



Cultural Contexts of Health and Well-being

Toolkit, No. 1

Migration and health: enhancing intercultural competence and diversity sensitivity

ABSTRACT

Access to responsive, people-centred health systems is essential to ensure appropriate health care for refugees and migrants throughout the process of migration and settlement. Focusing on intercultural competence and diversity sensitivity, this toolkit contributes to a broader WHO strategy to develop an evidence-based response to the public health needs of refugees and migrants. Aimed at health authorities at national, subnational and local levels, as well as health care practitioners, researchers, patients and caregivers, it provides an accessible introduction to the key concepts underpinning intercultural competence and diversity sensitivity; provides an overview of the types of action that can be taken to improve health care at organizational, systemic, professional and individual health care provider levels; uses case studies to examine methods and techniques that can be used to promote migrant participation at different stages of policy and practice; and provides an overview of factors to be considered in any initiative developed to promote intercultural competence and diversity sensitivity in health care.

KEYWORDS: REFUGEES, TRANSIENTS AND MIGRANTS, CULTURAL DIVERSITY, CULTURAL COMPETENCY, CULTURALLY COMPETENT CARE

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BACKGROUND

This policy brief was developed through the WHO Regional Office for Europe. The evidence for health and well-being in context project team of the Division of Information, Evidence, Research and Innovation, including Claudia Stein (Director), Nils Fietje (Research Officer), and Andrea Scheel (Consultant), was responsible for and coordinated its development.

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Chapter 1. Introduction

Summary

It is estimated that more than 90 million international migrants live in the WHO European Region, which amounts to approximately 10% of the total European population and more than one third of all international migrants worldwide (1). The increasing diversity of populations and cultures in countries across the region creates new challenges for health care systems and providers. Although many refugees and migrants are healthy, they often face challenges and vulnerabilities that may undermine or threaten their health and well-being and impede access to appropriate health care services. Some migrant groups, such as unaccompanied minors, victims of trafficking, undocumented migrants, pregnant women and the elderly, also face vulnerabilities that require more specific forms of care and support. Importantly, even when refugees and migrants are able to access health care, the specific needs they face may be poorly understood and inadequately responded to (2).

Responding to these challenges requires that health services adapt in order to effectively provide for diverse populations and needs. Central to this is recognition of the need for intercultural competence and diversity sensitivity to be embedded within health care policy and provision.

Therefore, this toolkit has been developed to bring together information on good practice in implementing interculturally competent and diversity-sensitive health care, and to introduce tools and resources that might be applied to assist with this at various stages of the health care policy and provision process.

Background

It is estimated that more than 90 million international migrants live in the European Region, which amounts to approximately 10% of the total European population and one third of all international migrants worldwide.¹ Although particularly large numbers have arrived in the past few years, the influx of refugees and migrants into the Region is not an isolated phenomenon, but an ongoing reality that will have wider-ranging effects on European Member States in both the medium- and longer-term. Furthermore, whilst many of those arriving in the Region are young adults, there has been an increase in the demographic diversity of migrants, including many elderly and disabled persons, families and minors, many of whom are unaccompanied children.

This situation poses significant challenges to the health systems of recipient countries. Their ability to cope effectively and to fulfil the fundamental human rights of migrants is in large part dependent on the readiness of the health system, and on adequate response capabilities and effective multi-sectoral co-ordination mechanisms.

Informed by the 2030 Agenda for Sustainable Development, the European policy framework for health and well-being – Health 2020, and World Health Assembly resolution WHA61.17, WHO European Region Member States agreed at the High-level Meeting on Refugee and Migrant Health, which was held in Italy in November 2015, on the need for a common framework for collaborative action to address the public health and health system challenges presented by large-scale migration. Subsequently, a Strategy and Action Plan for Refugee and Migrant Health in the WHO European Region (2016) has been developed and adopted by all Member States, with clear priorities and actions for Member States and the WHO Regional Office to act upon.

¹ United Nations Department of Economic and Social Affairs, 2017.

Why this toolkit?

Access to responsive, people-centred health systems is essential to ensure appropriate health care for all refugees and migrants throughout the process of migration and settlement. This means that action is needed not only during the initial phases of arrival in a recipient country, but also in the medium-to-longer term.

Implementing effective action requires overcoming formal and informal barriers to health care, such as those posed by language, administrative hurdles, and lack of information about health entitlements, as well as ensuring provision of care that more directly addresses people's needs and priorities.

As the Strategy and Action Plan for Refugee and Migrant Health makes clear, achieving this requires the development and implementation of culturally sensitive approaches to health care provision. On one level, this means ensuring that people have sufficient access to interpreters and cultural mediators, and that health professionals and policy-makers receive appropriate training and support to understand and implement interculturally competent and diversity-sensitive interventions. Importantly, however, it also means fostering active and effective community participation and empowerment of migrants to ensure that their experiences and self-defined needs and priorities can be effectively responded to.

Participatory and patient-centred approaches to health care can be facilitated through diverse and innovative methods and techniques. This toolkit has, therefore, been developed to bring together information on, and experiences of, intercultural competence and diversity sensitivity, and to introduce tools and resources that might in turn be applied at various stages of the health care policy and provision process. In line with the Strategy and Action Plan for Refugee and Migrant Health, the toolkit also aims to build expertise and capacity and enable Member States to share examples of good practice on migrant health.

The toolkit has been developed by the WHO Europe Cultural Contexts of Health project, in collaboration with the WHO Migration and Health programme, as part of a broader strategy to develop an evidence-based response to the public health needs of refugees and migrants. The toolkit was piloted at the WHO School on Refugee and Migrant Health held in July 2017 in Syracuse, Italy, and revised to reflect participant feedback.

Definitions

Refugees, asylum seekers and migrants are heterogeneous groups and no universally accepted definitions of these groups exist. The working definitions of these terms as applied in this toolkit are contained in Annex 1. While in some contexts the definitions in Annex 1 may have important implications for entitlement and access to, health services, the definitions as applied in this toolkit do not denote any particular legal status or entitlement. The entitlement and access to health services for the various groups is determined by national regulations and legislation. In this document, the term migrant is used as an overarching category in line with resolution WHA61.17 (Health of migrants). Where used, the terms refugee and asylum seeker are included and applied in accordance with the 1951 Refugee Convention and as recommended by the United Nations High Commissioner for Refugees (UNHCR) and the International Organization for Migration (IOM).

Structure of the toolkit

The toolkit is divided into four parts, with further reading and additional information provided at the end of each.

- Chapter 2 provides a short introduction to the key concepts underpinning intercultural competence and diversity sensitivity.
- Chapter 3 provides an overview of the types of action that can be taken to improve intercultural competence and diversity sensitivity at organizational, systemic, professional and individual health care provider levels.
- Chapter 4 focuses on the methods and techniques that can be used to promote migrant participation at different stages of policy and practice.

- Chapter 5 provides an overview of key factors to be considered by policy-makers and practitioners in any initiative developed to promote intercultural competence and diversity sensitivity.

How to use this toolkit

This document provides a set of tools that can be used to help promote and embed intercultural competence and diversity sensitivity in health care. The tools listed are neither exhaustive nor prescriptive, but present a set of options that could be useful as an introduction to those interested in ensuring that health care is accessible, and deemed relevant and appropriate to refugees and migrants from diverse backgrounds.

The toolkit has been developed for health authorities and partners at the national, subnational and local levels to assess and optimize intercultural competence and diversity sensitivity. It can also be a useful resource for health care practitioners, researchers, patients and caregivers. The toolkit should be considered a living, flexible package which can be adapted to the national and local context. Stakeholders who are interested in implementing any of the tools, examples or opportunities outlined in this document are therefore advised to contact the WHO Regional Office for Europe to receive further information and technical support.

Chapter 3 presents a range of diagrams and case studies from across the WHO European Region to highlight how particular approaches have been applied to improve provision of health care to migrants.

Where appropriate, tools described in Chapter 4 have:

- a description and objectives section, which explains the main characteristics of the techniques;
- a methods section, providing advice on how to use the technique;
- a case study section, describing a real experience of applying the tool, good practice and lessons learned.

Chapter 5 presents an accessible checklist summary for use by policy- and decision-makers, managers and practitioners working to promote intercultural competence and diversity sensitivity.

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Chapter 2. Intercultural competence and diversity sensitivity in health care

Defining key concepts

In recent years, a number of terms have been used to conceptualize health care provision that is relevant to diverse population groups. **Cultural competence** is a broad concept commonly used to describe a variety of approaches and interventions that aim to improve the accessibility and effectiveness of health care. While precise definitions vary, most are variants of the following, conceptualizing cultural competence as:

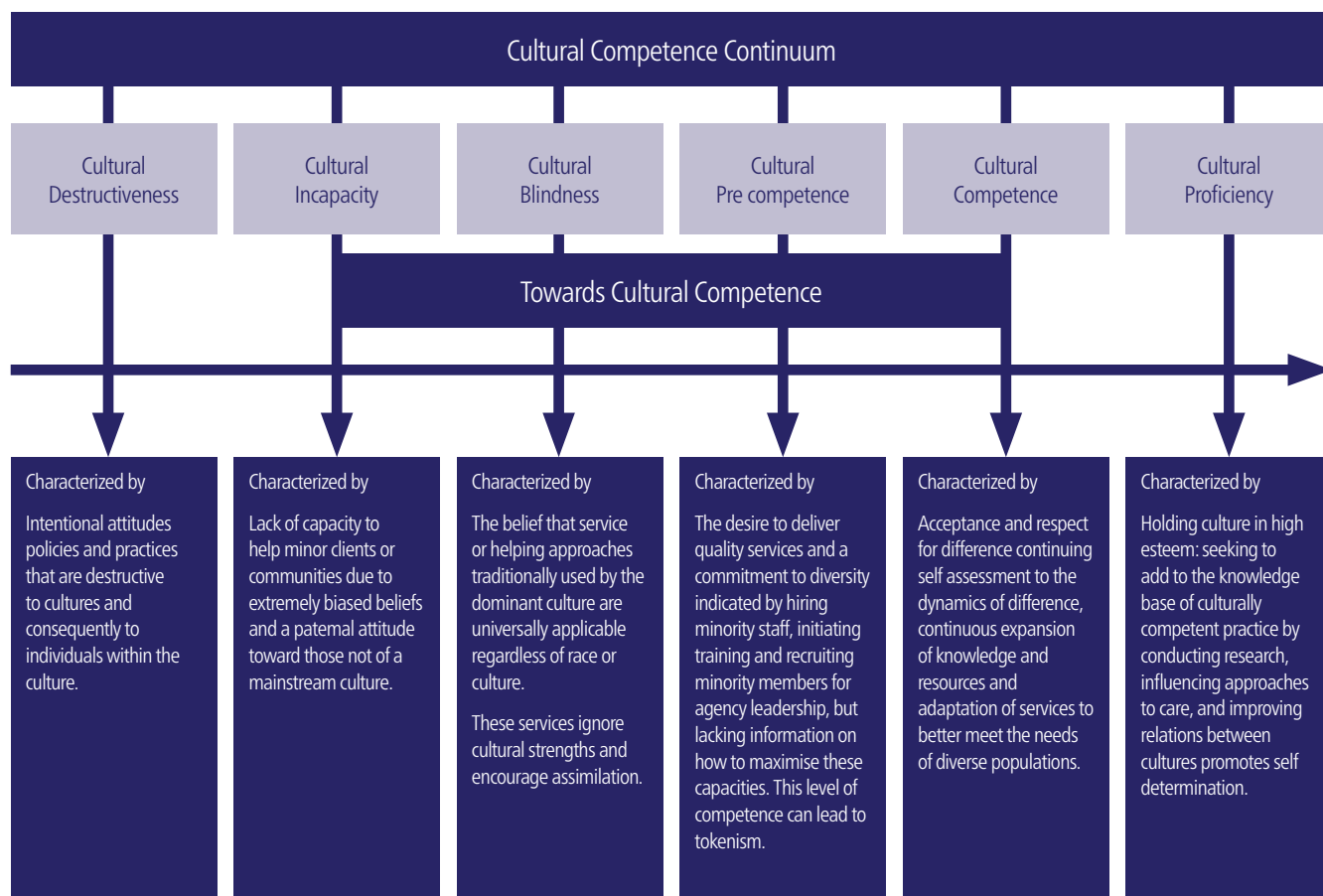
- “a set of congruent behaviours, attitudes, and policies that come together in a system, agency or amongst professionals and enables that system, agency or those professionals to work effectively in cross-cultural situations” (1);
- “[a health system that] acknowledges and incorporates – at all levels – the importance of culture, assessment of cross-cultural relations, vigilance towards the dynamics that result from cultural differences, expansion of cultural knowledge, and adaptation of services to meet culturally unique needs” (2).

Such definitions focus on the need for health professionals to be aware of culturally specific norms, beliefs and priorities, and the need for inclusive health care services for migrants and ethnic minority groups.

Different degrees of cultural competence demonstrate how different levels of engagement with culture manifest within health care systems and organizations.

This six-stage continuum in Fig. 2.1 (3) is a useful framework for providers to assess their professional and organizational level of cultural competence, and to help inform the development of culturally competent policies and practices.

Fig. 2.1 Cultural Competence Continuum



Source: (3)

Intercultural competence is similar to cultural competence and the terms are often used interchangeably. However, it is generally agreed that intercultural competence focuses more specifically on the interaction and dialogue between different cultures and the need to address health care needs within intercultural contexts. As such, intercultural competence is often considered to more effectively embrace the notion of **cultural humility**. Humility in this sense does not imply weakness or submission, rather a sense that one's own knowledge is limited (by stereotypes, and by the complexity of human identity) as to what makes up another person's culture and how they experience it.

Through acceptance of these limitations and engagement in a process of self-reflection, cultural humility can increase a person's awareness of their own biases and assumptions, and help them to learn from others, which means that the patient or client are viewed as key collaborators in the process of help and support (4).

Building on these concepts, recent years have also seen increasing use of the concept of **diversity sensitivity**. This promotes the idea that health professionals should be aware of different forms of cultural diversity – be it related to gender, ethnicity, age, socioeconomic status, religion, sexual orientation or other social markers; that difference should be integrated into the delivery of effective and equitable health care for patients; and that, regardless of its source, diversity can itself be a positive social contribution (5).

