



## Transforming health policies through migrant user involvement: Lessons learnt from three European countries

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### ABSTRACT

Designing and implementing equitable health policies requires the involvement of all stakeholders. However, disadvantaged groups are under-represented in European health participatory mechanisms. Migrants and ethnic minorities (MEMs), for example, are consistently left out of policy-making fora. Additionally, MEMs lack a voice on the programmes that are intended to benefit them. This can jeopardize the responsiveness of health policies to MEM needs and undermine the development of diversity sensitive care, making way for increased inequities in health. It is necessary therefore to investigate innovative strategies capable of fostering MEMs' participation. Community psychology is particularly promising in this respect as it aims to mobilize the resources that communities possess, rather than simply teaching people to use services developed by others. Moreover, it highlights collaborative/participatory research approaches, which privilege the involvement of all stakeholders. By employing a community psychology approach, this paper looks at three European countries –the Netherlands, Norway and Spain– and summarizes lessons learnt from their experiences with migrant user involvement. The cases reported address different aspects of involvement, including: community mobilization, sociopolitical development, and creation of community alliances and coalitions. Its analysis offers several insights that can transform policy-making into a more inclusive process.

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### La transformación de las políticas sanitarias mediante la implicación de los usuarios inmigrantes: lecciones aprendidas de tres países europeos

#### RESUMEN

Diseñar y poner en práctica políticas sanitarias justas precisa de la participación de todos los interesados. No obstante, los grupos desfavorecidos están infrarrepresentados en los mecanismos europeos de participación sanitaria. Por ejemplo, los inmigrantes y minorías étnicas quedan sistemáticamente apartados de los foros de diseño de políticas. Además, estos grupos carecen de opinión sobre los programas pensados en su beneficio, lo cual impide una respuesta de las políticas sanitarias a sus necesidades a la par que frena el desarrollo de una asistencia que tenga en cuenta la diversidad, dando origen a mayores injusticias en sanidad. Es necesario pues investigar en estrategias innovadoras que impulsen la participación de los inmigrantes y minorías étnicas. La psicología comunitaria es especialmente prometedora al respecto ya que busca movilizar los recursos propios de las comunidades más que enseñar a la gente a utilizar los servicios desarrollados por terceros. Además, recalca los enfoques de investigación colaboradores/participativos que privilegian la implicación de los interesados. A través de un enfoque de psicología comunitaria, este trabajo contempla tres países europeos –Holanda, Noruega y España– y resume las lecciones aprendidas de su experiencia con la participación de los usuarios inmigrantes. Los casos aportados abordan diversos aspectos de la participación, como la movilización comunitaria, el desarrollo sociopolítico y la creación de alianzas y coaliciones comunitarias. El análisis ofrece algunas ideas que pueden transformar el diseño de las políticas en un proceso más integrador.

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Designing and implementing equitable policies requires the involvement of all groups of beneficiaries and stakeholders (Gbkpi & Grote, 2002; Papadopoulos & Warin, 2007). However, disadvantaged user groups continue to be under-represented in the European health participatory sphere. Migrants and ethnic minorities (MEMs), for example, are consistently left out of policy-making fora (Crawford et al., 2003; De Freitas, 2011; Lohman et al., 2000) and they lack a voice over the policies and programmes that are intended to benefit them (Mladovsky, Rechel, Ingleby, & McKee, 2012).

Lack of clarity on the concept of representation and concerns about the representativeness of the lay citizens who take part in participatory fora have been found to lead to a devaluation of user involvement (Snape et al., 2014). Moreover, systematic under-representation of some groups can jeopardize the responsiveness of health policy and put at stake the development of diversity sensitive care, making way for increased inequities in health (WHO, 2006). It is necessary therefore to investigate the factors that enable MEMs' to get involved in health participatory mechanisms and to identify innovative strategies that can foster their participation in the design and implementation of health policy. This article looks into these matters by taking a community psychology approach to examine successful cases of migrant user involvement in three European countries – the Netherlands, Norway, and Spain. The analysis of these three cases offers several insights that can be used to transform policies toward more inclusive and effective citizen involvement in health policy and planning.

### Migrant User Involvement in Health Policy

Involving migrant users in health policy-making is a big challenge to those in charge of developing user involvement policy. Many barriers need to be overcome in order for health participatory mechanisms to become representative of Europe's increasingly diverse citizenries and to enable the various social groups to influence policy-making. In this section, we justify the need to redefine the concepts "health policy", "user" and "involvement" to include the notions of equity and cultural sensitivity. This redefinition is essential to problematize the challenge of promoting migrant users' involvement in an adequate way and to attempt to deal with it. We do this in light of a debate initiated by two European research initiatives – the COST Action IS1103 Adapting European Health Systems to Diversity and the EQUI-HEALTH action – that aim to assure the sustainability of healthcare systems as well as their sensitivity to cultural diversity.

