Austria, Belgium, Bosnia and Herzegovina, Czech Republic, Denmark, Estonia, Finland, Greece, Hungary, Ireland, Israel, Italy, Kyrgyzstan, Latvia, Lithuania, Malta, Netherlands, North Macedonia, Norway, Portugal, Romania, Slovenia, Spain, Sweden, Switzerland, Ukraine, and the United Kingdom of Great Britain and Northern Ireland. Some references provided examples of international collaborations and are cited for more than one country. The countries that have most examples are Ireland ($n = 16$) [25, 53, 63, 70, 72–74, 76, 82, 91, 124, 127–129, 132, 134] and the United Kingdom of Great Britain and Northern Ireland ($n = 16$) [25, 62, 63, 65, 67–69, 80, 81, 104, 127–129, 131, 133, 134], followed by the Netherlands ($n = 9$) [25, 32, 77, 96, 127–130, 134] (Table S3).

Migrants' involvement in practice was most common in *health service* development ($n = 44/59$) [25, 32, 60, 63, 64, 67–86, 88, 91, 93, 95, 96, 99, 102–104, 124–129, 131–134], followed by *health research* ($n = 34/59$) [25, 32, 53, 61–67, 71–73, 80–82, 84, 88, 90, 91, 93, 96, 102, 124–134] and *health policy* development ($n = 27/59$) [32, 60, 66, 67, 69–72, 82, 84, 87, 91–94,

97–99, 101, 104, 126–130, 132, 134]. There were 14/59 that provide examples of involving migrants in all three areas [32, 67, 71, 72, 82, 84, 91, 93, 126–129, 132, 134]. Migrants' involvement in practice was most common for all forms of migrants ($n = 20/59$) [25, 32, 53, 60, 68, 69, 71, 74, 76–78, 80, 124, 126–129, 132–134] and in entire health settings ($n = 17/59$) [60–62, 66, 67, 70–72, 74–76, 78–80, 82, 84, 126].

Levers and barriers to implementing policy for migrants' involvement in health decision-making

Of these examples of migrants' involvement in practice, there were 14 peer-reviewed empirical qualitative studies with data from across 10 countries: Austria, Belgium, England, Greece, Ireland, Israel, Kyrgyzstan, the Netherlands, Portugal, Scotland [25, 32, 53, 124–134] (Table 3).

These were analysed for levers and barriers to policy implementation. They were all participatory projects, which emphasised co-production in partnerships between diverse stakeholders, to identify concrete actions to advance research/services/policy. Most were related to primary healthcare settings ($n = 9$) and were inclusive of all kinds of migrants [25, 32, 53, 124, 126–129, 132–134]. Combined, these empirical papers relate to involvement of migrants from 29 countries of origin: Afghanistan, Albania, Benin, Cape Verde, Chile, China, Congo, Croatia, Czech Republic, Eritrea, Former USSR, Ghana, India, Indonesia, Iran, Iraq, Sri Lanka, Morocco, Nigeria, Pakistan, Philippines, Poland, Portugal, Russia, Slovakia, Somalia, Syria, Turkey Kurdistan and Turkey. Nine of these are in the WHO EU region: Albania, Croatia, Czech Republic, Former USSR, Poland, Portugal, Russia, Slovakia and Turkey.

Following Table 1, our NPT analysis of *sense-making* found one reference that explicitly emphasised that opportunities for participation are rare, so this represents a 'different' way of working to usual practice [32]. Another considered that policies for Public Patient Involvement in health research could be a lever to highlight the potential and rationale for this way of working [129].

