



Collection and integration of data on refugee and migrant health in the WHO European Region

Technical guidance

The Migration and Health programme

The Migration and Health programme is the first fully fledged programme on migration and health within WHO. Its primary goal is to support Member States in strengthening the health sector's capacity to provide evidence-informed responses to public health challenges related to migration and displacement. The programme is part of the Division of Country Support and Emergencies. It assists in policy implementation, promotes collaborative intercountry approaches and advances coherent health interventions along the migration pathways in order to promote the health of refugees and migrants and protect public health for all.

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Abstract

This technical guidance outlines current evidence, knowledge and best practice relating to the integration of migration health data into national health information systems. It highlights key principles, summarizes priority actions and challenges, maps existing international commitments and frameworks and provides practical policy considerations for promoting collection and integration of migration health data. Specific areas for intervention include establishing a multistakeholder working group for overseeing data collection and integration, creating a regulatory framework for preventing unauthorized access and use of health data for non-health purposes, integrating core variables into the data collection system and promoting data linkage. While the main intended audience of this technical guidance series is policy-makers across sectors at local, national and regional levels, the contents of this publication will also be of value for health-care practitioners, health planners and health information specialists and law enforcement officials.

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Abbreviations and acronyms

CARE	Common Approach for REfugees and other migrants' health (project)
ECDC	European Centre for Disease Prevention and Control
ECRI	European Commission against Racism and Intolerance
EEA	European Economic Area
EGMS	Expert Group on Migration Statistics
EGRIS	Expert Group on Refugee and Internally Displaced Persons Statistics
EU	European Union
GDPR	General Data Protection Regulation (EU)
HEN	Health Evidence Network
HIATUS	Health Information Assessment Tool on Asylum Seekers
HIS	health information systems
HMN	Health Metrics Network
IHR	International Health Regulations
IPUMS	Integrated Public Use Microdata Series
IOM	International Organization for Migration
Maamu	Finnish Migrant Health and Wellbeing Study
NCD	noncommunicable disease
NGO	nongovernmental organization
SDG	Sustainable Development Goal
STEPS	WHO STEPwise Approach to Surveillance
TB	tuberculosis
TG	technical guidance
UNHCR	United Nations High Commissioner for Refugees

Summary

The health of refugees and migrants is important from a human rights, public health and socioeconomic development perspective as well as for the achievement of the Sustainable Development Goals (SDGs). Refugees and migrants are disproportionately affected by communicable diseases such as HIV and tuberculosis (TB), and their risk for noncommunicable diseases (NCDs) increases with their duration of stay in the host country. Therefore, data availability and integration of such data into national health information systems (HIS) are crucial for policy planning and implementation of refugee- and migrant-sensitive policies and intervention programmes. Currently data collected on refugees and migrants are more focused on infectious diseases and are rarely well integrated into routine HIS. A system designed to manage health-care data is the cross-cutting component of the health system on which overall policy and regulation of all the other health system areas can be based. The current COVID-19 (SARS-CoV-2) pandemic further highlights the urgent need for integration of migration health data into every national HIS in order to support the inclusion of refugees and migrants in preparedness and response plans.

The current status quo in the WHO European Region for migration health data clearly indicates the need for improved data collection and integration. Health data may be available but cannot be disaggregated by migratory status – and migratory status data exist but are currently not connected and/or integrated with health data. Further, the migration health data that do exist are currently not representative of all migrant populations.

The challenges for both the collection and the harmonization of migration health data have been well documented. Refugees and migrants are a heterogeneous group, and even now there is no internationally accepted definition of the term migrant. Other barriers for collecting data from this population include difficulties in accessing key migrant subgroups, mistrust and language barriers. Harmonization of migration health data proves difficult because of the varying indicators and definitions used. Furthermore, there is limited sharing of data between agencies, partly because of incompatible software systems and data protection regulations on both national and regional levels.