**Health policy.** The Oxford English Dictionary defines policy as "a course or principle of action adopted or proposed by an organization or individual". Following this, health policy could be defined as course of action taken by an organisation or individual to address issues related to people's health or well-being. This definition is somewhat simplistic, however. According to Ingleby (2012), health policies are a product of actions by several actors. They result from actions by supranational agencies and national, regional and local authorities, as well as by professional, educational, research, and civil society organisations, as all these actors play a role in and share responsibility for health. This is all the more evident if we understand equity in health as the absence of avoidable differences in health status between different populations and equitable healthcare as different care for different needs. Consequently, the concept of health policy needs to be understood under a multilevel perspective, which highlights the complex interdependence of multiple stakeholders in adapting healthcare systems to diversity. These stakeholders include, among others, members of migrant and ethnic minority groups whose voices need to be heard when developing and implementing health policy (Ingleby, 2012).

**User.** The notion "user" has been employed to mean many different things. Sometimes the concept is used to refer to patients

(or consumers) who use healthcare services. Other times it is employed to refer to the whole community (or citizens) to whom healthcare services are – or should be – accountable. The distinction between *patients* and *communities* is crucial: if only patients were involved in healthcare governance, there would be no input from other citizens in the community who do not use healthcare services, but perhaps need to, and would probably be more willing to do so if those services were better adapted to their needs. Ignoring this can lead potential service users, who are formally entitled to use healthcare services, to feel that those services do not respond to their needs and, as a result, to continue excluding themselves from using them, as well as from taking an active role in their governance. Hence, the way in which the term "user" is defined has an influence on who is entitled to receive healthcare, the degree of care accessibility (in terms of coverage and affordability) and the responsiveness of the services offered to the communities.

Migrants from low-income countries are often confronted with situations at the host country in which their rights are ignored, if not violated. A clear example of this is the adoption of recent cuts on healthcare entitlements in several European countries that target migrant groups specifically. But there are also examples in which the formal acknowledgement of cultural diversity has produced a paradoxical effect, namely, the exclusion of the most vulnerable among formally recognised ethnic minority communities. This has been the case, for example, of Roma citizens coming from Eastern Europe, who face difficulties in having their right to healthcare recognised because of national gipsy minorities' full claim over the existing resources.

**Involvement.** The debates described above are supplemented by what is usually designated as "involvement" or "participation". Two broad perspectives on user involvement can be distinguished: consumerist and democratic (Conklin, Morris, & Nolte, 2001). From a consumerist perspective, user involvement is viewed as an expression of needs, requirements, or demands that influence service outcomes. This is a top-down approach in which participation is externally driven. It consists of engaging patients or potential consumers in discussions about healthcare issues with the purpose of eliciting their views and opinions about the services provided, so that the outcomes of clinical practice can be improved. This may lead to a number of problematic situations, including: lack of commitment by healthcare providers and inappropriate development of participatory initiatives; participation by users aimed solely at solving their own problems, rather than representing an interest group; and, an over-representation of powerful user associations, to the disadvantage of less resourceful associations as is usually the case with the associations that represent migrant and ethnic minorities. These and other problems account for an imbalance of power between users and service providers that discourage the effective participation of users in improving services and perpetuate the *status quo*.

Some of these limitations can be overcome through a democratic approach to involvement. Democratic participation is a bottom-up approach, based on the notion of sharing power. According to this view, users have the right to be involved in the decisions that concern them and a duty as citizens to participate in shaping society. The core assumption here is that the empowerment of vulnerable groups allows them to recognize the sources of their disadvantage and to become actively engaged in changing them and in defining the course of their lives. But democratic involvement of migrant users implies the need to overcome several barriers such as lack of information about participatory mechanisms, fear of stigmatization (e.g., associated with exposing one's mental illness), limited language skills; digital exclusion; limited knowledge of one's rights, and insufficient resources to exercise influence (De Freitas, 2011, 2013). For these reasons, the use of standard methods to implement participation may not help much in improving the accessibility and quality of healthcare services for groups such as migrants and ethnic minorities. Moreover, setting up a

dialogue with communities is much harder than getting in touch with patients. Whether the focus is on patients or communities, special efforts have to be made to ensure a significant contribution from under-represented minority groups.

### **The Community Psychology Approach to Migrant User Involvement in Health Policy**

Community psychology (CP) offers a pivotal perspective to address migrant user involvement in health policy as it adopts a social justice approach that encourages the psycho-political empowerment of the citizenry. Justice is about “the fair and equitable distribution of resources and about the fair and equitable treatment of other human beings” (Prilleltensky, 2012, p. 9). Social justice approaches aim to ensure that all citizens are treated fairly by social systems, that they have full access to community services and resources, and that they receive equitable treatment and good quality care. In practice, however, these conditions are far from being met. Strong evidence suggests that immigrants experience discrimination in their everyday life, from seeking services to accessing goods (Balcazar, Suarez-Balcazar, Taylor-Ritzler, & Keys, 2010; Suarez-Balcazar & Kinney, 2006). Studies also show that racism and discrimination are important factors contributing to widespread health inequities (Brach & Fraserirector, 2000; Braithwaite, Taylor, & Treadwell, 2009).