In line with participatory designs, the *engagement* of stakeholders was based on existing or new partnerships with some combination of community, academic and health stakeholders. Where specified, these were initiated by academic [25, 127] or community stakeholders [32]. The partnerships thus comprised diverse stakeholders who do not ordinarily meet [25, 32, 53, 130–134]. Only one paper explicitly reported resistance to this: primary care providers in one country in a European project were reluctant to explore service adaptations with migrants; there was no such reluctance in the four other countries involved [134]. Otherwise the participatory approaches, and participatory tools and techniques used (described further below), were a lever for both building relationships and sustaining involvement of stakeholders over time [32, 127, 129, 131, 132]. Enrolment relied on gatekeepers and the use of snowball and network

TABLE 2 Summary of policies that explicitly promote migrants' involvement in health decision-making ($n = 20$)

Reference	Author, year of publication	Title	Country/ region of relevance	Policy	Services	Research
<i>International frameworks, action plans for refugees and migrants—general</i>						
[4]	WHO, 2019	Promoting the health of refugees and migrants: Draft global action plan, 2019–2023 https://apps.who.int/gb/ebwha/pdf_files/WHA72/A72_25-en.pdf	Global	*		
[106]	WHO, 2018	Promoting the health of refugees and migrants: Framework of priorities and guiding principles to promote the health of refugees and migrants	WHO Europe	*	*	
[110]	European Health Policy Forum, 2018	EU Health Policy Platform: Call to action on migration and health	Europe	*	*	*
[111]	International Labour Organization, 2017	Promoting a rights-based approach to migration, health, and HIV and AIDS: A Framework for action		*	*	
[112]	WHO, 2018	Report on the health of refugees and migrants in the WHO European Region	WHO Europe	*	*	
[113]	Matlin et al., 2017	Charting an agenda of solutions on the health of migrants and refugees	Global	*	*	*
[115]	Grover, 2013	Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health	Global	*	*	
[121]	WHO Europe, 2015	Stepping up action on refugee and migrant health Towards a WHO European framework for collaborative action	WHO Europe		*	
[122]	UNHCR, 2012	A guidance note on health insurance schemes for refugees and other persons of concern to UNHCR	Global		*	
<i>International and national guidance documents—specific health topic/population</i>						
[108]	WHO, 2018	Health promotion for improved refugee and migrant health: Technical guidance	WHO Europe	*	*	
[114]	WHO, 2018	Health of older refugees and migrants: policy brief	EU	*	*	*
[116]	Keane, 2016	Migrant health—The health of asylum seekers, refugees and relocated individuals	Ireland	*		
[117]	Nickerson et al., 2017	Trauma and mental health in forcibly displaced populations	Global		*	*
[118]	Mental Health Reform, 2016	Ethnic Minorities and mental health: Guidelines for mental health services and staff on working with people from ethnic minority communities	Ireland	*	*	
[119]	Iglesias et al., 2012	1st Research Exchange Workshop on Social Determinants of Migrants' Health	Europe (and Asia)	*	*	*
[120]	Negro et al., 2018	EASL [European Association for the Study of the Liver] position statement on liver disease and migrant health	Europe		*	
[123]	Rape Crisis Network Ireland	Asylum seekers and refugees surviving on hold	Ireland		*	
<i>National-level policy that explicitly promotes migrants' involvement</i>						
[105]	Welsh Government, 2018	Health and well-being provision for refugees and asylum seekers	Wales		*	
[107]	Department of Justice and Equality, 2016	National Traveller and Roma Inclusion Strategy 2017–2021	Ireland	*	*	*
[109]	Health Service Executive, 2018	Second National Intercultural Health Strategy 2018–2023	Ireland	*	*	*

sampling techniques arising from these partnerships; existing relationships between stakeholders were leveraged to identify other stakeholders to be involved. Regarding the specifics of enrolling migrants, de Freitas and Martin [32] provide a detailed account of levers for migrants' motivation to get involved in a mental health initiative: there were personal reasons (e.g. to reduce isolation) and collective reasons (e.g. to have an input into adaptation and improvement of services for others). The importance of using face-to-face methods to seek out migrants who are not the 'usual' volunteers for initiatives was emphasised [32], as well as the particular barriers that can exist to engaging undocumented migrants [129, 132] and migrants with lower literacy levels [124, 132]. Either participating migrants had the language of the host country [125, 127, 129, 134] or a peer research model was used to overcome barriers that can be caused by cultural and linguistic differences [53, 125, 132, 133].