Such thinking is also linked to the concept of **patient-centred care**, which is defined as “providing care that is respectful of, and responsive to, individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions” (6). Importantly, the principles of patient-centred care reinforce the need to recognize that people should be treated first and foremost as individuals, rather than as members of particular social groups. This is also linked to the notion of **intersectionality**, which highlights how social indicators such as socioeconomic class, ethnicity and gender operate as interactive, mutually constituted identity markers that situate both individuals and groups within social hierarchies, and recognizes that effective policy and practice responses to diversity must address all contributing factors that put people at risk of exclusion.

To become more interculturally competent and diversity-sensitive, a system needs to:

- recognize and value diversity;
- have the capacity and willingness for cultural self-assessment;
- be conscious of the dynamics that can occur when cultures interact;
- adapt service design and delivery so that it positively reflects and responds to diversity between and within cultures.

Why is interculturally competent and diversity-sensitive health care necessary?

Health professionals are increasingly required to deliver care to diverse population groups. There is considerable evidence of health disparities, structural inequalities, and poorer quality health care and health outcomes amongst people from minority cultural and linguistic backgrounds. Many migrants in the WHO European Region for example, face challenges and vulnerabilities (such as language proficiency, family responsibilities, social isolation, poverty, logistical challenges) that may undermine or threaten their health and well-being and impede access to appropriate health care services. Even when they are able to access health care, the specific needs they face may be poorly understood and inadequately responded to.

Research has shown that such issues relate not only to language and socioeconomic barriers, but to ways of thinking about and understanding health and effective responses to ill health. The ways that people perceive health care services, as well as the social networks they utilize to respond to health issues may also impact upon subjective understandings and responses relating to health service accessibility and use. Research has also emphasized the importance of recognizing how expectations around issues such as diet, hygiene, confidentiality, breaking of bad news, end-of-life decisions and human dignity can present very real dilemmas in daily health care practice (7).

Therefore, responding effectively to these challenges requires that health services adapt in order to provide for diverse populations and needs.

“Equity in healthcare involves offering ‘different care’ rather than a ‘one size fits all’ approach to service provision that discriminates against those whose needs differ from the majority” (8).

Evidence demonstrating a clear link between the implementation of interculturally competent health care and improved patient outcomes is mixed (9–11). However, it is generally accepted that intercultural competence can improve health care access, utilization and provider outcomes, and that overlooking culture – or alternatively, essentializing cultural difference – can influence the likelihood of poorer health care experiences and outcomes (see Box 2.1).

Box 2.1 Cultural stereotyping

A programme for Somali Bantu refugees was developed in a community health centre near Boston, in the United States of America. The programme, which was designed to accommodate cultural distinctiveness, was challenged as providers became aware of significant cultural variation and sub-ethnic conflict within the group, and significant individual idiosyncrasy among its members. One Somali patient for example, who was identified as Bantu by the health practice, herself rejected that label, and preferred to identify with a higher-status group known as the Madibaan. She had difficulty fitting in with the larger community of Bantu refugees registered with the clinic, who she viewed as being beneath her own social status. Additionally, the Somali staff employed to provide services to Bantu refugees were a mix of both Bantu and non-Bantu identities, and often argued over who was assigned to treat patients who they did not deem to be part of their own ethnic group. In this clinic, rich data about the group-based cultural characteristics of Bantus were communicated to medical personnel ahead of time, yet this information was often not relevant or had negative effects on the daily work of the clinic. In this case, standardized cultural information led to stereotyping and was not deemed to improve the quality of care.

Source: (13) and (14).

To avoid static and narrow conceptualizations of culture, it is useful to consider a more holistic definition that conceives of culture as a way of life, rather than simply as religious, social or ethnic characteristics that are delimited by geographical boundaries. The United Nations Educational, Scientific and Cultural Organization's (UNESCO) definition is particularly useful in this regard:

[Culture is] “the set of distinctive spiritual, material, intellectual and emotional features of society or a social group, and that it encompasses in addition to art and literature, lifestyles, ways of living together, value systems, traditions and beliefs” (15).

A whole-organization approach

The delivery of interculturally competent and diversity-sensitive services requires the engagement and understanding of individual health practitioners. However, this is highly unlikely to be effective if adopted only at this level. Achieving intercultural competence and diversity sensitivity requires a systemic and whole-organization approach in which discussions, training and interventions are embedded within the policy, regulations, strategic plans and infrastructure of health care organizations, alongside the development of knowledge, skills, values and attitudes of individuals (see Box 2.2).

Box 2.2 Embedding diversity sensitivity in the United Kingdom's NHS

Since 2000, all public authorities in the United Kingdom have had a legally enforceable general duty to eliminate unlawful racial discrimination (16), to promote equality of opportunity and good relations across racial groups, and to ensure racial equality in employment, training and promotion. Within this context, the National Health Service's policies are widely considered to be amongst the most responsive to health inequalities for migrants and ethnic minorities. Of particular note is the NHS's approach to embedding diversity sensitivity at systemic and organizational levels through its Equality Delivery System and its commitment to working with the Equality and Diversity Council to create a "personal, fair and diverse NHS". Within this, health services can be inspected based on Equality Act and NHS standards, notably the Personal Fair and Diverse Toolkits and Care Quality Commission guidelines for inspection. It should be noted that despite such systemic support for diversity, migrants with undocumented or insecure legal status in the United Kingdom face restrictive policies governing access to health care.

Source: (13).

Research has demonstrated the role of social networks in spreading innovations in health care as well as the role played by health care leaders in transmitting ideas and attitudes relating to cultural competence. However, it is also the case that such links can be detrimental if the norm disseminated across professional networks does not support diversity (3, 11). As Dauvrin (11) has stated,

As with systematic hand-washing, as long as being culturally competent is not considered to be a norm in health services, it is unlikely that training health professionals will make any difference in terms of reducing health inequalities and improving quality of care.

Leadership and support at a systemic and organizational level are therefore prerequisites for the successful mainstreaming of equality and diversity issues in health services. A useful way of conceptualizing the holistic approach needed to embed interculturally competent ways of working can be envisaged using the four-dimensional model shown opposite (Table 2.1).

Table 2.1 Four-dimensional model for increasing intercultural competence and diversity sensitivity in the health sector

| Dimension | Audience | Description |
|----------------|---|--|
| Systematic | National-, subregional- and local-level policy-makers | Effective policies and procedures, mechanisms for monitoring and sufficient resources are fundamental to fostering interculturally competent behaviour and practice at other levels. Policies exist to support the active involvement of culturally diverse communities in matters concerning their health and environment. This could be facilitated through regional collaborative frameworks to adapt health systems to the needs of diverse user groups. |
| Organizational | Health care managers at the national, subregional and local levels | The skills and resources required by client diversity are in place. A culture is created where intercultural competency is valued as integral to core business and consequently supported and evaluated. Management is committed to a process of diversity management including cultural and linguistic diversity at all staffing levels. |
| Professional | Institutions overseeing health care practice, education, accreditation and professional development | Overarching the other dimensions, at this level, intercultural competence is identified as an important component in education and professional development. It also results in specific professions developing intercultural competence standards to guide the working lives of individuals. |
| Individual | Health care managers, health care practitioners | Knowledge, attitudes and behaviours defining interculturally competent behaviour are maximized and made more effective by existing within a supportive health organization and wider health system. Individual health professionals feel supported to work with diverse communities to develop resistant, appropriate and sustainable health promotion programmes. |

Source: (17).

Building on this holistic framework, the Task Force on Migrant Friendly and Culturally Competent Healthcare (18) has identified five main standards that need to be addressed to ensure the delivery of equitable services in health care (Table 2.2).

Table 2.2 Standards to ensure delivery of equitable health services

| Standard | Aim |
|-------------------------------------|---|
| 1. Equity in policy | To promote equity by providing fair opportunities, reducing health inequities, and delivering sustainable and cost-effective policies |
| 2. Equitable access and utilization | To encourage health organizations to address barriers that prevent people from accessing and benefiting from health care services. This includes physical accessibility and geographical distribution of services. It also includes improving communication and information through effective interventions to address language barriers, to improve health literacy and to address power imbalances in patient-doctor communication, improving trust, respect, openness and empathy. This standard also encourages health care organizations to take action where eligibility rules and resource barriers compromise human rights. |
| 3. Equitable quality of care | The organization provides high-quality, person-centred care for all, whilst also acknowledging individual health experiences and perspectives in the co-construction of the care process, from diagnosis to discharge. |
| 4. Equity in participation | To ensure equitable opportunity for services users and community members to participate in service planning, delivery and evaluation. |
| 5. Promoting equity | Engagement by the organization to promote equity activities in other sectors of society, through, for example, participation in networks, think tanks and research initiatives to deliver innovative services to disadvantaged populations and intersectoral collaborations to address the wider determinants of health. |

Source: (18).

The following chapters examine the key issues that need to be incorporated into health care delivery in order to meet such standards. Chapter 3 focuses on the education and training of health care professionals and managers, and the need to ensure that interpreting and cultural mediation services are appropriate and effective. Chapter 4 demonstrates a range of methods and approaches that can be utilized to help enable community participation in health care design, delivery, monitoring and evaluation.

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Chapter 3. Health sector responses

Background

Considerable attention has been given to understanding the difficulties refugees and migrants face in accessing health services. Often, such attention has focused on the logistical, resource and legal constraints faced by migrants, as well as the barriers to service provision imposed by the health sector itself. Within such discussions, the concept of health literacy is often used to refer to the knowledge and skills required for migrants to make optimal use of the health system. Very often, however, programmes of health education for migrants show little or no regard for migrants' own health beliefs, and as a result, do not succeed.

As Ingleby (1) has noted, “migrants are not empty vessels simply waiting to be filled up by Western expertise; they have their own ideas and values, which may clash with those that underlie health care. Integration of migrants into health systems can only take place through dialogue, in which both sides show respect for each other's views.”

Achieving intercultural competence and diversity sensitivity is, therefore, a two-sided process. First, it requires that health professionals be able to reflect on their own perspectives, and recognize that all forms of knowledge, including scientific and medical practice, are inherently cultural. Being culturally aware and exercising cultural humility in this way enables health professionals to recognize their own preconceptions and biases and appreciate the existence of other perspectives and understandings.

Secondly, central to this is the need for health professionals to listen to the patient, and learn about the patient's beliefs and experiences relating to health and illness. This requires ensuring that mechanisms are in place to enable patients and community members to participate in dialogue and debate that helps to shape health care responses that reflect what they consider to be their needs, their concerns and their priorities.

Taking these issues into consideration, this chapter provides an overview of the types of education and training that can help embed intercultural competence and diversity sensitivity at individual, professional, organizational and systemic health care provider levels. The need to ensure that health care systems are adequately resourced is also addressed, with focus placed on the key role played by interpreters and cultural mediators.

Education and training in intercultural competence

There is currently no standardized education and training in intercultural competence for health professionals across the WHO European Region. Although cultural diversity is included in the curricula of many medical schools, content and implementation varies widely and little has been rigorously evaluated. Some training programmes have aimed to increase attitude-based skills, whilst others have focused more on cultural knowledge and practice. Programmes can offer generic education and training to all health workers, or may be geared towards particular professionals such as nurses or pharmacists.

In all cases, it is important that education and training be embedded more firmly as core university-level courses, so that all health professionals regard intercultural competence and diversity sensitivity as an inherent part of daily practice.

To date, very little training has been geared towards health managers and decision-makers, yet involvement of these groups is vital in demonstrating institutional commitment and in embedding changes in working practice.

Existing training programmes on intercultural competence tend to focus on the needs of particular communities or social groups. For example, the cross-national Migrant and Ethnic Minority Training Packages (MEM-TP) programme has involved the development of training materials to respond to the needs of migrant groups, including refugees and asylum seekers, irregular migrants, and migrants classed as vulnerable groups, for example, children, the elderly and trafficked persons (see Box 3.1).

This can help ensure that training is geared towards the specific needs of these groups. However, care must also be taken to avoid stereotyping through the use of recipe-book approaches to working with assumed communities. A link to the MEM-TP training package is provided at the end of this chapter.

Opportunities for sharing experiences and best practice amongst health care providers can also be important, both to ensure that patients' needs are addressed, and to help embed interculturally competent working practice across health systems. Box 3.2 provides an example of this kind of knowledge-sharing that is taking place in the United States.

Accreditation for training in intercultural competence and/or diversity sensitivity is important in helping to demonstrate organizational- and systemic-level support. In the United States, for example, enhanced National Culturally and Linguistically Appropriate Services (CLAS) Standards in Health and Health Care exist alongside a blueprint with guidance and strategies to help implement them. In Europe, the Slovak Medical Chamber and Slovak Chamber of Nurses accredited the MEM-TP training programme, and in Poland, all participants in the pilot training received a diploma issued by the Medical Center for Continuing Medicine.

Box 3.1 The MEM-TP programme

From 2013 to 2016, the European Commission supported a consortium of four organisations through the MEM-TP initiative to review, develop, test and evaluate training on migrant and ethnic minority health for front-line health professionals in primary care settings. Pilot training packages were delivered over three consecutive days to a total of 208 participants in Denmark, Italy, Poland, Romania, Slovakia and Spain. Evaluation of the project revealed differences in experience across the study sites. Overall, the training worked well when targeted at a different range of health professionals together. In Italy, for example, where the public health system is decentralized, the opportunity to learn from a diverse array of trainees was welcomed by participants. In Denmark, however, some of those involved found the course content too basic and felt that different levels of training would be more appropriate. Because health professionals across the European Region have very different educational profiles and experiences, adapting to local and professional contexts is key to the effective uptake and impact of training.

Source: (2).

Box 3.2 Knowledge-sharing

As part of the Migrant Clinicians Network (3), Project Extension for Community Healthcare Outcomes (ECHO) is an innovative learning and knowledge-sharing platform developed by the University of New Mexico. Through teleconferencing, telehealth technology, and clinical management tools, Project ECHO provides training, guidance, mentoring and networking for clinicians in underserved areas, to help build culturally sensitive care capacity within the primary care model.