A key principle of CP is that all social groups have the capacity to resist and repel unjust living conditions and to struggle to improve their health and well-being. CP has shown that cultural sensitivity in health and social care services, for example, is associated with the mobilisation and active involvement of ethnic minority groups in policy development. In previous studies, we observed how migrants themselves became active agents of transformation in the community services which oppressed them (García-Ramírez, Hernández-Plaza, Albar, Luque-Ribelles, & Suárez-Balcázar, 2012). Furthermore, CP shows that healthcare services that are sensitive to diversity contribute to migrant users’ process of liberation, fuelling their well-being as a consequence (*ibid.*). Paloma, García-Ramírez, de la Mata, and Asociación AMAL-Andaluza (2010), for example, show how a group of Moroccan migrant women increased their level of well-being by carrying out effective actions, adjusted to their needs and values, in order to overcome oppressive conditions in the Spanish receiving context. They also observed that citizens’ perceived ability to influence public policies is associated with higher levels of perceived health and well-being (Paloma, García-Ramírez, & Camacho, *in press*). Likewise, Balcazar et al. (2012) in the United States described how a group of Latino migrant parents whose children had disabilities developed critical awareness that led them to take action to increase their access to the social activities that their children needed. These examples provide evidence of the key role played by oppressed groups in transforming adverse social structures at the receiving countries. They also show how migrants’ well-being is, in part, a function of their ability to overcome the unjust contextual conditions that confront them.

CP can play an important role in assisting migrants and other oppressed groups in getting involved in transforming healthcare policies. Community psychologists are some of the strongest proponents of utilizing collaborative approaches such as community-based participatory research (CBPR) to facilitate the involvement of marginalized groups. CBPR has been widely employed to provide migrant populations with opportunities for action to identify, articulate, and address their concerns (Balcazar et al., 2012; Garcia-Ramirez, de la Mata, Paloma, & Hernandez-Plaza, 2011). They hold thus great potential to enable the participation of these groups in the formulation and implementation of health policy.

To summarise, CP looks at user involvement as a process of psycho-political empowerment that enables individuals to become

active members of society, as well as political actors capable of contributing to the development of a diversity sensitive healthcare system. This process implies a new vision of the world, and of citizens themselves, that can be achieved through increasing critical awareness, changing social references, reconstructing personal resources and acquiring agency to deal with new challenges and attain new objectives. User involvement also enables civic actions targeted at changing policies and establishing participatory healthcare governance. User involvement thus is a process by which citizens acquire social support and opportunities for developing competence, commitment, and mutual responsibility in decision-making processes as well as the power to negotiate entitlement and equal access to diversity sensitive healthcare services (García-Ramirez et al., 2011). In other words, CP views user involvement as a process that can enable “transformative policy change” (Nelson, 2013).

**Transformative change in policy.** Critical approaches to policy describe it as an activity or practice, and not just as a mere statement of intent. The following notion of social policy proposed by Westhues (2012) acknowledges this seemingly self-evident (but often neglected) feature of policy. Furthermore, it goes beyond the somewhat narrower focus of health policy, which is usually centred on health and healthcare, to address also issues of well-being and security, which are of significant importance to the health of the whole population, and especially to newly arrived migrants.

“Social policy is a course of action or inaction chosen by public authorities to address an issue that deals with human health, safety, or well-being. These public authorities include those who work directly with service users, bureaucrats working in international organizations and at all levels of government, and elected officials. Policy decisions at the international and governmental levels reflect the values acceptable to the dominant stakeholders at the time the decision is taken. Decisions taken by front line workers may reinforce the intent of these policy decisions, or may resist it when they are understood to be inconsistent with the values of the front-line professionals” (Westhues, 2012, p. 6).

This notion of social policy highlights two aspects of policy decision-making that are particularly relevant to this paper. First, it stresses a multilevel perspective to policy-making ranging from local to international levels. Second, it draws attention to the multiple actors involved in policy decisions, emphasising the fact that policy decisions, which do not reflect people’s values, may be defied, namely, through acts of civil disobedience. Indeed, civil disobedience linked to austerity-driven healthcare reforms appears to be on the rise in several European countries. In Spain, for example, medical doctors have refused to comply with governmental directives issued in 2012 to take away the right to healthcare of undocumented migrants. These instances of active refusal to obey what is perceived as unjust directives render evident the intricacies of policy decision-making. They also attest to the complexity involved in bringing on transformative changes in policy.

“Transformative policy change” is a term coined by Geoffrey Nelson (2013) to refer to changes in policy that incorporate the views of multiple actors and resort to the best available evidence, while aiming to accommodate people’s values and to give them real power to influence the decisions that impact their lives. According to Nelson, transformative changes in policy can benefit from an evidence-based approach and a discursive approach. The former asserts that policy should be informed by research-based evidence (Pawson, 2006). Those who produce research evidence may require training on knowledge transfer, as the presentation of research results is not always intelligible to lay people. Moreover, researchers need to be aware of, and cautious about, the way problem framing impacts on results as this can cause biases and irreparable harm. The discursive approach understands policy-making as a political and

value-laden process that deals with a choice of directions and, as a result, can bring advantage to some groups and disadvantage to others. This approach also highlights the need to understand discourse not as reflective of objective social problems, but as a reality itself, which needs to be explained and taken into consideration (Fisher, 2003). Achieving transformative policy change depends thus, as Nelson (2013) explains, on three fundamental processes: (1) explicit problem framing, (2) citizen participation in policy formulation, and (3) an allocation of the resources necessary to policy formulation and implementation.