Integration of migration health data directly into national HIS is a more comprehensive approach that makes implementation of policies far easier and more sustainable in the long term. It also increases the availability of migration health data and supports data comparisons with the host population. There are risks associated with the creation of a separate system specifically for refugees and migrants; comparability heavily decreases and such a system is often technically complex, resource intensive and, overall, unsustainable for many countries to maintain.

The essential resources needed to operate functioning HIS include personnel, financing, logistics and information technology, along with guidance from regulatory

and legislative components. The collaboration of multiple ministries and organizations is necessary for collection of migration health data. Furthermore, migrants themselves or their representatives, including nongovernmental organizations (NGOs), should be involved in both the structuring and the integration of migration health data into national HIS.

In this technical guidance (TG), the variables needed to capture migration health data are focused on the domain of determinants of health (socioeconomic, behavioural, environmental, demographic and political factors). This is based on the presumption that variables in other domains (health status and health system), already exists in national HIS as they are relevant for the entire population and are used to monitor and evaluate the health of the host population. The integration of a set of core variables into HIS will facilitate disaggregation of HIS data by migratory status. These core variables include country of birth, country of citizenship, year and month of arrival and country of birth of both parents. A set of recommended variables can support further disaggregation of health data by migrant subgroups and include reasons for migration, knowledge of the official language(s) of the host country, whether migrants have ever resided abroad and legal status (Table 1 below has more details on these variables).

No single data source can provide all the information needed for HIS, much less for migration health data. Consequently, a combination of sources is necessary, which calls for cooperation and linkage between datasets from different entities, organizations and ministries. Qualitative data sources should also be considered and integrated within routine data collection systems as this will support further exploration of the health needs of refugees and migrants.

Data linkage of multiple data sources to create comprehensive datasets for individuals or events can be achieved in a variety of ways depending on the structure and needs of the national HIS. Such linkage will enhance the availability and completeness of migration health data. Certain strategies can be employed to increase the response of refugees and migrants in routine data collection: oversampling, purposive-sampling, multilingual surveys and the use of cultural mediators. The principles of informed consent and the anonymization of data should be encouraged as standards in data collection for all refugees and migrants. Steps should also be taken to safeguard this sensitive data from being used for non-health purposes; options for safeguarding include firewalls, laws that regulate the use of private data and direct anonymization of sensitive data.

Raw data alone are rarely useful. Therefore, migration health data need to be transformed into information that can become a baseline and guide for evidence and knowledge. Reporting on migration health should be in accordance with reporting frameworks (e.g. for the SDGs and Health 2020) and should not create an added burden in reporting for Member States if it is integrated within already existing structures. Collected migration health data should, in turn, benefit the health of refugees and migrants, for example by allowing researchers easy access to the data and using the

results to inform policy and targeted interventions. In order to harmonize migration health data at regional and global levels, migration health variables, data collection and synthesis at national levels have to be harmonized first.

Overall, the recommendations for migration health data collection and dissemination focus on targeted integration into national HIS to support the sustainability, ease, effectiveness and quality of migration health data. Routinely collected migration health data, using core variables, will allow for disaggregation by migratory status in order to better understand the health needs of this population.

Introduction

The importance of refugee and migrant health

As a result of increased mobility, societies have become more diverse as have their health needs and the risks that need to be addressed through a public health approach (1). In 2019, over 96 million refugees and migrants were estimated to be in the WHO European Region, corresponding to about 35% of the world's population of refugees and migrants and about 10% of the total population of the Region (2).

The right to health is a fundamental human right for everyone, including refugees and migrants (3). The principle of leaving no one behind in the SDGs and the promotion of universal health coverage strive towards ensuring good health for everyone (4). Promoting equitable access to health care and health promotion for refugees and migrants has several benefits, including economical and health benefits as it diminishes the risk of late presentation of diseases, with greater associated personal and economic costs, and plays a key role in improved public health outcomes (5,6). Refugees and migrants have a developmental role in both communities of origin and communities of destination through their intellectual, social and financial contributions to social and economic development (6,7). Migrants of working age often have higher labour force participation than non-migrants of the same age group (8). Remittances sent home by refugees and migrants directly contribute to poverty reduction and improvement of health and education for the families left behind (3,9). Beyond the economic sphere, refugees and migrants contribute culturally to their societies, through food production, sports, arts and fashion (10), as well as to overall development (11).