The ECHO model develops knowledge and capacity among community clinicians through:

- *Case-based learning: using case studies, expert specialists lead clinicians through cases they may encounter regarding the health concern at hand.*
- *Knowledge networks: regularly scheduled teleclinics, led by expert specialists and community partners, provide opportunities for ongoing dialogue and troubleshooting over time.*
- *Learning loops: clinicians encountering similar situations in the exam room can share their best practices and co-manage diverse patients in real world situations and practice.*

Source: (3).

In light of evaluations of recent education and training programmes in Europe, Table 3.1 details recommendations made on programme conception, design, delivery and targeting.

Table 3.1 Delivery of Training

| Programme element | Recommendation |
|-------------------|---|
| Conception | <ul style="list-style-type: none"> • Meet with potential service users and stakeholders to discuss their experiences, needs and priorities • Review existing training against service user and stakeholder needs |
| Design | <ul style="list-style-type: none"> • Involve service users and stakeholders in design • Include background information on the community concerned and on their health needs because the size and characteristics of populations such as migrant and ethnic minority groups vary across and within countries • Adapt the content, length and timing of training materials to the local context • Focus content on diversity sensitivity rather than exclusively on cultural difference • Link content to key organizational support mechanisms, for example, quality improvement planning, policy and procedures, to help embed institutional commitment • Consider including evidence on patient safety and the financial benefits of cultural competence in the training • Pilot and evaluate training courses before scaling up • Seek accreditation for courses to help demonstrate institutional commitment and embed norms of working practice |
| Delivery | <ul style="list-style-type: none"> • Involve service users and stakeholders in delivery of training • Allow sufficient time to fully exploit training materials, with enough time for participant discussion and experience-sharing • Include participatory and experiential exercises and examples of good practice. A so-called recipe approach that encourages passive acquisition of knowledge of different ethnic groups should be avoided • Use a multidisciplinary training team (for example, anthropologists, sociologists, public health experts, medical doctors) to facilitate diverse perspectives and approaches • Ensure the concept of intercultural competence is understood and integrated alongside alternative approaches, such as intersectionality or person-centred care • Focus on patient- and staff-related outcomes |
| Targeting | <ul style="list-style-type: none"> • Interventions should be specifically geared towards stakeholder populations; otherwise, their success may be limited. This is especially the case for potentially vulnerable groups, such as Roma • Seek to involve health professionals with low levels of previous experience or interest in cultural competence • Involve health managers and decision-makers to help embed intercultural competence and diversity sensitivity as a norm |

Source: adapted and reproduced by permission of the publisher from (2) and (4).

Resourcing interculturally competent health care

In a context in which health professionals and policy-makers face increasing pressures on time and resourcing, adapting health care to the needs of diverse groups may seem daunting. However, Boxes 3.3 and 3.4 demonstrate approaches that have been shown to improve migrants' access to health care whilst making more effective use of existing resources.

Box 3.3 Facilitating migrant access to health care

Access to a continuum of care from a family physician is essential for migrant health and well-being. In many cases, however, migrants face barriers accessing health services, and health services themselves face severe staff and resource shortages. The Memorial University Gateway project (MUN MED) in Newfoundland, Canada, is a medical student initiative run in partnership with a refugee settlement agency that provides access to, and continuity of, health care for new refugees, whilst offering medical students exposure to cross-cultural health care.

In this project, first- and second-year medical students conduct medical histories, and provide basic physical screening of patients before matching them with a physician. The history and screening sessions take place weekly at the resettlement agency language school under the supervision of an attending physician and public health nurse. Patients are referred directly to dentists, optometrists, ophthalmologists, ear, nose and throat specialists and other health care providers as necessary. Information collected is entered into a database that summarizes the history and screening into a report. The report and any referrals made are then forwarded to the physician the patient has been matched with.

Six years into the project, an evaluation found that, despite the context of severe health care shortage, 100% of the resettlement agency patients were participating in the physician matching service and were effectively matched with a family physician. The findings also demonstrate the importance of early physician involvement, with 75% of those undergoing screening being in immediate need of a referral or specialist service. General practitioners found the medical histories provided by the project very useful in understanding their patients. Research is being undertaken to assess whether participation in the project influenced the medical careers of the students and their attitudes towards taking on refugee patients.

Evidence also suggests that **diversity in the health workforce** can strengthen the provision of health services for migrants (6). This can be achieved through the promotion of inclusive recruitment strategies, and by ensuring that diversity sensitivity is embedded within health professionals' training. Indeed, encouraging the participation of trainees from diverse backgrounds enables regular and ongoing opportunities for peers to critically reflect on their assumptions and norms whilst learning from one another (7). At a time when many countries are experiencing health worker shortages, it is also important to recognize the skills and qualifications that many migrants bring with them, and the potential that this brings for enriching existing health services. Although debate exists over the complexity and resourcing involved in transferring qualifications gained in other countries, Box 3.4 demonstrates that it is possible and can be beneficial to both health systems and migrants.

Box 3.4 Recognition of health care qualifications in Portugal

Prior to the recent financial crisis, Portugal was praised for its responsive health care policies and services for migrants. One such initiative was the professional integration programme that recognized the skills of the many legal migrants with health care qualifications who were living in Portugal. In 2002, the Jesuit Refugee Service in Portugal initiated the Project of Recognition of Qualifications of Immigrant Doctors with funding from the Calouste Gulbenkian Foundation. The main goal of the project was to create the necessary conditions that would not only enable immigrant doctors to work in their profession in Portugal, but also deal with the shortage of qualified Portuguese health professionals. Between 2002–2005, 120 doctors received training tailored to their individual needs.

While the project was implemented on a national level, its main activities took place in Lisbon, Coimbra and Porto, the only cities to host medical faculties capable of providing diploma recognition. Financial support was given to pay for the training and associated costs such as textbooks and Medical Council registration. Importantly, trainees also received social and psychological support, and language courses specializing in medical terminology. Contacts were also set up with Migration Services, the Medical Council and the Ministry of Health, in order to facilitate the legal and bureaucratic process, and to place doctors in the labour market. Eighty-nine per cent of immigrant doctors who underwent the training qualified and went on to work as health care professionals in Portugal. This not only helped their social and professional integration, but through operating at a national level, helped ensure that a level of diversity within health care was achieved across different regions. The success of the project led to a similar project for migrant nurses that ran between 2005–2007.

Recognition of the needs of particularly vulnerable groups within the migrant population, for example, unaccompanied minors, undocumented migrants, victims of trafficking, pregnant women, is also vital to the delivery of effective health care, and can be achieved through the provision of targeted support that effectively enhances existing resources. In Sweden, for example, the Kulturdoula programme trains migrant women to provide emotional, practical and linguistic support to other migrant women during pregnancy and childbirth to help them overcome some of the barriers they face in accessing and experiencing supportive care.

Whilst undocumented migrants are known to face particular challenges due to their precarious legal status and their limited access to health care, non-government organization-run clinics such as the Red Cross Health Clinic for Undocumented Migrants in Denmark and Doctors of the World in the United Kingdom demonstrate that this can be done effectively when sufficiently resourced.

Interpreting

Adequate training for health professionals is crucial in helping ensure intercultural competence and diversity sensitivity. However, such training will only be of partial use if not accompanied by effective strategies to facilitate communication between patients and health care providers. Language and communication barriers have been identified as a major concern across many WHO European Region Member States (9, 10). Not only do these barriers risk people being misunderstood, they also risk misdiagnosis, and misunderstanding relating to treatment advice. Being understood also represents a key component of trust in the doctor-patient relationship, and is highly associated with patient satisfaction (11). From a resource perspective, research has shown that extensive physical examinations and diagnostic tests are sometimes required to compensate for communication difficulties, and that administrative procedures can be prolonged and complicated through poor communication (9).

Yet despite widespread recognition of language and communication issues, professional, trained interpreters are not always used in routine practice even when the benefits of this, and of the risks of using untrained interpreters, are known.

Many health care providers manage by drawing on informal strategies to support communication in consultations, for example, using family or friends as interpreters. Such strategies can be effective in certain situations, but they also risk compromising people's access to, and experience of, health care when interpreting is of poor quality, when health issues are deemed sensitive or when sociocultural norms relating to issues such as gender and age negatively influence practices of care and support for particular households members. Concerns relating to exploitation and the potential for harm are also raised when children are used as interpreters (11).

Most current guidelines, therefore, advocate the use of trained interpreters, and recognize that formal interpreters who are trained and adhere to a professional code of practice are accepted as best practice.

However, such guidelines do not tend to address the complexity of clinical interactions nor, importantly, given recent economic circumstances across much of the WHO European Region, the cost or availability of formal interpreters, which can fall to patients and/or to health services. It is also the case that some patients do not feel comfortable using formal interpreters who come from their own community. Clinicians, therefore, still underutilize trained interpreters despite being aware of the risks in so doing.

Rather than giving advice that is unlikely to be followed, Fig. 3.1–3.3 draw on Gray's (12) tools to guide policy-makers and health professionals through an evidence-based process to assess actual risk in a given situation, and to make the best choice for that case.

Fig. 3.1 Systemic and health practice requirements for interpretation

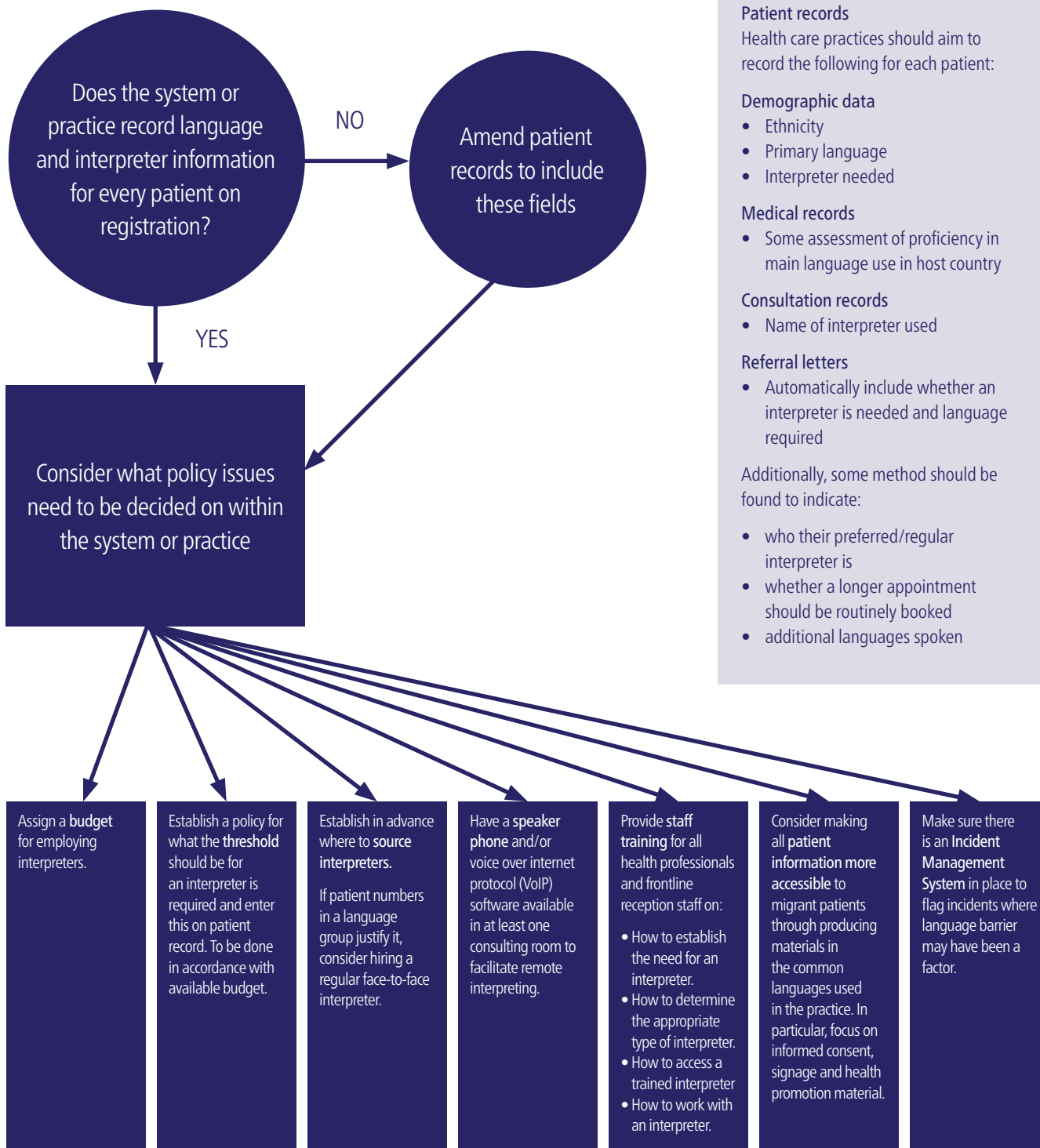


Fig. 3.1 focuses on systemic and health practice levels, to demonstrate the basic requirements for patient records, and on policy issues to be addressed where patients from migrant backgrounds are present. Action areas described focus on budgeting; sourcing interpreters; staff training; and patient information systems.

The following flowchart (Fig. 3.2) encourages health professionals to consider the language abilities of any patient from a migrant background as they relate to the language of the host country. This tool helps enable health professionals to decide whether an individual patient requires an interpreter, and how this can be assessed alongside the nature of the clinical consultation, and the vulnerability and the wishes of the patient.

Fig. 3.3 guides health professionals through decision-making over whether to use a trained interpreter. As mentioned earlier, most policies and guidelines recommend that a trained interpreter should be used in health consultations. However, recognizing that this is not always possible and that there may, in some circumstances, be benefits to using untrained interpreters, Fig. 3.3 provides a step-by-step guide on how to choose the best interpreter on a case-by-case basis.

If it is decided that a trained interpreter is necessary, Fig. 3.4 guides health professionals through the process of determining the best type of interpreter for the situation at hand.

Although good quality face-to-face interpreting is known to be associated with improved clinical care, it can be expensive and inconvenient. Whilst telephone-based interpreting may compromise quality and distance the patient from the interpreter, it can provide vital and immediate support (see Box 3.5). The increasing availability of personal computers and voice over internet protocol (VoIP) software such as Skype means that interpreting through videoconferencing is also now a possibility.