Transforming healthcare policies to become more sensitive to diversity requires us to understand that engaging all stakeholders in policy-making is key to the success of the process but it is also one of its biggest challenges. Contexts of diversity are complex settings characterized by a plurality of legitimate perspectives. Consequently, there is neither one way of looking at a particular problem nor can there be the expectation that one simple solution will fit with the needs and interests of all those involved. Achieving transformative policy change requires that the various stakeholders participate in exchanging viewpoints and arguments within an empowering and organized participatory environment open to everyone and based on the values of effective partnership (e.g., reflexivity, respect for difference, mutual commitment, collaborative work) (Pedregal et al., 2011). The involvement of citizens in this process necessitates an adequate allocation of resources as well as citizens' ability to take control of the resources they need to influence decision-making. Furthermore, citizen involvement in transformative healthcare policy-making needs to be implemented as a process of community mobilization leading to the development of critical awareness and collective commitment and action.

### Cases of Migrant User Involvement in three European Countries

In what follows, we look at three European countries where healthcare systems reform is taking pace as a result of economic crisis – the Netherlands, Norway and Spain – and summarize the lessons learnt from their experiences with migrant and ethnic minority user involvement. The cases reported address different aspects of participation including: (1) community mobilization (the Dutch case), (2) stakeholders' sociopolitical development (the Norwegian case), and (3) the creation of community alliances and coalitions (the Spanish case).

**Community mobilization for mental health promotion among Cape Verdean immigrants in the Netherlands.** MEMs in the Netherlands are insufficiently involved in healthcare governance (De Freitas, 2011; Lohman et al., 2000). However, there are a few relevant exceptions. Here we examine the experience of a community-based advocacy project that succeeded to foster the participation of immigrants from Cape Verde in mental health promotion. This initiative was named Project Apoio, which means 'support' in the Portuguese language.

Cape Verdean immigrants in the Netherlands are a minority among minorities. For many years, they were known as 'silent migrants': the relative small size of the Cape Verdean community, its spatial concentration in Rotterdam and its lack of assertiveness in claiming rights made Cape Verdeans somewhat invisible to public authorities (De Freitas, in press). Until the mid-1990s, the Cape Verdeans were excluded from the Rotterdam's public health authority 'city health inquiry' and from the local health policy plan (Butte, 1991; Strooij, 1996). When the first studies came out in the early 2000s, it became clear that Cape Verdeans reported a high rate of psychosocial problems (Huiskamp, Vis, Swart, & Voorham, 2000) but they did very little use of mental healthcare services (Dieperink, Van Dijk, & Wierdsma, 2002). Later studies indicated that Cape Verdeans' access to mental healthcare was limited by various barriers

including the stigmatisation of mental illness, lack of information about mental healthcare and difficulties in navigating the Dutch healthcare system (De Freitas, 2005, 2006). These inequalities in access to healthcare, which also affect other MEM groups in the Netherlands (Ingleby, Chimienti, Hatziprokopiou, Ormond, & De Freitas, 2005), led many Cape Verdeans to seek care across Dutch borders (Beijers & De Freitas, 2008). For some, this carried emotional and financial costs that were not easy to overcome (De Freitas & Mendes, 2013). Realising these problems, the advocacy organisation for mental healthcare users in Rotterdam – Basisberaad GGZ Rijnmond – and the umbrella organisation for Cape Verdean associations in the Netherlands – Avanço Foundation – joined efforts to set up Project Apoio in 2000.

Project Apoio was a community-based intervention designed to increase the responsiveness of mental healthcare and to promote Cape Verdeans' psychosocial well-being (De Freitas, 2011). Adopting a community mobilization approach (Fawcett et al., 2000), the project began by hiring a social worker of Cape Verdean origin and assigning her the task of building a close partnership with the Cape Verdean community to assess its needs and assets.

Cape Verdeans were encouraged to take part in defining problems, designing solutions and making decisions from the project's onset. One of its first initiatives was an invitation made to the community to choose the project's name. This was done through a contest in the Cape Verdean radio in Rotterdam. Following this, the project promoted the creation of a user committee – Comissão de Apoio – to decide upon and implement the project's aims and to participate in the recruitment of new members. Over time, the committee grew to include twenty 'experts by experience' who took the task of going into the community to share their knowledge about mental ill-health and recovery. This entailed visiting people in their homes, hosting a radio programme about mental illness and inviting community members to a theatre play about psychiatric advanced directives, which was written and acted by committee members themselves. It also involved the organisation of information sessions aimed at raising Cape Verdeans' awareness to the sources of their disadvantage (e.g., discrimination, limited access to care) and to the participatory mechanisms they could use to change them. Planning and implementing these actions enabled committee members to acknowledge their rights and to acquire organisational and communication skills, which are all crucial resources to exercise influence over decision-making. For several of them, this was also a highly empowering experience: mobilising other members of their community to exercise a more full citizenship made them feel more confident in their ability to act and to take charge of their lives.