Promoting the health of refugees and migrants improves overall population health outcomes, maximizes the benefits of mobility and diversity and helps countries to achieve the SDGs (9). However, progress towards these goals cannot be measured without systematically collected reliable data on both health and health-related indicators for refugees and migrants. High-quality data are important for assessing risk factors and health needs for refugees and migrants, to safeguard and promote their health status and to facilitate evidence-informed policy-making and implementation.

Health systems and HIS

WHO defines a good health system as one that “aims to improve the health of individuals and societies, protect the population from health threats and the economic consequences of health loss, and provide equal access to care” (12). In 2007, WHO adopted a framework for health systems consisting of six building blocks: (i) service delivery, (ii) health workforce, (iii) HIS, (iv) medicine and technologies, (v) financing, and (vi) leadership/governance (12). The overall outcomes of the building blocks are improved health, responsiveness, social and financial risk protection, and improved efficiency (12). These are also the guiding principles for setting targets and indicators

for health systems (12), such as the SDGs and the global compacts (i.e. the Global Compact on Refugees (13)).

A system designed to manage health-care data is the cross-cutting component that collects, stores, manages and transmits data on all aspects of health care and forms the basis for the overall policy and regulation of all the other system blocks (12). There is no precise definition for HIS and the term may be used to describe routine collection of health data, health information technology, health management information systems and other activities (14). MEASURE Evaluation refers to HIS as “a system involving producers, users, and other factors contributing to the production and use of health information” (14). HIS are also described as the interaction between different sectors (home, other ministries) and the health ecosystem, with a goal of producing information that can support decision-making along all levels of well-being and within the health system (15). HIS have four main functions: (i) data generation, (ii) compilation, (iii) analysis and synthesis, and (iv) dissemination and use (16). Well-functioning HIS provide a basis for public health policy-making and are fundamental for improving the health and well-being of populations and reducing inequalities (17).

The need for migration health data

Within HIS, disaggregation of health data by migratory status is important to respond to the health needs of refugees and migrants with relation to infectious diseases, NCDs and health inequities. This need has been highlighted recently with the ongoing COVID-19 pandemic (18). Difficulties in collecting migration health data leads to issues in identifying specific at-risk groups for infectious diseases, such as COVID-19, and thereby impacts implementation of targeted health services for refugees and migrants and for the general population as a whole (19). Available observations and data indicate that refugees and migrants, and other minorities, are disproportionately affected by the pandemic (18,20–27). This is linked to the vulnerabilities some migrants face associated with poor living conditions and working environments (28,29), limited access to health care (legal and practical barriers) (18), large flows of migrant workers returning home or stranded by travel restrictions (30–32) and the relative income instability for this population group related to the pandemic (31,33). These vulnerabilities need to be accounted for when devising public health responses to disease outbreaks and other similar events. However, data on such vulnerability are not often available within or for HIS. The ability to provide public health messages targeted for this population to support resolution of this pandemic (21,34) is dependent on migration health data being readily available.

Consequently, early detection and treatment in this group is justifiable not only from a human rights perspective but also from a public health perspective (21). The WHO interim guidance for refugee and migrant health (35), the guidance on infection prevention and control of COVID-19 in migrant and refugee reception and detention centres from the European Centre for Disease Prevention and Control (ECDC) (36) and the COVID-19 Global Strategic Preparedness and Response Plan

from the International Organization for Migration (IOM) (37) all emphasize the importance of addressing the needs of refugees and migrants in reducing COVID-19-related illnesses and deaths. Alongside this, the WHO European Programme of Work stipulates that country preparedness plans must also address refugee and migrant health needs (38). The lack of availability and integration of data on refugees and migrants has increased the risk of virus transmission within and beyond refugee and migrant communities and this adversely affects disease containment efforts (18,21). A similar pattern is also observed for HIV where, in some countries, a large proportion of newly diagnosed HIV cases occur in refugees and migrants (39), although the reasons for this are not clear. Some studies indicate that a significant proportion of these individuals are infected after arrival in the host country (40,41).