Fig. 3.2 Assessing the need for an interpreter

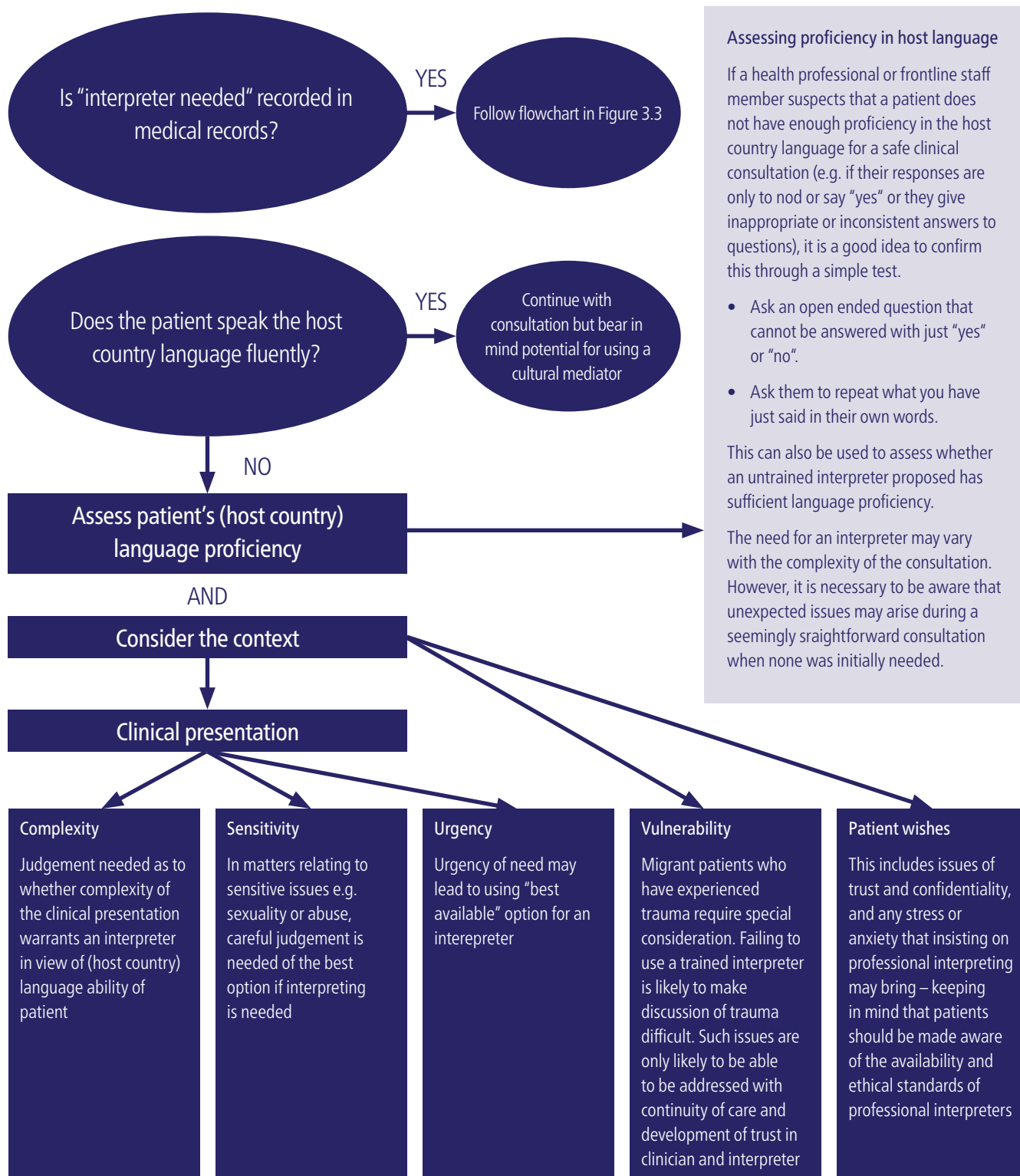


Fig. 3.3 Choosing the best interpreter on a case-by-case basis

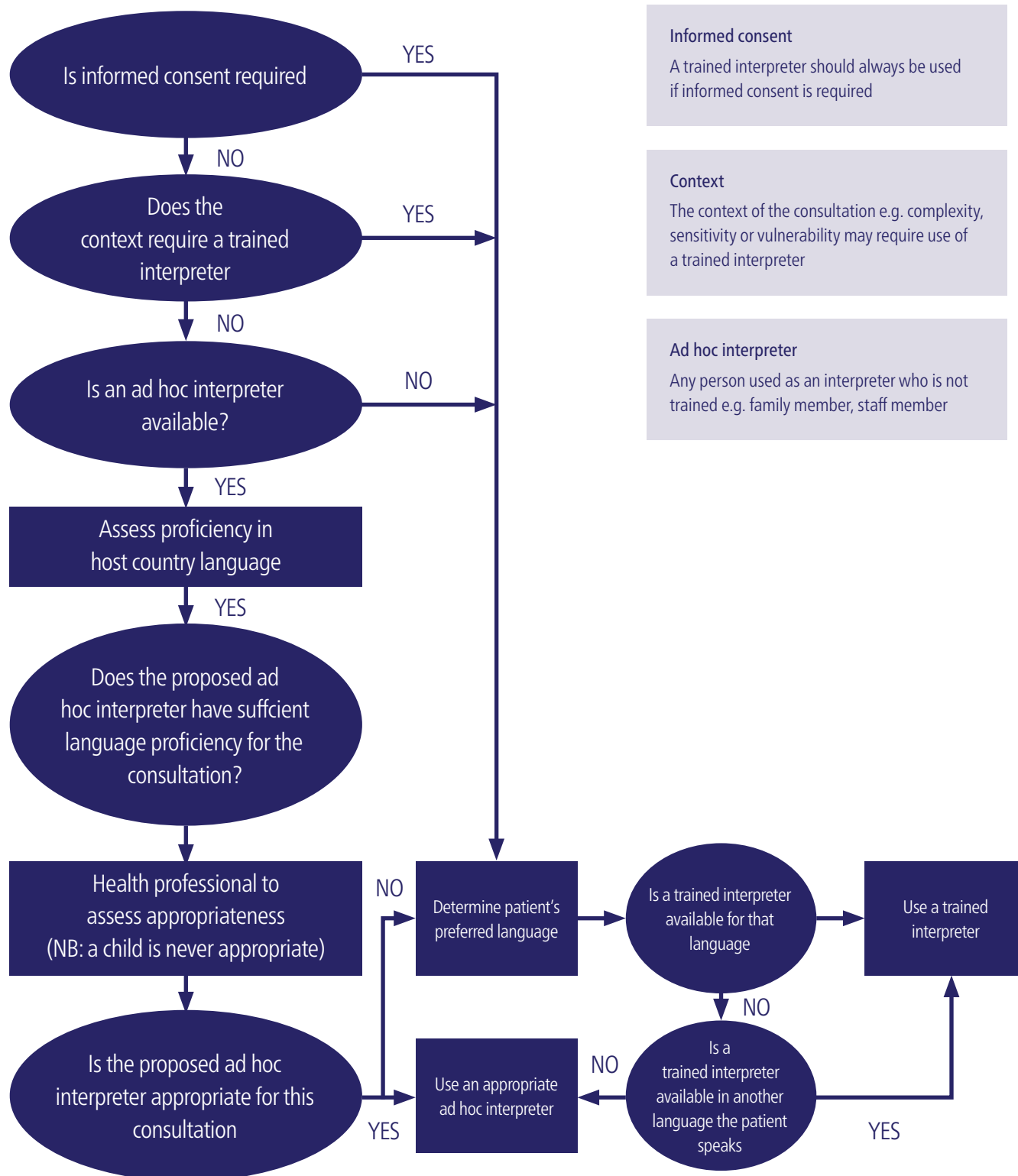
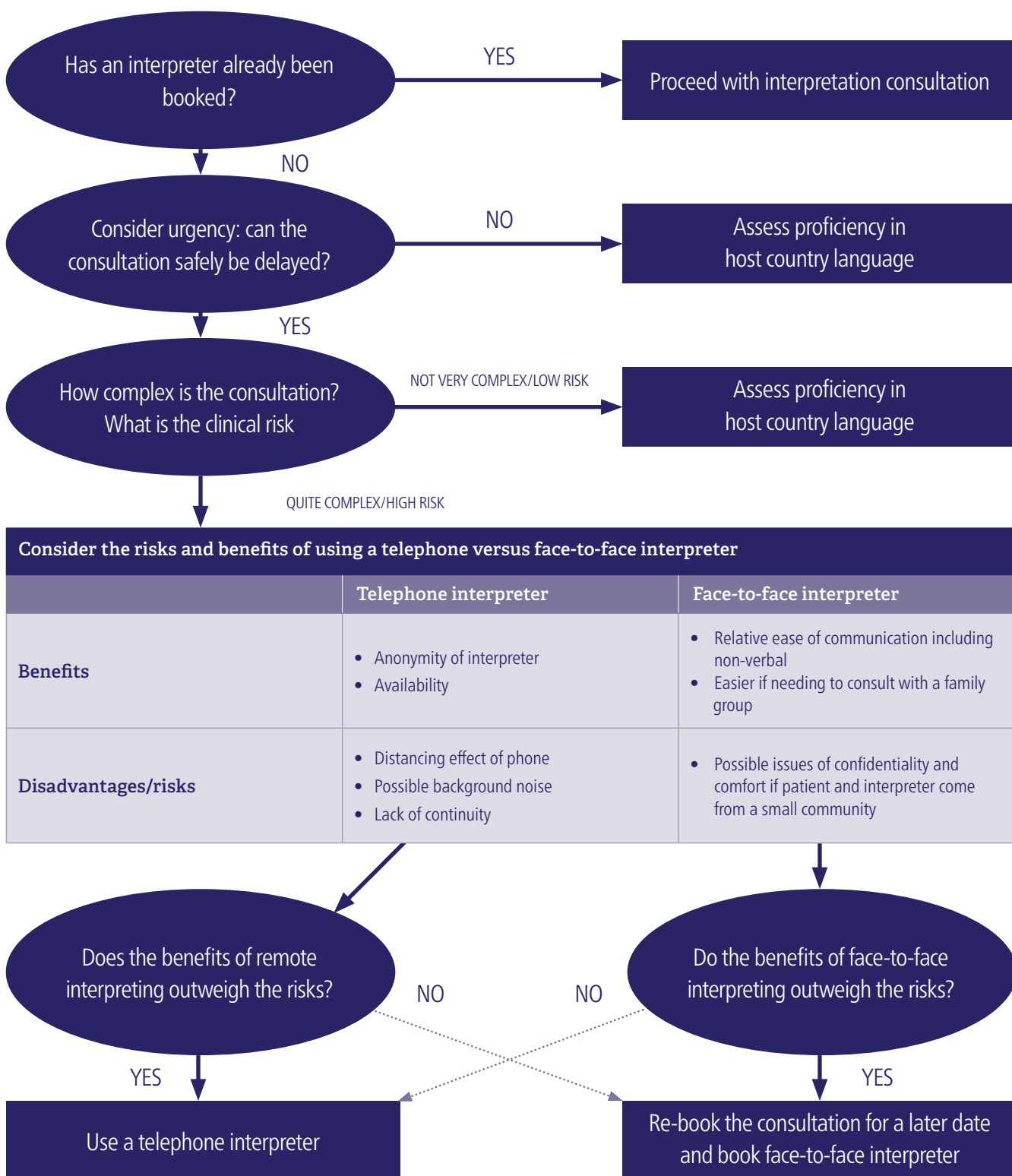


Fig. 3.4 Using trained interpreters in general practice



If it is decided that a trained interpreter is necessary, Fig. 3.4 guides health professionals through the process of determining the best type of interpreter for the situation at hand, while Table 3.2 outlines the different interpreter options available.

Table 3.2 Different interpreter options

| | Type of interpreter | Advantages | Disadvantages | Caveats/comments |
|-------------------------------|---------------------------|---|---|---|
| Professional | All | <ul style="list-style-type: none"> Trained in the skill of interpreting Excellent language skills Training in medical terminology Training in ethics | <ul style="list-style-type: none"> Not determined | <ul style="list-style-type: none"> Not determined |
| | In-house | <ul style="list-style-type: none"> Continuity and ability to develop a relationship of trust Face-to-face interaction Easier if needing to consult with a family group | <ul style="list-style-type: none"> If in a small ethnic community, patients may have issues with confidentiality and comfort | <ul style="list-style-type: none"> Only possible if a large enough language group exists in a practice and there is a budget for it |
| | External service provider | <ul style="list-style-type: none"> Face-to-face interaction Easier if needing to consult with a family group | <ul style="list-style-type: none"> If in a small ethnic community, patients may have issues with confidentiality and comfort Lack of continuity | <ul style="list-style-type: none"> Must be booked in advance |
| | Telephone | <ul style="list-style-type: none"> Anonymity of interpreter Greater availability when dealing with small language groups Available at short notice Helps protect privacy of the patient Avoids the disturbance of having an extra person in the room | <ul style="list-style-type: none"> Distancing effect of phone, including lack of visual communication (such as gestures) Possible background noise Difficult to engage quality of interpreting Lack of continuity | <ul style="list-style-type: none"> Distancing effect may be partially relieved through videoconferencing, even though this is likely to be more costly and require advance booking. Service may only be available during business hours |
| Non-professional ^a | Bilingual staff member | <ul style="list-style-type: none"> Available at short notice Potential continuity | <ul style="list-style-type: none"> Potential role confusion Uncertain language skill Lack of interpreter training Patient expectations of more than interpreting | <ul style="list-style-type: none"> Need to be fully briefed about how to interpret Agreement to work in this role needs to be sought ahead of time |
| | Family/friend | <ul style="list-style-type: none"> Continuity Advocacy Ongoing support outside consultation Trusted by patient Comfort to the patient <p>NB these benefits are not necessarily present and clinicians need to assess if this is the case</p> | <ul style="list-style-type: none"> Uncertain language skill Likely lack of medical training Potential for inaccuracy and omissions Threat to confidentiality and privacy Potential for difficulty with sensitive discussions Potential conflict with usual family roles and dynamics Own agenda of the interpreter | <ul style="list-style-type: none"> Appropriate only for less complex clinical presentation Clinician will need to assess language ability and appropriateness |

^a The use of non-professional interpreters is not recommended by WHO, but is included here as an option to consider under exceptional circumstances.