Apoio's members were also engaged in advocacy actions to increase diversity competence in mental healthcare. To that end, they organised public debates that enabled the community to come together with health officials, mental health professionals, local politicians, and academics. These encounters had a very positive outcome: the creation of a therapeutic group at a mental healthcare service in Rotterdam designed specifically for Cape Verdeans. This initiative resulted from a collaboration between Apoio and a psychologist committed to community intervention who took the challenge of tailoring care to Cape Verdeans' needs, namely, by employing an approach (i.e., group therapy), language (i.e., Portuguese and Cape Verdean Kriol) and terminology (e.g., using the term 'stress' instead of 'mental illness') that made sense to them.

Despite many accomplishments, Project Apoio ceased to exist in 2009 when the organisation that hosted the project went bankrupt and no other organisation showed interest in collaborating with its members to guarantee its sustainability.

**Stakeholders' sociopolitical development through a community health promotion centre in Norway.** In 1994, a walk-in clinic called *Workshop of Primary Healthcare (PMV)* was

established in Old Oslo, an east-end, inner-city borough of the Norwegian capital – long regarded as one of the most deprived areas in town, and with an immigrant population around 30%. At that time epidemiological studies had begun to uncover alarming, and still growing, differences in life expectancy between people living in this area and the inhabitants of more affluent areas in Oslo West. Increased spending on social welfare had put other services like disease prevention and healthcare under pressure and healthcare workers were frustrated because *our* best solutions to what we [professionals] perceived as their problems were offered without the expected response. With financial support from the *Old City of Oslo Project*, and aiming for better dialogue and enhanced collaboration between clients and providers, we sought to develop a centre for health promotion outside the established services – PMV. This centre became very popular among immigrant women, who got increasingly involved in health promoting work.

In hindsight, two ground-breaking questions seem to have kicked off the collaborative process. The first question was: “Are you willing to help us so we can enhance our understanding of what it is like to be an immigrant in Norway and thus perhaps be able to offer you more adequate services?” This question implies a belief that immigrant women possessed knowledge that was useful for us. The next question was triggered by their need for income: “What do you think you can do for the community that we can pay you for?” Opening negotiations, this question not only presupposed active participation from the women, but also allowed a discussion about which of their capacities would be most appreciated in a Norwegian context. The women suggested a cooking course through which they would train healthcare workers in traditional Pakistani cooking.

Due to the women’s skills, the cooking course became a great success. An external evaluation also showed that the Pakistani women enhanced their self-esteem through this undertaking. They now wanted to make their own choices, develop their language skills and step out of isolation. Parenting had become easier and, because their cooking skills were much appreciated, some even got jobs (Søholt, 1996). As part of the preparation, other professionals were invited to tell about their work and to provide information on topics the women asked for. Thus, the cooking course created a space for integration and the building of bridging social capital. But it did not stop there. Supported and supervised by the staff, the women started to organize and run health information groups in their own language. In those groups, participants acquired concepts and understandings that gave them more overview and control of their own situation and everyday life (Søholt, 1997). Focusing on the participants’ skills, the group leader inspired them to look for more opportunities for action. Many of them got committed to work on social determinants of health including social isolation, lifestyle problems, criminality (Gotaas & Højdahl, 2006) and harmful traditional practices. Several of them also got organized into women’s leagues and unions in order to support their interests.

In 1997, PMV was hosted by an NGO named *Church City Mission in Oslo*, not least because the possibility of developing and expanding this kind of initiative within formal healthcare services seemed to be virtually absent. The NGO had harboured the wish to include immigrants in its work but lacked competency at the time for such an undertaking. Today, 20 years after the project was initiated, PMV is still part of this NGO. Its staff consists of five formally educated consultants and three “cultural mediators”, i.e., lay people who made of mediation a profession and who act as mentors for more than 30 volunteers.

Over the years, cultural mediation has been formalized and made teachable. PVM developed a curriculum and provides training. To become a trainee, candidates should have trans-cultural experience, help-seeking experience and knowledge about Norwegian society and its service provision. The aim of cultural mediation is, however, not to revoke or influence decisions, but to enhance mutual

understanding so that the clients can get on with their life in a meaningful way, while the services develop skills and understanding in cultural sensitivity.

A cultural mediator can be engaged both by clients and by service providers. PMV’s independent position as part of an NGO has been an asset, and so is the mediators’ status as volunteers. But PMV is not just harboured by the NGO. Over the years, PMV has been repeatedly involved in the development of the NGO’s strategy plans. More recently, it has also encouraged and assisted the NGO in developing a plethora of centres that provide services to immigrants. Some of these centres have been opened in collaboration with the Red Cross and other NGOs. They include a walk-in clinic for irregular migrants, housing facilities for East African refugees affected by mental illness or addiction, a housing facility for poor irregular migrants, a centre that provides coaching for immigrant organizations, an empowerment centre for migrant women in Bergen (EMPO) and a rehabilitation centre for women suffering from war trauma in Mogadishu (Søholt, Ibrahim, & Hansen, 2009).