The health concerns of refugees and migrants are rarely considered a public health threat within a host country, although some groups of refugees and subgroups of migrants, such as irregular migrants, are disproportionately affected by infectious diseases (42). This is seen in a number of European Union (EU) and European Economic Area (EEA; EU plus Iceland, Liechtenstein and Norway) Member States, with subgroups of migrant populations having higher prevalence of infectious diseases such as TB, hepatitis B and hepatitis C (42). Recommendations from ECDC include appropriate screening and vaccination programmes for migrants who have arrived in the EU/EEA within the past five years (42), while noting that improvements are still needed within surveillance to ensure more complete and better-quality data to support more accurate estimates on disease rates, morbidity and mortality among migrants (42).

The global fight against NCDs also requires data that are disaggregated by migratory status. Studies have shown that refugees and migrants have lower prevalence rates for NCDs on arrival in destination countries compared with the host population but that rates begin to converge as duration of stay in the host country increases (5). Although refugees and migrants have a lower incidence of certain types of cancer, they are more likely to be diagnosed at a later stage than the host population in the WHO European Region (5). The WHO STEPwise Approach to Surveillance (STEPS) on NCDs among the Syrian refugee community in Turkey showed that 58.7% were at high risk for developing NCDs (43). The increased risk for developing NCDs among refugees and migrants highlights the importance of targeted health promotion and disease prevention programmes. However, these programmes cannot be implemented properly unless quality data on refugees and migrants are available and integrated within national HIS.

In order to understand factors affecting the health status (mortality, morbidity, disability and well-being) of refugees and migrants, data pertaining to their health status alone would not suffice. Data on socioeconomic, behavioural, environmental, demographic and political factors, broadly known as determinants of health, are also important (16,44). These factors are unique to the context in which the health system operates. In addition to determinants such as education, income and occupation that are relevant for all individuals, refugees and migrants have specific determinants that are of relevance to their health, such as ability to understand the language in the host

country, entitlements to social protection and health-care services and duration of stay in a host country (5,7,45–47). It is important to collect and synthesize data on health status and determinants of health (these terms combined will be referred to as migration health data in this TG) to promote intersectoral action and a whole-of-government approach since safeguarding and promoting the health of refugees and migrants goes beyond the health sector. The WHO Strategy and Action Plan for Refugee and Migrant Health in the WHO European Region clearly calls for Member States to develop and strengthen migrant-sensitive health-care systems (45). For this to be realized, consistent, reliable health and morbidity data are needed for refugees and migrants.

Some data on health of refugees and migrants are routinely collected but collection is often concentrated around infectious diseases and only some data are taken into routine HIS (5,48). Equally, not all national or health-related data are disaggregated by migratory status. Consequently, data need to be collected, analysed and disseminated regarding the health status and all health determinants for refugees and migrants together with the rest of the population in a country (45,46).

Objectives of the TG

This TG aims to provide practical guidance for integrating migration health data into national HIS and for creating a basis for harmonization of data reporting across Member States in the WHO European Region. Integration of migration health data into the national HIS will improve the overall HIS as well as strengthen the health system for the entire population, including other vulnerable groups. Therefore, it should be part of the overall health system strengthening process.

The TG follows the principles discussed in the WHO health system evaluation framework (12). The current evidence is outlined, followed by the core technical content organized according to the six HIS components as suggested by the Health Metrics Network (HMN) framework (16). The target audience for this TG includes those in policy-making roles at local, national and international levels; health planners; ministries of health and other relevant ministries; international organizations; health researchers; national statistics offices; health information specialists; and other relevant stakeholders. Although this TG is centred on the WHO European Region, the contents, with context-specific adaptations, may also be relevant for countries and regions outside of the WHO European Region.