Ethics in interpreting

In most instances, the work of professional interpreters will be guided by a set of principles or rules that are enshrined in codes of ethical and/or professional conduct. Such principles are likely to encompass the need for interpreters to: respect their clients' rights to privacy and confidentiality; disclose any real or perceived conflicts of interest; to relay information accurately and impartially between parties; and to maintain professional detachment from the issues being discussed.

However, ethical considerations in cross-cultural communication are not always clear-cut, particularly when informal interpreters are involved. Research amongst Turkish Muslim migrants in Germany, for example, has found that important issues such as breaking of bad news and end-of-life care may be approached in very different ways depending on the cultural background of those involved.

Box 3.5 Remote interpreting services in Switzerland

In 2011, the National Telephone Interpreting Service (NTIS) was established in Switzerland. Run by the placement agency AOZ-Medios and funded by the Federal Office of Public Health, the NTIS operates 24 hours a day throughout the year. The 12 main languages covered are: Albanian, Arabic, Bosnian/Croatian/Serbian, Italian, Kurdish (three dialects), Portuguese, Russian, Somali, Spanish, Tamil, Tigrinya and Turkish. However, interpreting services are provided in more than 50 languages on request.

The NTIS was primarily developed to cope with emergencies in the health sector, when no interpreter or mediator could intervene in situ. However, the services are also used by other institutions, reaching approximately 2 000 clients from the health, education and social sectors.

The NTIS is recommended for short, simple conversations of little emotional content and limited consequences, as well as for emergencies, when immediate interpretation is required. All the interpreters employed at the NTIS are trained in remote interpreting, are certified by INTERPRET and adhere to a professional code of conduct. Call cost is 3 Swiss francs per minute, and from 30 Swiss francs (approximately US\$ 30) per intervention. With a high demand for the service and its cost-effectiveness, the NTIS has been identified as an example of good practice that could be replicated in other contexts and at different scales.

Whilst informing a patient honestly about their medical condition and respecting an individual's right to know were essential elements of the health professional's ethos, such practice was considered traumatic, insensitive and unacceptable by some Turkish Muslim families (13). In such cases, religious counselling and compassionate care for the patient was felt to be preferable. Such situations have important implications for what information an interpreter may feel they should impart to or withhold from the patient. This demonstrates clearly how ideas around ethical practice can shift across diverse cultural contexts and stresses the importance of all concerned being able to discuss such issues openly and without fear of judgement or recrimination.

Intercultural mediation

Not fully understanding the health care system can affect migrants' access to, and use of, available services. Very often, migrants are regarded as having low health literacy, when in fact it may simply be that they have not been provided with adequate information. Previous experience with other health care systems can also leave migrants with different expectations of their roles and the roles of health professionals, and may result in uncertainty and mistrust. Providing accessible written information such as leaflets in multiple languages can help to explain health care access, entitlement and procedures, even though evidence suggest that this is not always effective (15, 16). However, the availability of **cultural mediators** or so-called health navigators is also important. Cultural mediators are known to work within government-owned health services across a number of countries in the WHO European Region including Italy, Spain and Switzerland.

The terms interpreter and mediator are often used interchangeably, yet whilst the roles are complementary, important differences exist. Interpreters are charged with facilitating verbal communication and understanding. The role of intercultural mediators is wider and may even be helpful when language does not pose a barrier. Intercultural mediators usually come from the same cultural background as the patient.

Intercultural mediators act as a bridge between patients and health professionals, and can therefore play a key role in bringing these elements together. Importantly, cultural mediators can also help to ensure that migrants receive appropriate follow-up services that fall beyond the remit of the health sector; for example, by helping migrants to access housing, welfare support and legal services.

Role of intercultural mediators

- inform patients of their entitlements to health and other services;
- help patients navigate the health system;
- help facilitate effective, respectful and culturally aware dialogue between health care providers and users;
- mediate when tensions arise between health care providers and users due to cultural misunderstandings;
- help health care professionals monitor the progress of patients;
- help ensure patients receive appropriate follow-up services within the health system and with other key welfare, social and legal services;
- advocate for patient and community needs.

In Malmö, Sweden, International Health Advisors (IHAs) perform a role similar to intercultural mediators, in that a key element of their work involves raising awareness of the Swedish health care system. IHAs selected are migrants who already had a medical background prior to their arrival in Sweden. This means that with training, they are well placed to teach community members about staying healthy, providing classes on issues as diverse as healthy eating, physical activity, sexual and reproductive health and drugs (17).

For intercultural mediation to be effective, mediators need to be acknowledged as powerful actors in the health system, and for their role to become accepted as a norm. Examples such as those in Boxes 3.6 and 3.7 demonstrate how intercultural mediation can become embedded within health systems.

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Box 3.6 Intercultural mediation in Belgium

In 1991, a three-year training project for intercultural mediators was launched in Belgium. By 2000, the project had been integrated within the regular structures of the health care system and is now funded by the Ministry of Public Health. Training was updated in 2008 and 2015, ensuring relevance and coherence with current needs.

Fifty-two general hospitals and 12 psychiatric hospitals currently have on-site intercultural mediation services. Intercultural mediators act as bridges between patients and health professionals and have been involved in interpreting, health education and advocacy. In 2013 alone, intercultural mediators were involved in over 110 000 interventions in Belgium.

Extensive evaluations undertaken in 1993–1995 and in 1997–2000 found that the project was highly effective and led to an increase in quality of care. The length of stay in the host country was found not to decrease the need for intercultural mediation, emphasizing its value for longer-term as well as recently arrived migrants. In addition to face-to-face interventions, the Ministry of Public Health now funds an intercultural mediation pilot project using online teleconferencing and has plans to extend the project to the non-residential care sector.

Belgium's intercultural mediation project has been identified as an example of good practice from which lessons learned can be transferred elsewhere in the WHO European Region.

Source: (13) and (18).

Box 3.7 Migrant-Friendly Health Centres, Catalonia, Spain**Background**

The Migrant-Friendly Health Centres project was developed in 2003–2006 as a collaborative undertaking between the Asociación Salud y Familia (ASF) and the public health system (PHC) in Catalonia. ASF is a non-governmental, non-profit organization which designs and promotes operational models for improving access and use of health services by vulnerable groups. Project stakeholders meet regularly to discuss and monitor the project, and participating hospitals and the ASF have created a permanent group with the participation of high-level management.

Objectives

The main objectives of the project were to:

- Improve the general conditions for the provision of health care to the immigrant population;
- Increase the availability of culturally adapted services;
- Improve communication by breaking down language and cultural barriers between health care staff and immigrants;
- Reduce unnecessary burdens on workload through reduction of intercultural conflict;
- Increase appropriate use of services and the level of satisfaction among patients from the immigrant population.

Results

Twenty-five intercultural mediators worked in five hospitals and 19 primary health care centres and offered direct intercultural support to over 38 000 immigrant patients from diverse backgrounds. As a result, the public health system has adapted, with an intercultural focus, numerous information and health education materials, and has initiated a revision process for procedures that had generated intercultural conflict. There was also a notable rise in continual intercultural training for health care staff.

Conclusions

The availability of permanent intercultural mediators within the project offers immediate improvements in the care given to immigrant patients, while simultaneously facilitating a specific and substantial development in staff members' intercultural competencies through daily exposure and continued intercultural training. As a result, intercultural organizational development has become part of the public health system agenda.

It is vital that intercultural mediators be given **professional recognition**, both to acknowledge their important role in health care, and to ensure that the work they are doing is regulated and appropriate to local needs. Systems for accrediting intercultural mediation across the WHO European Region are sporadic. The Train Intercultural Mediators for a Multicultural Europe (TIME) project explores practices of training and employing intercultural mediators throughout the European Union. It promotes the exchange of good practices in the field by proposing model training programmes, analyses existing structures in partner countries and proposes recommendations for the validation of training for intercultural mediators. Best practices from across Europe are integrated into the products and transferred through them. These programmes are aligned with the National Qualifications Frameworks (NQF), the European Qualification Frameworks (EQF) and the European Credit System for Vocational Education and Training (ECVET). Validation, certification and accreditation procedures in the partnership countries are being explored. University programmes, such as the one-year diploma and the Masters course on interpreting and mediation in social and medical settings run by Paris Diderot University, France, can also help ensure that training responds to the needs of society, and that those with such qualifications have good employment prospects in an occupation that is recognized and respected (weblinks to these courses are given at the end of the chapter). In order to provide appropriate interpretation and cultural mediation for migrants, it is necessary for health planners to know what skills are available to them in their locality, and to ensure that mediators are appropriately qualified to respond to changing needs. Box 3.8 outlines an innovative scheme to register and monitor cultural mediators in Italy.

Box 3.8 Registration of intercultural mediators

In 2006, the Rome Municipality set up a Public Registry of Intercultural Mediators in Rome and the Lazio Region. Enrolment is required for mediators who want to work inside public offices such as social services, hospitals and schools, and strict criteria relating to language skills and competence are established for inclusion in the registry. The registry is updated annually to verify mediator competence and propose training courses to update knowledge in a way that is responsive to current needs in the region. In 2015, there were 520 enrolled mediators from 80 different countries.

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Resources

The SH-CAPAC project (<https://www.sh-capac.org>) provides guidance to countries wishing to conduct population-based assessments to identify health needs, available health protection resources and gaps that need to be filled. It also provides a resource package for ensuring access to health care for refugees, asylum seekers and migrants across European Union countries. This resource identifies a series of barriers for accessing care and formulates recommendations for overcoming them. Also available is a training strategy for developing migrant-sensitive services.

The University of Malmö runs the Kulturdoula project to train migrant women to support other pregnant migrant women. Details of the project can be found at (<https://malmo.se/Foretagande--jobb/Lediga-jobb-i-Malmo-stad/Svart-att-fa-jobb/Arbetsmarknadsinsatser/Insatser/Yalla-Sofielund/Vara-verksamheter/Kulturdoula.html>).

Although targeted primarily at clinicians in the United States, the Migrant Clinicians Network has a range of tools and resources for use by primary health care providers working with migrant populations, available at <http://www.migrantclinician.org>.

The TIME project partnership (2015) offers training packages on intercultural mediation: (http://www.mediation-time.eu/index.php?option=com_content&view=article&id=3&Itemid=122&lang=en) and an overview of good practice and lessons learned from existing intercultural mediation projects.

For advice on how to transfer lessons learned to other country contexts, see (http://www.mediation-time.eu/images/TIME_O2_Good_practices_and_transfer_recommendations.pdf).

Paris Diderot University has undergraduate and postgraduate courses on intercultural mediation, which can be found at: (<http://www.univ-paris-diderot.fr/sc/site.php?bc=formations&np=MENTIONDIP?ND=1067>). (<http://www.univ-paris-diderot.fr/sc/site.php?bc=formations&np=SPECIALITE?NS=945>).

Information on the Public Registry of Intercultural Mediators can be found at (http://www.comune.roma.it/wps/portal/pcr?contentId=NEW116825&jp_pagecode=newsview.wp&ahew=contentId:jp_pagecode).

Health care for migrants on the move - interpreting and cultural mediation services are important for all migrants, whether they are settled or on the move. However, providing health-related information and support for migrants as they move across countries or await legal decisions on their migration status is particularly challenging, especially given the large-scale movement of people currently seen across parts of the WHO European Region.

Information on supporting transient populations in the WHO European Region is available via:

Toolkit for Assessing Health System Capacity to Manage Large Influxes of Refugees, Asylum-Seekers and Migrants (WHO 2016) (<http://www.euro.who.int/en/health-topics/health-determinants/migration-and-health/publications/2016/toolkit-for-assessing-health-system-capacity-to-manage-large-influxes-of-refugees,-asylum-seekers-and-migrants-2016>).

Toolkit on Social Participation: Methods and techniques for ensuring the social participation of Roma populations and other social groups in the design, implementation, monitoring and evaluation of policies and programmes to improve their health (WHO 2016)

(<http://www.euro.who.int/en/health-topics/health-determinants/roma-health/publications/2016/toolkit-on-social-participation.-methods-and-techniques-for-ensuring-the-social-participation-of-roma-populations-and-other-social-groups-in-the-design,-implementation,-monitoring-and-evaluation-of-policies-and-programmes-to-improve-their-health-2016>).

In addition to cross-European training projects such as MEM-TP, a number of countries have now established working groups to improve culturally sensitive curricula in medical training. One example in Germany is the Committee on Intercultural and Global Health Issues within the Association for Medical Education, established in September 2013. Another is the Working Group on Intercultural Awareness in Practical Medicine, which is also part of the German Academy for Ethics in Medicine, founded in September 2011.

Chapter 4. Community participation

Background

It is essential to understand the values and expectations that people attach to health and well-being before it is possible to respond effectively to their needs. If people are not consulted and involved in the design of their own health services, then services will not be optimally accessible, relevant or inclusive.

Undertaking this kind of enquiry or research with rather than on migrant groups gives voice to subjectively defined expectations, needs, priorities and experiences and can help to build trust. Participation in decision-making and practice has also been linked to community empowerment and can enable communities to invest in, and take shared ownership of, health processes and interventions. Such approaches are, therefore, central to the development of interculturally competent and diversity-sensitive health care.

Health care providers cannot create community participation. However, they can create spaces that enable and encourage participation, and, by embedding such approaches at a systemic level, they can help ensure that partnerships are sustained.

This chapter provides an overview of the concept of participation and its ethical implications, and demonstrates a range of tools that can be used at different stages of the health care process as they relate to:

- diagnosis;
- planning;
- implementation;
- monitoring and evaluation.

Case studies are provided to demonstrate how these tools have been applied. Where possible, case studies have been selected because they have been evaluated and recognized through this process as showcasing good practice. Because the tools described here are not exhaustive, further resources are listed at the end of the chapter.

Conceptualizing community participation in health care

Participatory approaches are increasingly used in health-related research and interventions, and can enable rich data collection, analysis and follow-up action. A wide range of participatory methods exist, including diagramming, mapping, budgeting, photography and video. Some of these methods are discussed here, while further methods and resources are provided at the end of the chapter. Participatory methods can be used in combination with or alongside more traditional methods such as surveys. Indeed, by recognizing participants' perspectives, values, norms and priorities, participatory approaches can help to:

- complement the findings of more traditional studies in public health, such as randomized control trials and observational studies;
- inform new hypothesis-driven studies and refine survey instruments;
- explain the limited success of past policy and practice initiatives;
- inform the initiation and implementation of new policy and practice (1).