Immigrant women want, like all of us, to be seen as resourceful beings, worthy of respect. They also want their needs to be acknowledged and responded to. However, *their* needs only became evident when they had defined *their* goals, in this case to develop a cooking course for health professionals. This goal created a need for information – about customers’ preferences, how to write recipes, etc. Preparing for the cooking course took 6 months. However, it seems to have been of great importance not to stress deadlines, but to advertise the official course only when the women felt ready for it. In this project, the stakeholders slowly started to change their way of thinking when the women’s resourcefulness was made visible and the good results documented and presented, for example, in forums where political decisions were made. This suggests that external evaluations are of great importance both for keeping the process going and for making other people aware of the potential of this way of working.

#### **Promoting breastfeeding among Virgen Macarena Hospital migrant users through the creation of healthcare stakeholder coalitions in Spain.**

In Andalusia, births by immigrant women account for around 30% of the total births, with a clear trend towards further increase (Oliver, Baraza, & Martínez, 2007). Higher maternal, newborn, and child morbidity rates among immigrant women and their children are evidence of inequities and deficiencies in treatment during pregnancy, at childbirth and in the postnatal period (Machado, Fernandes, & Padilla, 2009). This was the challenge faced by nurses and midwives of the Virgen Macarena Hospital (VMH) maternity service in Seville, when they decided to revise their practices related to the promotion of breastfeeding and to develop work standards sensitive to the cultural diversity of women who become mothers.

The framework employed was supported by a re-definition of equity in healthcare based on the ‘Standards of Practice for Culturally Competent Healthcare’ proposed by the Transcultural Nursing Society (Douglas et al., 2009) and the Amsterdam Declaration of the Migrant Friendly Hospitals network. According to these standards, user involvement within coalitions helps users to be critically aware of their values and beliefs, more effective communicators (communication being understood as a symmetrical relationship), and to acquire political competence for the implementation and evaluation of culturally-relevant competent healthcare (see Wandersman, 2003; Wandersman, Imm, Chinman, & Kaftarian, 2000).

To build up this healthcare stakeholder coalition (HSC), natural alliances and people already working in breastfeeding promotion were identified and invited to join the coalition. Four nurses from the maternity service involved in breastfeeding programs, two specialized care midwives, and two primary care midwives were invited to become members of the coalition. Four physicians, two paediatricians, and two gynaecologists were also invited to

participate. Importantly, two activist immigrant women, representative of the largest immigrant groups in the area served by the VMH (i.e., Moroccan and Latin American), also participated in the process. Other members of the coalition included a representative of an association involved in the promotion of breastfeeding, the directors of the Obstetrics and Gynaecology services, a nurse from the 'Research Room', and a psychologist from the CESPYP. The maternity nurse supervisor led the coalition.

Although all members of the coalition shared a common concern with the need to promote breastfeeding among immigrant women, very soon it was clear that each group had its own particular goals. Nurses and midwives were looking for working procedures and ways of action defined and agreed with physicians and other healthcare professionals. Immigrant women wanted to incorporate their cultural practices into medical protocols and increase their opportunities to make decisions in conditions equal to those enjoyed by autochthonous women. Primary care professionals wanted to reach consensus on coordinated actions before, during, and after childbirth, with specialized health professionals at the hospital.

In order to merge the interests and needs of all the groups involved, short-term goals were defined, focusing on the need to develop abilities for collaborative work. Theoretical and practical workshops were held, focusing on collaborative work in coalitions and the promotion of sensitivity to the cultural diversity of users among health professionals. A system of communication and information within the coalition was developed, based on a list of information distribution by e-mail, a telephone list, a free access blog and a three-monthly informative bulletin. All members of the coalition were familiarized with the use of Internet and electronic mail, and were trained in communication skills in scientific and community contexts.

For the longer term, the following goals were established: (a) to integrate scientific evidence with the experience of professionals, the perceived needs identified by associations of both immigrant and autochthonous users and the resources available for implementation of actions; (b) to prepare the contexts where changes in professional practices were to happen, with the aim of facilitating their acceptance by all the professionals involved; and (c) to establish appropriate evaluation systems. Concerning the review of existing scientific evidence, users' cultural practices and living conditions were critically examined for relevance and possible incorporation in future protocols. In this way, the protocol for action was constructed on a collaborative basis. Furthermore, culturally-sensitive informative posters were prepared, focusing on breastfeeding and the work being undertaken by the coalition, and were displayed in different locations of the hospital, primary care centres, and the organizations involved in the coalition. Considerable effort was put into disseminating information verbally among health professionals. Informative leaflets on breastfeeding were also distributed, adapted to diverse cultural traditions, and translated into several languages (e.g., English, Chinese, Arabic).