Key points: refugee and migrant health

- Health of refugees and migrants is important from a human rights, public health and socioeconomic development perspectives and as well as for the achievement of the SDGs.
- Refugees and migrants are disproportionately affected by many communicable diseases such as HIV and TB, and their risk for NCDs increases with their time of stay in the host country.
- Data availability and integration are crucial for policy planning and implementation of refugee- and migrant-sensitive policies and intervention programmes.
- HIS are the cross-cutting component of the health system that provides the basis for the overall policy and regulation of all the other health system blocks.
- The COVID-19 crisis further highlights the urgent need for integration of migration health data within HIS to support the inclusion of refugees and migrants in preparedness and response plans.
- Data collected on refugees and migrants are often focused on infectious diseases and are rarely well integrated into routine HIS.

Methodology

The core evidence for this TG comes from the extensive review of literature conducted and reported in the Health Evidence Network (HEN) synthesis report 66 (HEN 66), which considered evidence on availability and integration of refugee and migrant health data in HIS in the WHO European Region (48). The TG was further complemented by extensive targeted desk reviews and expert consultations. A limitation was the predominant inclusion of publications available in English, thereby not capturing evidence for the entire WHO European Region. The development of the TG was led by Uppsala University (International Maternal and Child Health) and guided by the WHO–Pécs Task Force on Migration Health Information Systems (49).

The term refugee is clearly defined in the 1951 Convention and Protocol Relating to the Status of Refugees (50).¹ However, there is no universal definition for a migrant, plus there are multiple definitions for migrant subgroups. Challenges in defining various groups of migrants were acknowledged as long ago as 1949 (51) and still persist (5, 19, 48). This lack of clarity impacts the collection and comparison of health and health-related indicators and ultimately the health of refugees and migrants. Global initiatives led by the United Nations are seeking to revise and recommend a new definition of migrant to support efforts to improve the availability of migration data in the context of SDGs (52).

While it is important to have a clear definition of the population groups covered by HIS in any country, it is beyond the scope of this TG to develop a new definition that reflects the different legal, political and social aspects present across the 53 Member States in the WHO European Region. This TG has adopted the definition of international migrant as “any person who changes his or her country of usual residence”, which was provided by the United Nations in 1998 (53); the 2019 version of International Migration Stock from the United Nations Department of Economic and Social Affairs equates international migrants with foreign born (2). As in HEN 66, the composite term refugees and migrants will be used to refer to both groups in this TG. It will include a heterogeneous set of several distinct and overlapping subgroups, such as asylum seekers, labour migrants, newly arrived migrants, international students and migrants in irregular situation (irregular migrants).

This TG focuses on how to collect and integrate data on refugee and migrant health and its determinants within routine HIS. During this process, the TG also suggests variables and indicators that would enable HIS to disaggregate health data based on migratory status, even when definitions might vary between countries. The impact on health from placing an individual into one migrant subgroup varies from country to country depending on entitlements and the health system responsiveness (6, 19), among other factors. Two other population groups that share similarities and often