Despite these advantages, it is crucial to recognize that participation takes a variety of forms, some of which have considerably greater potential than others for rebalancing power relations and achieving the outcomes or changes desired by participants.

Participation is often modelled as a ladder or spectrum ranging from the lowest level, focusing around top-down information transfer (where spaces of participation risk reasserting dominant views and delegitimizing alternative forms of knowledge), to the highest level, focusing on participant empowerment and effective change.

White (2) provides an insightful approach that helps to conceptualize the various forms and functions of participation (Box 4.1).

It is also helpful to recognize that a range of constraints, including people's feelings of powerlessness, may challenge opportunities for participation, and that these issues may affect some groups more than others. Concurrently, the pay-offs from participation may seem too low and too distant for some people, whilst the costs of involvement (particularly if the time costs and the potential for stigma are high) may seem unattractive. Understanding the factors that influence people's decisions to get involved and to stay engaged is, therefore, imperative. Such factors are a combination of i) demand-side factors (that is, the incentives that encourage users to become involved; ii) supply-side factors (the resources users need to participate, and efforts to mobilize them), and iii) the institutional dynamics of involvement itself (the way participatory processes, positively or negatively, affect continued involvement) (3). As is demonstrated in Box 4.2, it is vital that these factors be seen as being mutually constitutive and flexible and that it be recognized that they can develop and evolve through the process of participation itself.

Box 4.1 Forms and functions of participation

1. **Nominal participation** is often used by more powerful actors to give legitimacy to development plans. Less powerful people become involved in it through a desire for inclusion. However, it is little more than a display, and does not result in change.
2. **Instrumental participation** sees community participation being used as a means towards a stated end – often the efficient use of the skills and knowledge of community members in project implementation.
3. **Representative participation** involves giving community members a voice in the decision-making and implementation process of projects or policies that affect them. For the more powerful, representative participation increases the chances of their intervention being sustainable; for the less powerful, it may offer a chance for leverage.
4. **Transformative participation** results in the empowerment of those involved, and in turn alters the structures and institutions that lead to marginalization and exclusion.

In addition to working with communities themselves, it is important to develop ongoing networks and relationships with migrant support groups, and other agencies that render services to them. This provides opportunities to engage in reciprocal learning, valuing the perspectives and lived experiences of others, supports ongoing dialogue and helps avoid duplication of effort and resourcing. Building relationships can also broaden the capacity of policy-makers and practitioners, and increase access to resources and funding.

Because many organizations experience high staff turnover and changes in governance, it can be difficult to maintain partnerships between organizations. It is important, therefore, that linkages do not rely on individuals but, where appropriate, can be cemented through formalized partnerships and agreements. Additionally, systems need to be developed so that linkages become a standard part of organizational processes, through, for example, regular meetings and discussions, and information-sharing.

Box 4.2 Promoting and sustaining involvement of marginalized groups in health care in the Netherlands

Project Apoio was created by a user organization in Rotterdam to promote Cape Verdean migrants' rights and access to mental health care, and has been recognized as an example of good practice in community engagement by the Dutch Intercultural Centre for Mental Health Expertise. Project Apoio created several participatory initiatives including comissão de apoio, a user committee set up to disseminate information on the project, enable dialogue between users, providers and health authorities, and foster Cape Verdeans' access to psychosocial care; and grupo de conversa, a peer support group promoting exchange of emotional, informational and social support between people affected by psychosocial distress.

Many Cape Verdeans were initially reluctant to become involved in the project. However, face-to-face invitations from the Project Coordinator enabled participants to recognize their entitlement to participation and served to reassure them of the legitimacy and importance of their contribution. This was further reinforced through initiatives such as a theatre play aimed at raising awareness of the stigma of mental health, which helped build participants' confidence. Other motivations for involvement included a desire to reduce isolation, overcome the stigma attached to mental illness and make use of mental health care, as well as a collective commitment to promote social justice. For many, Project Apoio's participatory initiatives were the first opportunity to talk about mental illness, meet others with similar problems, and find a safe route into mental health care. Over time, facilitating access for other community members became a strong motivation to remain involved, thus turning what had been a debilitating lack of information and confidence into an enabling incentive for participation.

Recognizing that access to mental health services was only a part of the issue they faced, participants also attended information sessions about users' rights, legal and institutional support and the instruments

Box 4.2 (contd)

available to redress unfair treatment. This enabled awareness-raising over the structural causes of the disadvantages they faced, and helped people to overcome self-doubt relating to their personal capabilities. They then collaborated in delivering these sessions at public meetings, enabling them to acquire important knowledge and gain confidence to influence local decision-makers into meeting their community's unsatisfied needs.

Importantly, Project Apoio provided a hybrid space that offered receptive connections to the state, whilst avoiding domination by professional or bureaucratic concerns. This resulted in unsettling of existing power balances so that discussions and decision-making around health care needs and priorities could be more equitable.

Source: (4).

Practical and ethical issues

The participation of migrants in health care development and implementation presents both practical and ethical challenges. Practicalities of access are particularly challenging when refugees and migrants are living in temporary settlements, or when migrants do not have secure legal status. In addition, data collection may require the assistance of interpreters and cultural mediators, which itself involves resource and quality issues.

Many community organizations exist to support migrants and it is important that health services work with such organizations to embed intercultural competence and diversity sensitivity. However, community participation does not mean liaising exclusively with well-organized community groups, who may not be able to represent individual needs, or the needs of smaller, less well-organized or completely marginalized groups and individuals. It is important, therefore, to recognize difference within communities and to ensure that individuals and groups at risk of being excluded are included in mainstream activities.

Similarly, whilst it is necessary to ensure that the perspectives and experiences of patients are incorporated into health care practice, it is also vital that the perspectives of those who are not currently in, or using, the system be taken on board. Understanding why people are not using health care is especially crucial since they may need to and might be more willing to do so if it were better adapted to their needs (5). Well-recognized methods of involving patient user groups to inform health care services (for example, through patient and public involvement (6) may, therefore, remain only partially effective in improving accessibility and experience for migrant groups.

Establishing dialogue with migrant communities is also challenging, since it is often unclear whom the community encompasses and who can best represent it. Consideration of these issues is important in helping ensure that the voices of migrants and other minority groups are heard and that involvement is embedded in working in a manner that is meaningful rather than tokenistic.

There are also deeper issues relating to the impact of participation itself, especially when it concerns people who may be living in vulnerable or precarious situations. In particular, it is important to ensure that findings from any participatory research are not misused, or found to misrepresent the feelings and experiences of those they claim to speak for, and that consent to take part in such research is fully informed. The model discussed in Box 4.3 demonstrates how participatory action research can be undertaken with migrant groups in a manner that addresses such ethical concerns.

Box 4.3 Ethical working

The Centre for Refugee Research (CRR) in Australia uses a five-pronged model to address issues relating to ethical working, particularly as this relates to informed consent. First, in CRR projects, refugees are considered partners rather than simply participants. This means that the scope of research, how it will be conducted, who it will involve, and what will be done with the data and findings, as well as the accountability of the researcher are all negotiated with refugee groups and individuals rather than set out in advance by the researchers.

Second, the projects are constructed as participatory action research, meaning that data generated can be applied in action. The data generated from this action can then become the basis for further enquiry and evaluation. This involves maintaining a continuing relationship between researchers and participants, helping ensure that refugee groups can develop effective responses to their needs, and that mechanisms for building up accountability and trust between participants and researchers are continually reinforced.

Third, CCR projects seek to embody an ethic of reciprocity, in which all partners in the relationship can bring something to the encounter. Fourth, because of the previous three elements, informed consent becomes an ongoing relational process rather than a one-off event. This means that participants are continually able to negotiate their role in the research, and ensure that their needs and priorities remain central in the research process. Within this, ongoing consent is sought at two levels: first, to avoid placing pressure on individuals, consent is sought at the group or collective level. In view of the possibility that the group itself may place pressure on individuals, consent is then also sought from each individual.

Finally, the CRR model advocates the use of a critical friend to act as an ethical auditor who asks continuous questions about actions and decisions relating to all aspects of the project in order to keep the ethical dimensions of the research under scrutiny.

Diagnose

Top-down approaches to health care mean that policy and practice decisions are often underpinned by taken-for-granted assumptions regarding the ways that health issues are perceived and dealt with. Participatory diagnosis can reveal alternative framings of health issues, by providing insights into the ways that people perceive, make sense of, and respond to, their health and well-being, and the ways that they establish and prioritize health care needs and expectations.

By identifying and understanding subjectively defined problems and needs in a given context, it is possible to establish health care priorities and gain insights into what intervention strategies are deemed relevant and acceptable.

Participatory diagnosis involves analysis of the health status of a community, the perceived needs and priorities of the community, the health services that are currently available to the community, and the attitudes towards them by community members. The concept of community here may be defined geographically or by shared characteristics such as age, gender or other agreed social markers.

Participatory photography

Participatory photography (also known as auto-photography, photo-elicitation or PhotoVoice) is a method that uses images created by members of a community to initiate discussion and action around a common experience or issue.

At the diagnosis stage, the use of participatory photography can help to provide insights into the ways that people define particular health and well-being issues, as well as the broader contexts in which such issues are experienced in daily life. As is shown in Box 4.4, photography can also help challenge assumptions concerning behaviours and attitudes related to health and well-being.

Method

The first stage involves selecting or inviting people to act as community photographers. Usually, those selected will represent a particular sociodemographic of the community in accordance with pre-agreed criteria such as state of health, age or socioeconomic status.

Training is usually required to ensure that photographers are familiar with the use of the cameras and the objectives of the information-gathering. The purpose of the data collected should be discussed and agreed on with participants. This might involve a broadly defined subject area in which participants are free to interpret how to represent their experiences, or they may be asked to collect more specific data that reflects particular aspects of their lifestyle, health condition or the specific needs they have. Following training, sufficient time is needed to enable photographers to capture images. Once fieldwork is complete, cameras are handed back to the technical or research team, who develop the images. Disposable cameras are often used due to resource limitations.

Once photographs have been developed, they can be discussed and debated by the community with focus placed on understanding what is in the image; what it represents; what problems or circumstances it reflects; and what can be done to improve or learn from the situation. The same steps can be taken with stakeholders in health-related policy and practice both to triangulate data, and to establish diverse insights into the situation at hand. Appropriate lines of action can then be agreed on by stakeholders to deal effectively with the issue. Box 4.4 describes the application of participatory photography amongst Pakistani migrants in Denmark.

Box 4.4 Photo-elicitation amongst Pakistani migrants in Denmark

Denmark has a well-established tradition of disseminating public health information via information campaigns relating to exercise, diet, smoking and alcohol. Until recently, however, such initiatives have not attempted to incorporate cultural diversity, or to consider how food is embedded in the social practices and relations of everyday life. At the same time, there has been a rising prevalence of type 2 diabetes mellitus and coronary heart disease amongst Pakistanis living in Denmark. This has been accompanied by official advice to these groups to adopt a more Danish diet based on rye bread and dairy products. Researchers used photo-elicitation and narrative interviews to study the food practices of Pakistani families in Denmark to understand how food is embedded in people's everyday lives and interactions.

By asking participants to take photographs of their food and then discuss the pictures they took, the researchers found that Pakistanis in Denmark did not consume unhealthy food out of ignorance. Instead, they actively sought to balance recommended healthy food practices with other cultural practices and behaviours and with the practicalities of life and work schedules. They concluded that public health policies should shift from a deficit model (that is, seeking to address assumed deficiencies in knowledge and motivation) to one based on encouraging healthier food in social practices and making healthier convenience food options more widely available.

Source: (8).

Participatory video

Participatory video can be used to help develop and implement diversity-sensitive health care interventions. It can be applied to aid community learning and engagement, particularly when marginalized groups have the opportunity to impart health information in a manner that is deemed appropriate and relevant to community experiences, needs and priorities.

Video making is also a dialogic process that allows those involved to iteratively reflect on the information they are producing and analyse their own realities and experiences critically. The process of film-making is, therefore, often as important as the film itself.

Method

Involving people in making and editing a film, as well as holding workshops to discuss these processes, can be time consuming, and should only be attempted with the prior agreement of all stakeholders. The first stage involves selecting or inviting people to act as community film-makers. Usually, those selected will represent a particular sociodemographic of the community in accordance with pre-agreed criteria such as state of health, age or socioeconomic status. The purpose of the video should be discussed and agreed on with participants.

Training is required to ensure that film-makers are familiar with the use of the equipment. Following training, film-makers should be given sufficient time to develop storyboards and undertake filming.

Once the film is completed, it can be discussed and debated by project stakeholders. At the implementation stage, focus should be placed on understanding and agreeing whose issues or circumstances are reflected; who the film is to be addressed to; and how health services can be improved to respond to the situation depicted.

Box 4.5 describes the use of participatory video to implement more effective breast screening amongst diverse groups of migrant women in the United Kingdom.

Box 4.5 Use of participatory video in health promotion

The Communication for Health (C4H) project was funded by the National Health Service Cancer Screening Programmes in the United Kingdom to address the low uptake of cancer screening amongst migrant and ethnic minority women. Until this point, information on cancer screening was perceived to be overly didactic, to lack language and cultural sensitivity, and to pay little attention to the social context in which decisions about breast screening were made. Images within videos were considered to depict crude stereotypes of migrants and ethnic minorities and to reinforce top-down power relations between health care providers and patients.

The C4H project engaged women from four diverse migrant groups in the production of a new NHS breast screening video. The women were involved in co-writing scripts, co-directing, acting in and evaluating the video. The women received training to use video cameras and worked alongside a professional film-making crew and bilingual community health educators. The storylines in the film drew on the subjective perspectives and experiences of the women and provided an important opportunity for myths about screening to be uncovered and communicated to others in their communities in a way that embedded meaningful cultural references and markers in the messages conveyed. Diversity within each community was also played out in the videos, with different characters representing different social backgrounds, emotions and responses to the breast screening invitation, and women discussing the subject of breast screening in a diverse range of social settings.