Subsequently, the coalition drafted and reached consensus on a plan oriented to achieving the implementation of proposed changes in healthcare practices – the protocol. A pilot execution of this protocol was conducted over one month, followed by an evaluation of the coalition's work. This process allowed the coalition to examine critically the defined objectives, the efficacy of planned activities in the achievement of previously-defined objectives, and the possible need to make adjustments or changes in proposed actions. Collaborative work was disseminated in scientific and community meetings, incorporating the feedback obtained and the lessons learnt.

### Lessons Learnt

Migrant user involvement in health participatory fora in Europe, and elsewhere, is unquestionably scarce (Crawford et al., 2003; De Freitas, 2011; Montesanti, 2014). The exclusion of migrants and

ethnic minorities from participatory mechanisms limits the power of participation to foster transformative change in health policy and healthcare and to promote equity in health. However, this unfavourable situation can be overturned. As this paper shows, migrant and ethnic minority (MEM) groups in the Netherlands, Norway, and Spain can get effectively involved in healthcare governance. This was achieved through participatory practices such as community mobilisation, stakeholders' sociopolitical development, and community alliances and coalitions, which show great potential in enabling MEMs' participation in policy decision-making.

Further analysis of the three participatory initiatives described allows us to draw some conclusions concerning the nature of MEMs' involvement in policy-making. First, MEMs' participation tends to occur at the local level and appears difficult to scale up to the national level. This was the case with the participatory initiatives developed in the Netherlands and Spain, though less so in Norway, where the participatory process initiated in Oslo was successfully implemented in other branches of the NGO across the country, and even got an offshoot in Mogadishu, Somalia. Second, MEMs' influence lingers on the lower levels of policy-making, namely at the voluntary sector and healthcare services level. None of the groups researched had a strong enough lobby or political clout to influence policy change at the regional and national levels. Finally, policy changes driven through MEMs' involvement appear to be temporary and transitory. With the exception of the Norwegian case, neither the Dutch nor the Spanish participatory experiences benefited from continuity and their effects on policy change were transitory.

Current debates about the inclusiveness of user involvement in healthcare governance are guided by two key concerns: how to scale up best practices that enable MEMs' participation and how to equalize opportunities for influence in policy-making arenas, so that MEMs and other traditionally excluded groups can have a say over the decisions that affect their lives and produce transformative policy change. Ideally, user involvement by disadvantaged groups would emerge through the actions of grassroots movements forming to represent their rights and to pave their way into the participatory arena. However, many such groups live in highly oppressive contexts that structurally undermine their ability and willingness to come together and struggle. With this concern in mind, and taking the lessons learnt from the three cases described earlier, it might be useful to reflect upon strategies that can be employed to enhance the participation of disadvantaged groups, and more particularly of disadvantaged MEM groups. These strategies, we argue, need to focus both on user groups and on participatory mechanisms.

**Strategies to promote migrant users' involvement.** Involvement processes need to be tailored to specific communities and mindful of the social settings where they take place (Tambuyzer, Pieters, & Van Audenhove, 2014). User involvement is a value-laden, culturally and contextually bound, political concept, which is interpreted differently across social groups and cultural, organisational, and political cultures (Gaventa, 2006; Renedo & Marston, 2011; Snape et al., 2014; Tse, Tang, & Dip, 2012). Effective involvement of MEM communities thus requires an identification of the factors that drive their participation and an understanding of the ways by which culture and context impact on their willingness and ability to get involved.

The cases reported here show that MEMs' involvement is driven by a range of factors, which include: (1) users' concerns and values, (2) the skills and resources available to them, (3) the existing mobilisation capacity of their own community, and (4) the availability of opportunities for participation. Taking these factors into consideration, we suggest the following strategies to enhance MEMs' participation:

(1) Addressing communities or neighbourhoods directly and identifying small groups to initiate a process of psycho-political development, that is, to analyse their life circumstances in a non-oppressive context.

(2) Enabling these small groups to release their capacity to act (Popay, 2014) by providing them opportunities to exercise their right and duty to participate, to develop their communication, organisation, and negotiation skills, and to access information.

(3) Encouraging the various small groups to get interconnected and to constitute a pressure group to transform services and policies.

(4) Informing representatives of small groups of opportunities to participate in institutional participatory mechanisms and of how they can find their way into those mechanisms.

(5) Assessing community representatives' notions and views of involvement and whether their expectations are being met.

(6) Discussing the appropriateness of the goals set by representatives and working together to reframe unfounded expectations and goals and/or to re-direct their pursuit to more suitable channels.

In reaching out to MEM communities some issues need to be given due consideration:

(a) Approaching communities as an expert does not seem to work. Rather, one can approach them as a member of the community, who is in the position to share a specific type of knowledge and, at the same time, is willing to incorporate the knowledge of other members of the community. For this to work, it is fundamental to establish symmetric and transparent relationships, as well as to be flexible in order to adapt to the rhythm and dynamics of the community, which are often very different from the rhythms of academic institutions, healthcare services, or governmental agencies.

(b) It is crucial to initiate contact with communities through agents of the community itself, who can work as links between the community and the institutional and/or academic agents.

(c) It is important to encourage collaboration by resorting to the means of communication employed by the communities themselves (e.g., community newspapers, radios, etc.).