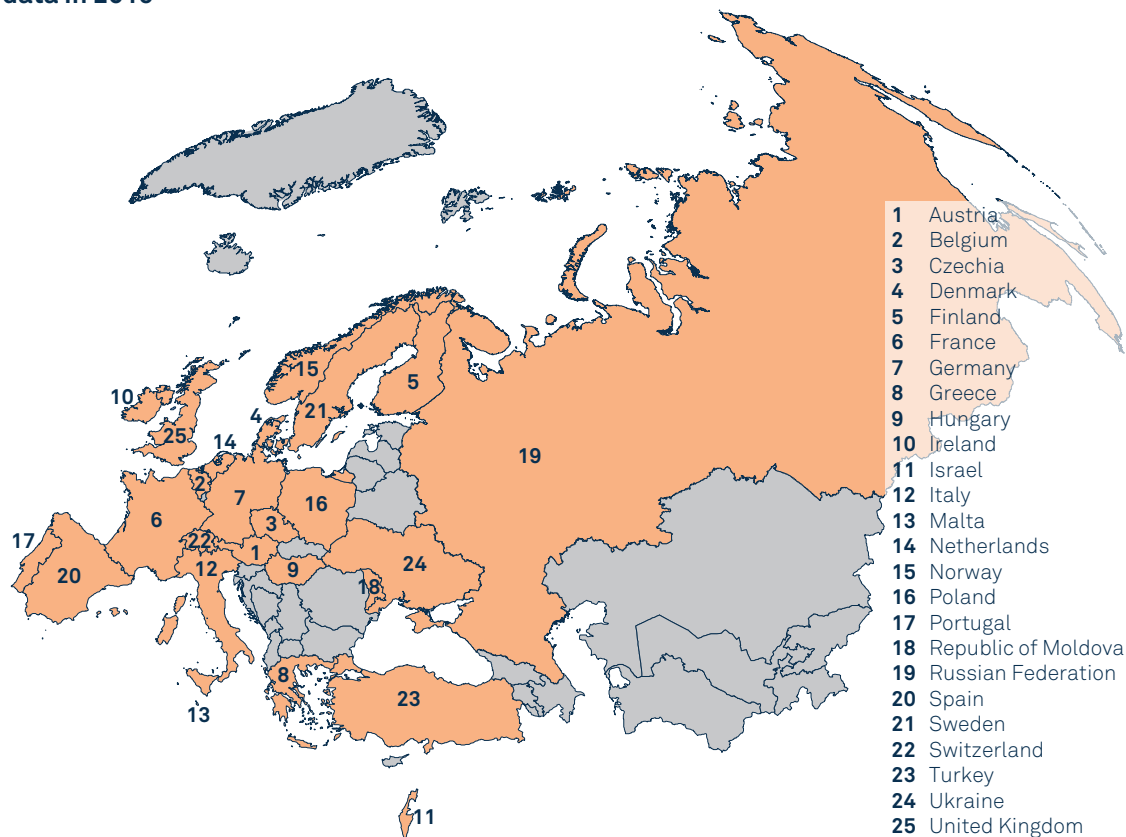
1 “Someone who is unable or unwilling to return to their country of origin owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion.”

overlap with refugees and migrants on factors affecting their health are ethnic minorities (categories vary from country to country (54)) and offspring of migrants (often referred to as second-generation migrants); these are not explicitly covered by this TG. Similarly the TG does not cover specifically internally displaced people and internal migrants, who may have specific health and medical needs and are also observed in the WHO European Region. However, if data on the core set of variables recommended by this TG are collected, health risks and inequity faced by these other groups could be identified within the routine HIS (16,44).

Overview

Fig. 1 shows the Member States in the WHO European Region that are collecting migrant health data in some context within their routine HIS. These were identified in HEN 66 through a synthesis of abstracts from over 600 studies (48).

Fig. 1. Member States of the WHO European Region with available refugee and migrant health data in 2019



Source: Bozorgmehr et al., 2019 (48).

Evidence

The need for improved data collection and integration

With the increase in cross-border population movements in recent years, the importance of reliable, accessible and timely refugee and migrant health data for public health planning has been emphasized (48). The call to strengthen data collection for refugee and migrant health has been made by intergovernmental agencies such as WHO (5,38,45,46,55,56) and by the United Nations through its global compacts (13,57), the European Commission (58,59), the Council of Europe (60) and researchers worldwide (61–65). The breadth of policies and statements issued in recent years from these stakeholders accentuates what is missing in the arena of migration health data and stresses the importance of strengthening data collection and integration practices.

Migration health data that are being collected currently are very often not comparable across countries and datasets, sometimes even within the same country; the main reasons are varying definitions of migrant and differences in data collection methods (19,62). The inability to compare data and the frequent scarcity of data could lead to inconclusive or wrong interpretations and conclusions (5,19,48). In addition to the policy initiatives highlighted above, some actions are being taken to strengthen collection, analysis, reporting and harmonization of migration health data. The recently published HEN 66 (48) and the establishment of the United Nations Expert Group on Migration Statistics (EGMS) (66), the Expert Group on Refugee and Internally Displaced Persons Statistics (EGRIS) (67) and the WHO–Pécs Task Force (49) are such initiatives.