The reported *enactment* of partnerships showed strong congruence with the participatory designs, meaning that there were clear descriptions and examples of *co-production in partnerships* to inform research questions [131], recruitment [132], fieldwork [25, 125, 129, 131], analysis and/or interpretation of data [25, 53, 124, 125, 129, 131] and dissemination [131, 132]. There were examples of training migrants in research approaches or the research topic of interest [53, 125, 127, 130, 133] and training researchers and other stakeholders to strengthen their skills to work in a participatory way with migrants [25, 125]. The specific role of academics in partnerships was noted in relation to their skills to design training and fieldwork protocols to support peer researchers [25, 53], to guide data analysis [53, 131] and to incorporate the use of theory in projects [25, 32]. There were many examples of migrants and other stakeholders working and learning together to examine problems and identify solutions to progress their project and activities [25, 32, 53, 125, 127, 129, 132, 134]. Partnerships benefit from the resources migrants bring (knowledge, skills, confidence) and can also build these resources among migrants [32, 124, 127]. It was clear that creating a 'safe space' for this was key [32, 125, 133] and the richness of Participatory Learning and Action (PLA) tools and techniques to create such a safe and democratic space was notable [25, 53, 127, 129, 132, 134]. In one case, the use of peer researchers and PLA helped overcome barriers to recruiting undocumented migrants and migrants with low literacy [132]. The use of theatre performances for dissemination was another innovative methodology [133]. Thus, participatory approaches that foster partnership working combined with suitable participatory tools and techniques were a lever for enactment. It is important that there are adequate resources (staff expertise and time, finances, institutional commitment) to sustain partnerships to avoid one-off, short-term initiatives [32, 127, 129, 132, 134].

Isolating the specific impacts of migrants' involvement in a project is not straightforward, as there can be multiple contextual influences [127]. Reported *appraisals* were formal [25, 32, 127, 132] and informal [125, 129, 131, 133]. Contextual factors sometimes limited the impact of partnership working,

for example constraining the implementation of guidelines and training initiatives in some primary care settings due to policy changes or financing models. This can cause disappointment and research fatigue that become a barrier to migrants' involvement in subsequent projects, although this is not always the case [129]. Further, the extensive time commitment required for participatory work, particularly for healthcare personnel, is a barrier that needs attention to support the use of partnerships [25, 127, 132, 134]. The positive, tangible outcomes for project goals included guideline development [53], adaptations to healthcare services [32, 127, 129, 134] and completed fieldwork to inform policy in areas such as gender and sexual-based violence [130], health insurance [125] and mental health [133]. There were positive tangible outcomes for migrants including reduced social isolation [32, 131, 132], an art exhibition with positive portrayals of asylum seekers [131], research methods skills [129, 131–133], and enhanced health literacy and self-management skills [32]. In terms of unanticipated 'ripple effects' that are characteristic of participatory approaches [23], there were examples of increased agency, ownership, empowerment and confidence [32, 127, 131, 132]. There were also positive organisational ripple effects including service developments and new collaborations and actions for evidence-based policy [32, 127, 133].

DISCUSSION

This comprehensive narrative review of migrants' involvement in health decision-making found that while there are relevant policies promoting migrants' involvement at regional and global levels, there is a dearth of national-level policies. Evidence in English-language publications was found across almost half of the countries in the region, in the domains of policymaking, service development and research. A theoretical analysis of levers and barriers to migrants' involvement in practice highlights a strong pattern of participatory research projects in primary care. The intersectoral partnerships and commitment to co-production that participatory designs promote *became a lever* to address all sorts of barriers to enrolling stakeholders and enabling them to work together. There was evidence in these participatory projects of positive impact on research, service adaptations and policy dialogues as well as on migrants' personal and social circumstances.

We found evidence of some policies and guidance promoting the involvement of migrants in health decision-making in the region. It is positive to see international policies as well as ones from professional organisations that offer guidance about specific groups of migrants/for specific healthcare professionals. The lack of *national policies* is notable and is in line with previous analyses [51, 52]. Interestingly, in spite of not having a comprehensive policy environment as noted in the 2016 MIPEX analysis [52], there is a good degree of activity in practice. We identified migrants' involvement in health decision-making in almost half the countries in the

TABLE 3 Summary of peer-reviewed empirical papers analysed for levers and barriers to migrants' involvement in health decision-making in practice