(d) Initiatives reaching out to communities should not be focused on a single and specific issue (e.g., health, education, etc.), but more broadly on citizens' concerns. In this way, the needs experienced by these communities can be more thoroughly identified and community members will be more likely to participate in a committed way.

**Strategies to promote inclusive health participatory mechanisms.** Two types of barriers can negatively affect the inclusiveness of participatory mechanisms and fora: barriers that impede representatives of certain groups from getting into those fora and barriers that hinder the ability of representatives to influence decision-making once they take part in participatory processes. The former set of barriers include lack of information about opportunities for participation, economic and time constraints, language barriers, opposing social norms, stigma attached to illness (e.g., mental illness), and limited self-confidence (Campbell & McLean, 2002; De Freitas, 2011; Mohanty, 2007; Sozomenou, Mitchell, Fitzgerald, Malak, & Silove, 2000). The latter barriers entail asymmetries in symbolic and material power (e.g., access to technical knowledge, status), staff's resistance to participation, inappropriate style of meetings, unattractive participatory goals and actions, failure to accommodate cultural diversity, invalidation of users' voices as unrepresentative, disempowering participatory experiences, stress, and participation fatigue (Barnes, 1999; Crawford et al., 2003; De Freitas, 2011, 2013; Lindow, 1999; Popay et al., 2010; Renedo & Marston, 2011).

Promoting inclusive participatory mechanisms requires acting on the barriers that obstruct their permeability to disadvantaged groups, and on the impediments that prevent those groups from releasing their capacity and exercising influence once they find themselves engaged in participatory processes (De Freitas, 2014; Popay, 2014). Put simply, it requires addressing issues of representation and power.

Representation issues have not been sufficiently addressed by current policy on user involvement. Service users and other members

of the community are usually treated as a homogeneous group of people when in fact they have different needs, values and interests. Lay citizens also have various types of knowledge and ways of expressing it. Yet, how the different social groups are to be represented in participatory mechanisms, how their representatives are to be selected, and how their views are to be consulted and articulated in participatory initiatives, are problems that remain unanswered. The argument that articulate service users are unrepresentative of the "common user" can be used to silence the voices that defy the *status quo* (Lindow, 1999) precisely because current policy on user involvement in healthcare governance does not deal with the issue of representation adequately.

Unequal power relationships limit possibilities for agency and voice by those at the bottom of the hierarchy and are likely to undermine meaningful and transformative participation (Cornwall, 2004), which requires a transfer of power from the "haves" to the "have-nots". Empowering all the stakeholders, who engage in participatory initiatives to listen and to make sense of each other's knowledge, values and views, is of critical concern. In view of our findings, and taking notice of the fundamental elements of transformative policy change proposed by Nelson (2013), we suggest that addressing this concern and the concerns described earlier, calls upon reflection and action on at least three fronts:

(1) Framing the problem of lack of substantive participation in healthcare governance by traditionally excluded groups (including MEMs), and other disadvantaged groups, in an appropriate manner. This might be done in light of health equity and social justice arguments, or rather by linking the systematic exclusion of some groups from participatory mechanisms to the risk of increased injustice and health inequities among these groups, as a result of upcoming policies and services becoming increasingly blind to their needs;

(2) Formulating inclusive user involvement policy aimed at fostering the representativeness of participatory mechanisms and fora and at promoting equal opportunities for influence for all those involved. This may require that participatory fora are mandated to seek representation from the various groups while safeguarding the right of other represented groups to take part in those spaces, even when not all groups are represented. It may also require that the goals of participatory initiatives, and its limitations, are made clear to all stakeholders involved so that people know which degree of influence they can expect to have and which of their concerns are likely to be addressed (Cotterell, et al., 2011; De Freitas, 2013; García-Ramírez, Paloma, Suarez-Balcazar, & Balcazar, 2009). Finally, it may be necessary to develop empowering initiatives that not only foster respectful exchange between stakeholders but also stimulate them to collaborate during decision-making processes by promoting the values of effective partnership (e.g., reflexivity, communication, mutual learning) (Nelson et al., in press). These initiatives should not be aimed solely at service users and other lay citizens. Policy-makers, managers and professionals also need to be empowered in order to be able to incorporate other types of knowledge into decision-making (Rose, Fleischmann, Tonkiss, Campbell, & Wykes, 2004).

(3) Allocating the resources necessary for transformative participation to take place (e.g., human and financial resources, infrastructure, etc.). These resources should be allocated to both participatory mechanisms instituted by the state and civil society organisations that play a key role in shaping and setting forth lay citizens' voices.

## Final Remarks

The need to open up health participatory fora to members of disadvantaged minority groups and to include them in decision-making processes has been highlighted by several policy documents and studies (CSDH, 2008; Mladovsky et al., 2012; Padilla, Portugal,

Ingleby, De Freitas, & Lebas, 2009; Portugal et al., 2007; WHO, 2010). This paper attempts to point out strategies that can be employed in the pursuit of that goal while acknowledging that there is not a single, encompassing solution to the problem of inclusiveness in health participatory governance.

### Conflict of Interest

The authors of this article declare no conflict of interest.

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