Data disaggregated by migratory status are often incomplete in routinely collected data (68–71), resulting in inaccurate analysis or results where it is difficult to review the actual health status of refugees and migrants (68). Although linked national registers found in Denmark and Sweden provide high-quality data (48,72,73), limitations arise through the shortage of individual-level data (e.g. reasons for migration or comorbidities outside the range of the specific disease register) as well as the difficulties researchers have in accessing these datasets (72,74). In Denmark, only researchers living in Denmark or affiliated with a local institution have access to register data, creating a barrier for international studies, which require merging of datasets (72). A systemic review found that a limited number of migration variables were being collected in the EU/EEA notification system for infectious diseases (country of birth or country of nationality) and that being able to collect more dimensions of migration health data could support disaggregated analysis (75).

To understand the importance of reliable migration health data, the specific case of HIV is informative. Despite high prevalence of newly diagnosed HIV among some refugees and migrants in the EU/EEA (39), there is limited collection and integration of migration health indicators into national HIS. Refugees and migrants form a significant proportion of all newly diagnosed HIV cases in Europe (39,76), yet different studies have shown that infection is acquired by a significant proportion after they have arrived in the

Region, indicating the risks refugees and migrants face in their host country (77–79). Such knowledge is important when assessing public health challenges and framing effective responses (48). One analysis found that only Austria and France were able to obtain such information by disaggregating data for all four stages of the HIV continuum by migratory status: infection, asymptomatic, symptomatic and progression of HIV to AIDS (79). This lack of disaggregated data is a particular concern because refugees and migrants are most likely to be diagnosed at a late stage (80); this increases the risk of onward transmission and missed prevention opportunities (prophylaxis both before and after) in what is a significant group (38,79). This is particularly of concern for irregular migrants and migrants in eastern Europe and central Asia, who are particularly vulnerable because they are the least likely to get tested and enrolled in HIV care and treatment and to achieve viral suppression (81–84). For the two Member States reporting migrant data (Austria and France), only 51% of refugees and migrants received HIV treatment compared with 75% of the national population (80). There are also examples of countries where refugees and migrants often seek care in private health sector clinics not licensed to collect their health data or do not show up for health checks at all through fears of losing their job or residence permit if diagnosed with HIV. Hence, they remain forgotten and out of reach of the HIV surveillance system (85). This lack of migration health data in various countries makes monitoring this population across the HIV continuum very challenging and can lead to unfavourable outcomes.

Actual migration data can be quite scarce; official asylum statistics are provided by EU Member States to Eurostat, the statistical agency of the EU. Yet often definitions, collection systems and processes of dissemination of these data differ among the 28 EU Member States (86). This has the potential to create misinterpretation of data by the media and policy-makers as definitions for the variables being collected and what is being reported do not match; this obscures the true nature of refugee and migrant population flows (86,87). For example, border-crossing data have been used widely across the Region to represent the total numbers of migrants even though there is heavy duplication of individuals within these statistics. Furthermore, such data only give the number of people crossing the border, not the number of migrants residing within a country (86). Similarly, the United Nations High Commissioner for Refugees (UNHCR) recommends the use of caution for figures on asylum because there are no systematic means to ensure that the same individual is not being registered across multiple localities in the Region (88). These numbers can sway public opinion around acceptance of refugees and migrants through an anchoring effect, which was found to be impactful regardless of political affiliation (89), emphasizing the need for proper and reliable data.

Furthermore, immigration detention information is currently not being recorded on an EU level, leaving gaps in knowledge of duration in detention, conditions or access to medical care and other social services (86,90). While individual countries can provide information, many do not offer total transparency. As an example, the United Kingdom has started to provide more information under pressure from civil society advocates (86). Even so, evidence and information about country of origin are still hard

to determine in the United Kingdom detention system, causing difficulties for advocacy groups who provide translation and social service visits (91). It is important that routine data collection happens in such facilities because of the known health issues faced by refugees and migrants within these facilities (92,93) and the limited health care that the facilities provide (94).