Reference	Countries studied	Nature of migrants' involvement: research approach	Primary focus of the paper
Teunnisen et al., 2017	Austria, England, Greece, Ireland, the Netherlands	Involving migrants in participatory research to implement guidelines & training to improve communication: PLA	Process and outcomes of migrants' involvement on the adaptation and implementation of guidelines and training
Keygnaert, Vettenburg and Temmerman, 2012	Belgium, the Netherlands	Involving migrants as co-researchers in a study about gender based and sexual violence: Community Based Participatory Research (CBPR)	Findings about gender-based and sexual violence
Clini et al., 2018	England	Involving migrants as co-researchers to examine the impact of creative arts-based programmes on health and well-being: Participatory Action Research (PAR)	Findings about impact of creative arts-based programmes on health and well-being
De Freitas and Martin, 2014	Portugal	Involving migrants in a mental health advocacy project: participatory research	Findings about migrants' participation in the hybrid participatory space
O'Donnell et al., 2016	Ireland	Involving migrants in service planning for local primary care team using PLA	Analysis of migrants' access to primary care services and implications for service development
Gottlieb et al., 2017	Israel	Involving Eritrean asylum seekers in an assessment of their health needs and willingness to pay for health insurance: CBPR approach	Analysis of asylum seekers' health needs and willingness to pay for health insurance
Van den Muijsenbergh et al., 2020	England, Greece, Ireland, the Netherlands	Involving migrants in a follow-up analysis of a participatory implementation research project to improve communication in primary care consultations: PLA	Analysis of whether positive changes were sustained and whether there were ripple effects from the participatory approach adopted
de Brún et al., 2017	Austria, England, Greece, Ireland, the Netherlands	Involving migrants in participatory research to implement guidelines & training to improve communication: PLA	Analysis of stakeholders' experiences of PLA dialogues
Quinn, 2014	Scotland	Involving refugees and asylum seekers in a study to explore their beliefs and attitudes to mental health problems, and their experience of stigma and discrimination and of seeking help: CBPR	Findings about beliefs and attitudes to mental health problems
O'Reilly-de Brún et al 2015.,	Ireland	Involving migrants in the development of guidelines for enhancing communication in cross-cultural general practice consultations: PLA approach	Findings about best practice to support communication for inclusion in the guidelines

(Continues)

TABLE 3 (Continued)

Reference	Countries studied	Nature of migrants' involvement: research approach	Primary focus of the paper
O'Reilly-de Brún et al., 2016	Ireland	Involving migrants in the development of guidelines for enhancing communication in cross-cultural general practice consultations: PLA	Description and evaluation of PLA approach, tools and techniques used to involve migrants in the research
Lionis et al., 2017	Austria, England, Greece, Ireland, the Netherlands	Involving migrants in the selection of guidelines and training to implement in primary care to improve communication: PLA	Process and outcome of involving migrants in the selection of guidelines and training to implement in primary care to improve communication
O Reilly-de Brún et al., 2018	Austria, England, Greece, Ireland, the Netherlands	Involving migrants in participatory research to implement guidelines & Training to improve communication: PLA	Analysis of PLA approach, tools and techniques to support inter-stakeholder dialogues
Kim et al., 2020	Kyrgyzstan	Involving migrants in an exploration of migrant child health: CBPR	Process and outcome of a CBPR approach to intervention mapping for child health in migrant communities.

region in at least one of these areas: policymaking, service development and research. It is encouraging that analysis of the most recent country reports for MIPEX found evidence of improvements in migrants' involvement in several countries including Turkey, Greece, Slovakia and France [135]. It remains a concern, however, that there is not an even pattern of involvement across the region and that it is more likely to be for service development, rather than policy or research. This resonates with findings in the literature that migrants' involvement in health decision-making is rare [52, 74] and requires attention.

Our analysis goes beyond the 2016 MIPEX analyses because we communicated with WHO National Focal Points for country-specific information in WHO Euro countries that were not in the MIPEX project. Further, we completed a theoretical analysis of peer-reviewed empirical reports of migrants' involvement in decision-making in practice. The broader field of user involvement is frequently criticised for tokenism and lacking examples of meaningful involvement [16, 22, 23]. It is striking that our NPT analysis of implementing migrants' involvement in health decision-making in practice in this review shows evidence of effective participatory projects in eight countries with a variety of kinds of migrants from 29 countries of origin. It was encouraging that participatory designs and the inter-sectoral partnerships and a commitment to co-production that they promote *became a lever* to address all sorts of barriers to enrolling stakeholders and getting the work done together.