Source: (9).

Focus groups

Focus groups are now commonly used in research that seeks to gauge people's understandings and attitudes. They are well-recognized as a useful technique for enabling people to discuss sensitive issues in a supportive and often empathic environment, and are viewed as a useful way of engaging commonly marginalized groups. Although usually guided by a facilitator, focus groups provide opportunities for participants to shape the discussion in a manner that they deem reflective of their experiences and concerns, and to raise important issues that may not have been foreseen.

Method

A focus group is a guided discussion with a small group of people. The group needs to be small (usually between 6–10 people) for participants to feel comfortable in voicing their views and to allow all present time and space to contribute to the discussion. Participants from diverse backgrounds can be selected to discuss an issue that they (or their community) all face or experience, or because of their background similarities. In some cases, participants are not known to each other prior to the meeting. In others, focus groups are formed out of existing groups. Either way, it is important that any facilitator consider how such issues might affect group dynamics, as well as how any sensitivity around issues discussed might affect the potential for harm.

Focus groups can be run either as one-off sessions or as series of sessions. Although there is no set time limit for focus group discussions, they commonly last between one and two hours.

The case study provided in Box 4.6 demonstrates how the use of focus groups enabled health care providers to recognize and start to understand a previously unaddressed issue in the Swiss health system, namely the extent and experience of female genital mutilation amongst women migrants.

Box 4.6 Using focus groups to identify FGM-related concerns and priorities

In the early 2000s, Swiss health practitioners acknowledged the increasing numbers of African migrant women patients presenting with female genital mutilation (FGM). However, very little was known about the women's FGM-related experiences, needs and priorities, and no guidelines had been developed to address FGM in relation to gynaecological/obstetrical care.

Given the sensitivity of the issue, finding women who were willing to discuss their experience of FGM was difficult. However, care was taken both to work through existing community groups and to reach out to women who did not participate in these groups, for example, recruiting via visits to African restaurants, markets and shops.

Focus groups were chosen as the most suitable method to facilitate information exchange because they provided an opportunity for the women to: i) discuss sensitive and often stigmatized issues in a supportive environment; ii) raise and discuss issues that they identified as important; and iii) provide mutual support and empathy during and following the discussions. Anticipating that some people may not want to participate in a group discussion, women were also given an opportunity to take part in an individual interview. Interviews were also held with health professionals to understand their perceptions of, and responses to, FGM.

The focus group discussions revealed significant differences between the women's experiences and priorities and the assumptions and practices of health care professionals, particularly around issues such as sexual relationships, reinfibulation and caesarean sections. Recommendations were made to provide community-informed guidance for health professionals and to support opportunities for information exchange amongst migrant communities.

Participatory survey

A major criticism of conventional surveys is that questions are pre-defined, often by people with little or no lived experience of the issue at hand. The distinguishing feature of participatory surveys is that members of the population concerned identify and draw up the content and questions to be asked. This helps to ensure that the questions asked are deemed relevant, and can be phrased in a way that is sensitive and comprehensible to the target population. The process of developing and delivering participatory surveys makes it possible to achieve dual objectives. First, as with any survey, it provides insightful information on a particular health or social issue. Secondly, it requires a process of critical self- and collective reflection as community members deliberate on the contents of the survey, in turn developing capacity to analyse and prioritize the issues faced.

Method

A participatory survey begins with the identification of key topics on which information is needed, normally through a workshop bringing together different stakeholders. In addition to deciding upon the content of the survey, stakeholders should consider the possible responses to questions asked and how best they can be categorized in a culturally sensitive and meaningful manner. This may involve pre-defined answer options, for example, category boxes, Likert scale (1–5) responses, and/or may include options for more detailed narrative responses. Once the survey instrument has been developed, stakeholders need to agree how and where it can be most effectively piloted. After piloting, the survey should be revised to reflect any concerns or omissions identified. In participatory surveying, surveys tend to be administered by those who helped draw them up, and filtered through their networks until the broadest possible sample size is reached. The process of survey administration can itself help to create networks that can then potentially participate in any action agreed upon and carried out subsequent to the survey diagnosis. Whilst the survey sample is likely to be statistically non-representative, it is important to consider how best to ensure that it is made available and accessible to target groups, and how this may be affected by issues such as gender, age and socioeconomic status.

Once fieldwork is complete, survey responses are recorded and formatted. Results can then be analysed and fed back to stakeholders and participants. Box 4.7 describes a participatory survey undertaken by Latino migrants in Minnesota (11).

Box 4.7 Participatory surveying in Minnesota

Latinos' mental health needs are often unmet by existing health services in the United States. A participatory survey was developed and undertaken to assess the mental health status, beliefs and knowledge of resources among rural and urban Latinos residing in Minnesota, so that more effective and culturally-sensitive services could be planned.

In recognition of the commonalities and divergences of experience amongst Latino migrants in rural and urban areas, collaborations were formed between a local university and i) Centro Campesino, a grassroots Latino-led organization working to improve the lives of migrant agricultural workers and rural Latinos, and ii) Latino-serving schools and churches in urban areas to address health-related concerns for young Latinos.

The process of developing and pilot-testing a survey instrument required extensive communication, active listening and the consideration of numerous, sometimes divergent perspectives. Community partners provided guidance in critiquing existing mental health survey instruments and consent forms, and in developing a new instrument that used culturally sensitive concepts and questions. Amongst other things, the phrase mental health was replaced by a focus on emotional health, which was deemed to be less stigmatizing and more consistent with holistic views of physical and mental health commonly held in Latino communities. This was then adapted for adults and for young people, and made available in both Spanish and English. Following piloting and community feedback, the survey instrument was revised and refined with full involvement of community partners.

The project revealed that, among other things:

- i) the process of participatory surveying is time-intensive because it is dependent on collaborative decision-making through extensive communication and mutual trust. While the need for flexible timelines may be challenging to health care providers, policy-makers and funders, the end result is likely to be more effective and sustainable when all partners have equal ownership in the planning, process and outcomes.*
- ii) community partners can experience frequent changes to leadership and staffing, often reflecting grant commitments and insecure funding. Therefore, collaborations need to be flexible, responsive and creative, whilst having clear and agreed practice and policy implications.*
- iii) it is important that surveys be undertaken in an ethical manner, and that consent be obtained before participation occurs. However, it is essential to understand what participants deem ethical and how consent can most appropriately be negotiated, rather than assume that generically designed procedures, set out by often distant institutions, are necessarily most suitable.*

Planning

Participatory budgeting

Participatory budgeting (PB) covers a variety of mechanisms in which power or influence over local budgets and investments is delegated to citizens. The main objective is to establish the needs and priorities of particular communities or social groups and to ensure that they are reflected in spending.

PB can take place at a small, project-level scale, or at a city or even regional level. In practice, this is often limited to new investments rather than longer-term public spending, even though the latter has been demonstrated in parts of Latin America. Although it is possible to target such approaches within particular communities or social groups, this may increase the potential for tension if some people are seen to be benefiting over others. It is common, therefore, for participatory budgeting to be open to all residents in a defined geographical area. Key advantages of PB lie in its capacity to i) improve transparency around government or institutional spending, ii) improve communication between stakeholders, iii) build participant budgeting and negotiation skills; and iv) ensure that spending reflects local concerns and agreed solutions.

Method

It is necessary to decide which resources should be made available for community debate on budget planning. Once this is agreed, it is important to raise awareness and inform community members about the opportunity for PB and any related meetings, workshops or training events. To ensure a wide level of participation, this is best done through a variety of mechanisms, including advertising and social media campaigns and through existing structures of community networks. Box 4.8 (12) describes a successful participatory budgeting initiative that took place in a culturally diverse area of London².

² For further information on this project and other participatory budgeting initiatives, go to www.pbnetwork.org.uk

Box 4.8 You Decide – participatory budgeting in Tower Hamlets, London

Tower Hamlets is a dense urban administrative area in the East End of London. Despite being only five miles wide, it is home to almost 220 000 people speaking 110 languages. A participatory budgeting (PB) project known as *You Decide!* was carried out across the area in 2009–2010. Over £5 million was allocated to the project by the Government and the local Primary Care Trust over the two-year period.

The project had three key aims:

1. to improve perceptions and performance of local services by giving residents the power to design and choose priority services;
2. to help people from diverse backgrounds to participate in policy decision-making and improve their levels of involvement across other local authority services;
3. to improve local engagement in politics and in voluntary sector organizations.

Tower Hamlets is split into eight Local Area Partnership (LAP) areas, each of which was given an equal budget. To alert residents to the project, an advertising campaign involving press releases, posters, and leaflets was undertaken alongside a networked approach reaching out to community groups and other key contacts. Eight *You Decide* events took place, with 815 attendees. At each event, a menu of 33 services was presented, with information on what difference the additional funding would make should residents vote for it. Facilitators worked to encourage residents to talk to each other about the services on offer, and why they considered them important in the local area. This not only gave a voice to residents, but also enabled those involved in health care planning to better understand and respond to the perspectives of residents from diverse backgrounds. Discussions took place over food, adding a level of informality to the process.

Once residents had voted, the services nominated for funding drew up more detailed plans on how they were going to spend the funding, with further opportunities for resident input and revision.

An evaluation of the PB in 2009 found that almost two-thirds of the people who had participated felt that the process helped strengthen their level of influence over local services and their satisfaction with their local area, while 77% wanted the event repeated in the future. An evaluation in 2010 found that participants felt that they had developed skills linked to empowerment and that they could influence their local environment and services.

Source: (12).

Participatory strategic planning

Participatory strategic planning (PSP) is a consensus building approach that helps communities and/or user groups come together to agree how they can guide, prioritize and develop their work towards a desired future. This technique can be used at a range of scales, from the identification of organizational aims, to the development of large-scale strategy (see Box 4.9). PSP can help to build a sense of ownership and commitment in a group, which are important factors when seeking to reach a consensus on how to move forward.

Box 4.9 Health strategy development in Ireland

The Irish Health Service Executive's (HSE) first Intercultural Health Strategy 2007–12 was developed to facilitate more effective health care for the country's increasingly diverse population (12). The strategy was developed in a collaborative and consultative manner, where service users, staff and service providers were directly involved in the design and planning of services. A pre-consultation exercise enabled interested stakeholders to put forward their views concerning the current provision of health care for people from diverse cultural and ethnic backgrounds, together with suggestions for enhancing these services. This process was advertised through HSE networks and community websites, and the responses helped shape a series of focused questions to be used in subsequent consultation events across Ireland. These events were advertised through HSE communication channels, community networks and mainstream media, with invitations to these events circulated in Arabic, Chinese, English, French, Polish, Russian and Spanish. Support for interpretation and childcare was offered to facilitate optimal participation by service users.

The consultation events attracted a broad range of people, with Travellers and asylum seekers being particularly strongly represented. In recognition of the belief that no service user should be excluded from the process, other consultative mechanisms were utilized to ensure that more vulnerable, less visible groups were given opportunities to express their views. This included a series of individual interviews held with undocumented migrants and with migrant women, focus groups facilitated by NGOs active in the field of migrant health care, events hosted by the Ethnic Minority Health Forum and a survey sent out by the Immigrant Council of Ireland to members of eleven key migrant communities across Ireland. The consultation process fed directly into the development and subsequent implementation of the Intercultural Health Strategy and helped build important relationships across the health service and community sectors.

Method

While the participatory planning process will be influenced by the context in which it takes place, a core set of stages can be identified. Firstly, the group determines its vision for the future of the community or organization. This vision forms the backdrop to the planning process, and should be shared with as broad a cross-section of stakeholders as possible. Once a vision is established, PSP can be used to identify more specific aims and objectives that can be pursued in the medium term (usually up to five years), and achieved through the completion of strategic actions over the course of the planning process. Secondly, the group identifies the obstacles that are hindering it in reaching its vision. Then it moves on to agree strategies and both a short-term and longer-term timeline for implementation that will help the group overcome these issues in order to reach the collective vision. Each stage uses some form of consultation process. This may be a facilitated workshop, where ideas can be shared openly, but it can also involve methods such as focus groups and interviews, which help ensure the inclusion of less visible user groups.

At the planning stage, participatory approaches can also be used to test the feasibility and acceptability of an intervention to potential service users. Box 4.10 describes how participatory techniques were used to determine the perceived appropriateness of actively involving African migrant groups in developing HIV prevention interventions in London.

Box 4.10 The MAYISHA project, London

Sub-Saharan African communities in the United Kingdom bear a disproportionate burden of HIV-prevalent infection. The MAYISHA project aimed to determine the feasibility and acceptability of actively involving African migrant groups in sexual behaviour research relevant to planning and implementing local HIV prevention interventions. Ten representatives (key workers) from each of seven local African community-based organizations were included in the study research team. Key workers were involved in all stages of the study's design, development, implementation and evaluation. They facilitated access to, and communication with, the target communities through a wide range of community venues, and were involved in social mapping and surveying. A cadre of 25 trained volunteers from within the target communities was then selected to distribute questionnaires on sexual behaviour in their communities. The study provided new and important insights into the sexual health needs and priorities of migrant groups, and was well received by participants, who felt that using community members as researchers helped facilitate the research and ensure the findings were culturally informed.

Implementation

As discussed in Chapters 2 and 3, interculturally competent and diversity-sensitive health care requires a whole-system approach in which the perspectives and priorities of user groups play a defining role. However, the most effective forms of participation involve participation not only in diagnosis and planning, but also in project implementation and management. This can help ensure that health promotion messages and interventions are relevant, sustainable and empowering, particularly when new structures and cultures of working can be fostered.

Health promotion

Health promotion needs to be not only a tool for the transmission of health information from health professionals to the lay public, but also a communicative space in which expert and lay knowledge and power relationships can be negotiated. Health promotion messages that are drawn up without input from target groups will, therefore, likely have only limited effectiveness.

At the same time, it is important to recognize that people do not simply rely on the provision of top-down information from experts when making important decisions relating to their health and its management. Often, influential health information comes from within the community itself, which means that it is important for health policy-makers to work with communities to determine how existing dissemination networks, such as community radio and newsletters, can be used to effectively convey health messages. This may be especially important for reaching potentially vulnerable individuals such as the elderly as well as migrants who are not conversant in the language of the host country.