There were multiple examples of strategies to overcome language and cultural differences, power asymmetries or problems with representation. While the findings of our analysis are not indicative of the nature or quality of migrants' involvement in health decision-making in all settings, *they overturn the notion that migrants' involvement is less feasible than that of other population groups* because migrants are perceived to be 'hard to reach' [33] and *provide an imperative for promoting participatory approaches to projects in this area*.

Findings about contextual factors constraining or limiting the impact of participatory projects suggest that achieving concrete changes is best understood as a *goal* rather than a *guarantee* [136]. At the same time, initiatives are needed to minimise such contextual constraints so that the full potential of participatory approaches may be realised. Finally, adequate financial and human resources to support healthcare professionals' involvement in participatory projects are needed to enable inter-sectoral partnerships to benefit from their perspectives in the co-production processes [137]. Adequate resource allocation is also needed to foster the *continuity* of good migrants' involvement practice and to facilitate its *scaling up* to national and regional levels [49].

Following the principle of migrants' involvement in health decision-making, migrants should be involved at the beginning of all partnership and project development in relation to their health. It would be valuable to conduct

a comparative analysis of migrants' involvement in health decision-making in research, policy and practice activities. Each of these is a distinct form of participation [74, 137] with distinct dynamics and processes. Therefore, impacts may vary across them.

While we are aware that information may exist in languages other than English, the finding that references were identified in only 30/53 countries in the WHO European Region points to the need for support by a large share of WHO European Region's countries to adhere to WHO's recommendations to promote migrant involvement in health governance. There is a need to encourage member states to develop national policies to involve migrants in health decision-making. It would be valuable to create networking opportunities so that countries with more experience in the field can provide guidance and insight into others using the findings of this review (e.g. Table S3). In all countries, there should be an emphasis on the development of implementation plans and participatory projects to move past the current policy–practice gap. Training in participatory approaches to involving migrants in health decision-making is required. Formal appraisals of migrants' involvement in health decision-making should be conducted to document the range of intended and unanticipated ripple effects.

A limitation of this research was that it was restricted to English, selected databases and the WHO European Region. There may be evidence reported in other languages, sources and jurisdictions that are not included in our analysis. Thus, while we have numerically presented the proportion of countries in which such participation has been observed, this does not mean that participation is absent from the countries not mentioned. The 2020 MIPEx Health Strand was not available at the time of our search, and its findings are not included in our analysis. In our analysis of migrants' involvement in practice, we did not distinguish between different kinds of migrants (e.g. international vs national; migrant workers compared with people seeking protection). There may be shared or differential experiences that have not been identified here, and it would be valuable for future studies and literature reviews to analyse this closely.

The analysis of levers and barriers to implementation focused on peer-reviewed research; an analysis of the grey literature references might have provided additional evidence. The lack of data about NPT's sense-making construct in the peer-reviewed literature means that our analysis and interpretation are based on evidence for theoretical analysis rather than a complete theoretical analysis of migrants' involvement in health decision-making.

In conclusion, comprehensive implementation of policies (international, national, for professional groups, etc.) would mean that migrants' right to participate in health decision-making is equitable and not a function of the country that they are living in. It is necessary to develop explicit national policies promoting migrants' involvement in decision-making about policies, services and research and to ensure that they are implemented evenly in all countries

in the WHO European Region. Participatory approaches to involvement activities and research about involvement are encouraged because they lift perceived barriers to migrants' involvement. Allocation of human and financial resources is key to implement and sustain such participatory approaches with migrants.

ACKNOWLEDGEMENTS

David Ingleby for support with our MIPEx 2020 analysis; Meghan Gilfoyle for support with preparation of the manuscript. The work was funded by Health Research Board Grant HRA-PHR-2015-1344; Health Research Board and Irish Research Council Grant PPI-2017-009; University of Limerick. Open access funding provided by IReL.


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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.