Box 4.11 demonstrates the value of digital technology in spreading health information, and how this can be particularly beneficial for people as they move across countries with diverse health systems. An example of this is www.w2eu.info. It also reiterates the need for policy-makers to recognize the innovation, capabilities and resourcefulness that migrant communities themselves bring to health promotion and implementation initiatives.

Box 4.11 Use of social media in health access and promotion

Infomobile-Welcome 2 Europe (w2eu) is a self-organized open space network that provides support guidance and useful information for refugees who are on the move, through distribution of information cards and leaflets, its web resources, and the Alarmphone and WatchTheMed platforms. W2eu works as a collaborative initiative, with information fed into it from migrants, activists, NGOs and seafarers active in the Mediterranean region.

W2eu aims to raise public awareness about refugee issues through the dissemination of information, including refugee narratives, press releases, photos and video documentaries covering issues such as detention conditions and human rights violations. The w2eu website (w2eu.info) provides information to refugees and migrants that might be useful to them as they journey through Europe. Translated into four languages (Arabic, English, Farsi and French), it offers information on a country's migration and health policy as well as first-hand warnings and advice on diverse health and well-being-related issues. It also tells migrants where they can receive medical assistance in different European cities. Live information is also available on the situation at border crossings, and the participatory nature of the platform enables many different actors to identify, and respond to, ongoing issues causing distress.

Source: (15).

Many people migrating to Europe have access to mobile phone technology, which provides important and, as yet, relatively untapped opportunities for the dissemination of health information and for health promotion. The MAMA ACT app for pregnant migrant women, for example, has been developed by the University of Copenhagen to provide information regarding warning signs of complications in pregnancy and actions to be taken to address them³.

Research has found that many migrants are reluctant to share personal information online, preferring to remain anonymous for fear of reprisals, surveillance, detention and/or deportation. It is vital therefore, that any digital resources created with the intention of supporting the health needs of migrants in Europe respects the need for privacy and takes into account people's security concerns. It is also recommended that digital technology initiatives seek to repurpose existing resources rather than create from scratch, that they are easily accessible, trustworthy and sustainable.

³ MAMA ACT [website]. Copenhagen: University of Copenhagen; 2019 (<https://sulim.ku.dk/dansk/mamaact>, accessed 2 October 2019).

Co-management of services

The co-management of health services involves the community and the diverse groups it comprises participating and collaborating with institutions in the management of public health services. Co-management seeks to increase the commitment and co-responsibility of all stakeholders in designing and implementing health programmes. This may be undertaken across diverse levels, from local, project-based initiatives (as in Box 4.12) to wider-scale public health interventions.

Monitoring and evaluation

Monitoring is an ongoing process involving the collection and analysis of information to compare how well a project or policy is being implemented against expected results. Monitoring aims at providing stakeholders with regular feedback and indications of progress in the achievement of intended results. It usually involves collecting and analysing data on implementation processes, strategies and results, and recommending corrective measures.

Box 4.12 Co-management in the Wellbeing Project, Manchester

Studies show that social conditions in the host country are a key cause of depression amongst migrants. Social isolation, poverty, exclusion, discrimination, boredom, and loss of status and purpose all contribute to distress. Disempowered people are often less likely to make healthy lifestyle choices, and may have difficulty accessing mainstream health services.

Recognizing that mental health issues cannot be addressed through health services alone, the Wellbeing Project in Manchester, United Kingdom, worked with a wide variety of statutory and voluntary organizations (for example, health authorities, local education authorities, faith groups, environmental groups, and local football associations) to organize activities aimed at alleviating social isolation amongst refugees from different backgrounds. The provision of arts, sports and cultural activities enabled people to build up supportive and ongoing social networks. Refugees were involved in the organization and management of events, which enabled them to build up links with service providers and voluntary organizations and develop an understanding of the culture of the United Kingdom.

Source: (16).

Conventionally, both monitoring and evaluation have involved bringing in external experts to measure performance against pre-agreed indicators. In contrast, participatory monitoring and evaluation engage stakeholders as active participants and offer new ways of assessing and learning from change that are more inclusive and reflect the perspectives and aspirations of those most directly affected by the issue or intervention.

Participatory evaluation means the active involvement of all stakeholders who have played a role in the design and implementation of an action in appraising activities, programmes and policies. Participatory evaluation is especially helpful when the activity or implementation process has presented difficulties, when there are doubts about the real impact of the project on the beneficiary population, or when lessons can be learned in developing the activity further. The main principles that govern participatory evaluation are as follows.

- All stakeholders, especially representatives from migrant communities, should participate in all stages of the evaluation process, from making the decision to evaluate in the first place, to the final use of the evaluation findings.
- Participants should agree on the aspects of the project to be emphasized by the evaluation process, and on how it should be carried out.
- Evaluation should focus not only on health and health-related outputs, but on assessing the processes (such as design, implementation) that led to the outputs, and the ways that these processes can be redesigned or refocused if necessary.

Box 4.13 details a successful participatory evaluation carried out with migrants in Amsterdam.

Box 4.13 Evaluation of an sexually transmitted infections (STI) prevention programme in Amsterdam

Prior to 2003, STI/HIV prevention programmes for migrant groups in Amsterdam were relatively unsuccessful. Research has shown that this was largely due to a failure to sufficiently address the cultural norms and values of migrant groups, as well as the difficulties health professionals experienced in accessing migrant groups. In 2004, the Public Health Service (PHS) of Amsterdam started a new STI/HIV prevention programme by implementing culturally-specific projects to raise awareness and promote testing. The central programme strategy was to achieve and enhance the participation of migrant community-based organizations (CBOs) in all phases of programme development, implementation and monitoring, so that they could act as intermediaries between the PHS and their own communities to realize projects that addressed community needs.

Every year, 81 CBOs working with African, Antillean, Aruban and Surinamese migrants are invited to submit proposals for STI/HIV prevention projects. The proposals are assessed by both health professionals and CBOs, and awards of 1000 to 8000 euros are granted to cover project costs. The CBOs develop, implement and monitor the projects, and the PHS supports the CBOs by providing training and educational resources.

Understandings of the impact of CBO-led STI/HIV prevention programmes were limited. Therefore, in 2010, an evaluation was undertaken to assess the obstacles and successes of the projects carried out by the CBOs, the programme organization and the CBO participation levels. This involved documentary analysis of programme manuals, minutes of meetings and project reports as well as interviews with stakeholders and participant observation of CBO activity. Rather than adopt a deficits approach to understanding what did not work, the study used the principles of Appreciative Inquiry so that questions were positively formulated to build on the strengths and assets of interviewees, and helped identify the positive aspects of participation.

The evaluation provided important insights into the aspects of the programme that facilitated and sustained CBO participation, as well as the challenges they faced. Whilst not all CBOs perceived that they had achieved high-level participation, involving CBOs at all stages was found to enhance the efficacy of the programme, empower individuals and communities, and build sustainable relationships between the health and community sectors. Importantly, the grant scheme was found to enable triability, allowing CBOs to think creatively, and to test out new projects at relatively low costs, with little loss if they did not succeed (15).

Source: (17).

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Additional resources

The Institute of Development Studies at the University of Sussex, United Kingdom, has a long-running research programme on participatory methods and approaches, details of which can be found at: <https://www.participatorymethods.org>. This includes a range of case studies and resources, as well as information of the Participatory Monitoring and Accountability programme.

WHO Europe has published a comprehensive guide to innovation and implementation in e-health. This incorporates issues relating to telehealth, e-learning, social media, electronic health records and the use of big data. Whilst not focused on migrant groups per se, many of the lessons learned in examples cited are likely to be transferable to other populations and contexts. World Health Organization; 2016 (http://www.euro.who.int/__data/assets/pdf_file/0012/302331/From-Innovation-to-Implementation-eHealth-Report-EU.pdf).

Chapter 5. Key questions for policy-makers and practitioners

In working towards intercultural competence and diversity sensitivity, a variety of factors must be taken into account. Answers to a number of questions will help policy-makers and practitioners decide whether the actions and interventions they are planning are on target. Key characteristics relating to the four domains identified in Table 2.1. are given below.

Systemic level

Systemic level is aimed at national-, subregional- and local-level policy-makers.

Does the system have:

- a commitment to embed intercultural competence and diversity sensitivity in the health system, with high-level and visible backing from senior policy-makers and management;
- a commitment to remove any existing discriminatory policies and procedures that hinder the promotion and achievement of intercultural competence and diversity sensitivity;
- a mission statement that articulates its principles, rationale and values for culturally- and linguistically competent health services across the health system;
- a whole-system approach to supporting interculturally competent and diversity-sensitive health care that can respond to and support people as they move across the health system;
- an overarching strategy, or set of strategies, and policy infrastructure for embedding intercultural competence and diversity sensitivity across the health sector;
- a requirement for tendering and contracting procedures to include interculturally competent and diversity-sensitive practices;

- organizational performance measures that include skill sets relating to intercultural competence and diversity sensitivity;
- a process for systematically collecting demographic data and conducting community needs assessments, in order to inform system-level decisions regarding appropriate needs, priorities and services;
- policies in place to support the active involvement of culturally diverse communities in matters concerning their health and well-being;
- a practical commitment to intercultural competence and diversity sensitivity, demonstrated in monitoring and evaluation mechanisms.

Organisational level

Organizational level is aimed at health care managers at national, subregional and local level.

Does the organization have:

- a genuine commitment to intercultural competence and diversity sensitivity from organizational leaders, including management and senior leadership staff;
- a mission statement that articulates its principles, rationale and values for culturally and linguistically competent health services;
- policies and procedures in place that support and incorporate intercultural diversity in the delivery of services to culturally diverse group;
- structures in place to ensure meaningful participation of diverse patients, service users and communities in diagnosing health care needs and priorities and in health care planning and delivery;
- policies for and procedures in place to periodically review demographic trends in the area it serves;

- processes in place to systematically review policy and procedures in order to assess their relevance for the delivery of culturally competent services;
- policies and procedures for staff recruitment, hiring and retention that will achieve a culturally and linguistically diverse workforce;
- policies and resources to support ongoing professional development and in-service training for staff at all levels (including frontline administration/reception staff) on issues relating to intercultural competence and diversity sensitivity, for example, awareness, reflection, knowledge and skills;
- performance measures that include skill sets relating to intercultural competence and diversity sensitivity;
- resources and methods available to collaboratively work to identify, understand and appropriately respond to the health beliefs and practices of diverse populations;
- policies and resources for the provision of good-quality interpreting and cultural mediation services, and for the provision of health information in languages and formats relevant to the service delivery area;
- awareness of and appropriate responses to forms of diversity which affect everyday well-being, for example, diet, hygiene, treatment management, as well as those relating to key life events such as childbirth, breaking of bad news, end-of-life care;
- a register of health service staff who speak less frequently used languages, for use in emergency situations;
- structures in place to ensure that health promotion and information materials are available in languages and formats that reflect the needs of diverse user groups;
- structures in place to ensure i) meaningful participation of diverse patients, service users and communities in the monitoring and evaluation of services, and ii) enabling of follow-up strategies to ensure that evaluation findings are appropriately acted upon.

Professional level

Professional level is aimed at institutions overseeing health care practice, education, accreditation and professional development.

Does the profession have:

- structures in place to ensure that intercultural competence and diversity sensitivity are built into generic and specialist training;
- recognized standards in place to guide professionals working to achieve intercultural competence and diversity sensitivity;
- structures in place to support ongoing professional development and in-service training for staff at all levels on issues relating to intercultural competence and diversity sensitivity;
- an understanding, backed up with appropriate training materials, which ensures that professionals are aware that people are influenced by their cultural context and circumstances, but are not defined by them;
- structures in place to provide accreditation and professional recognition for staff working in an interculturally competent and diversity-sensitive manner;
- strategies in place to promote member attendance at workshops, seminars and other events relating to intercultural competence and diversity sensitivity;
- strategies and resources in place to embed community partnership and participation in health care initiatives;
- the ability to develop health promotion messages that are informed by, and resonate with, diverse communities.

Individual level

Individual level is aimed at health care managers and health care practitioners.

Does the individual have:

- the ability and attitude to reflect on their own beliefs and assumptions and how may they affect clinical decision-making and practice;
- the knowledge, capacity and willingness to use resources that enable effective cross-cultural communication (that is, via interpreters and cultural mediators);
- the ability to be open to diverse perspectives relating to health, well-being and treatment, and to understand and respond to any sensitivity around specific health issues;
- a willingness and ability to keep abreast of the major health and social care issues that affect the diverse communities they seek to serve;
- a willingness and capacity to undertake continuing professional development and training to develop the necessary skill set to foster interculturally competent and diversity-sensitive practice;
- a willingness and ability to engage with patients, service users and communities, to ensure that their needs and priorities are integral to effective health care support.

Annex 1. Definitions¹

Asylum seeker: An asylum seeker is an individual who is seeking international protection and sanctuary in a country other than the one of his/her usual settlement. In countries with individualized procedures, an asylum-seeker is someone whose claim has not yet been finally decided on by the country in which he or she has submitted it. Not every asylum seeker will ultimately be recognized as a refugee, but every refugee is initially an asylum seeker.

Migrant: At the international level, there is no universally accepted definition of the term migrant. Migrants may remain in the home country or host country (settlers), move on to another country (transit migrants) or move back and forth between countries (circular migrants such as seasonal workers).

Migration: The movement of a person or a group of persons from one geographical unit to another for temporary or permanent settlement. Temporary travel abroad for purposes of recreation, holiday, business, medical treatment or religious pilgrimage does not entail an act of migration because there is no change in the country of usual residence.

Refugee: A person who, owing to well-founded fear of persecution for reasons of race, religion, nationality, membership of a particular social group or political opinions, is outside the country of his/her nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country.

Unaccompanied minor: A minor who arrives on the territory of the Member States unaccompanied by an adult responsible for him or her, whether by law or by the practice of the Member State concerned, and for as long as he or she is not effectively taken into the care of such an adult; it includes a minor who is left unaccompanied after he or she has entered the territory of the Member States.

¹ Source: Strategy and action plan for refugee and migrant health in the WHO European Region, WHO Regional Committee for Europe, Sixty-sixth session, Copenhagen, Denmark, 12–15 September 2016

The WHO Regional Office for Europe

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

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