Currently, migration and health data exist separately in Member States of the WHO European Region, with migratory status data being captured by some organizations (e.g. Eurostat) through national statistics offices or immigration data within countries but not linked to health data. Similarly, health data are available for refugees and migrants in routine HIS yet cannot be disaggregated by migratory status. This illustrates how capturing migratory status as part of routine HIS or through data linkage would substantially enhance and enable a comprehensive overview of the health of refugees and migrants. In order to link these datasets, data on core variables needs to be collected across all data sources for HIS.

The strengthening of data collection, and consequently the HIS, is of importance for the entire populations of every Member State, not just for refugees and migrants. One review found that for epidemiological monitoring underreporting was likely to be worse for migrants than for host populations and that existing data collection systems should be strengthened for both the general population and refugees and migrants (95). This alone will likely improve the data availability on refugee and migrant health (48), although further steps must be integrated for an all-encompassing approach.

Accurate migration health data are a precursor to providing appropriate, efficient and effective health care for refugee and migrant populations (96). The availability of accurate data is essential at the policy and planning level to support evidence-informed decision-making, and at the service delivery level to ensure more effective health care (97). The collection of accurate migration health data is an essential move forward in both monitoring and improving health equity for this population (7), as well as for promoting the health of the entire population (48). An inclusive approach to disease monitoring and control is impossible without detailed data on all relevant population groups; consequently, data on refugees and migrants, together with those for other population subgroups, need to be included in the HIS and in national plans and strategies such as national crisis plans (21).

Key points: the current situation and the need for improved data collection and integration

- Health data are available but cannot be disaggregated by migratory status.
- Migratory status data exist but are often incomplete in routinely collected data and are currently not well connected with health data.
- The migration health data that are available do not represent all migrant subpopulations.
- A wide range of policies and statements have stressed the importance of strengthening data collection and integration practices for refugees and migrants.
- Current datasets make it difficult to analyse and review the health of refugees and migrants.
- The collecting of accurate migration health data is essential both for monitoring and improving health equity for this population and for promoting health for the entire population.

Overview of HIS in the WHO European Region

There is a great variety in the format of HIS across the WHO European Region, predominately in the way in which Member States collect and manage data, although also in how those data are used (analysed and disseminated) (12, 16). It has been found that many Member States in the Region lack routine systems to collect refugee and migrant health data (61,98,99), although this has been stated as a priority in several international strategies and goals.

HEN 66 found that only 25 of the 53 Member States in the Region collected any such data (Fig. 1), with the quality, readiness of availability and types of data source varying widely (48); information on the most vulnerable subgroups (asylum seekers, irregular migrants) was generally insufficient (96). However, 10 Member States have recently indicated that they plan to start incorporating migration health variables into their data collection systems (100). For those data sources that were found to include migration indicators, the integration of these into national HIS was overall limited (48).

On the national level, the most significant institutions for collection, analysis and dissemination of migration data are the national statistical offices (101). Some Member States have decentralized and more heavily fragmented health systems, while others operate under a more centralized model. This influences how and when data can be shared, and who has access. Knowledge on the different components of HIS in the Region are fragmented, and evidence was unevenly spread geographically (48). Member States without a general population health register include Germany, Israel, Italy, the Netherlands and Spain (48). In these Member States, data are

collected predominately through a wide range of surveys (101). Comprehensive wide register-based systems are found primarily in Nordic countries (48, 101). Statistical offices in countries where there are general population health register systems usually have more consistent access to other administrative registers, whereas in countries without such registers direct access to data from other authorities is limited and their role may be only to aggregate data (101).

Eurostat is the prominent institution in the EU that collects, compiles and disseminates statistics, including migration data (101). Eurostat is predominately responsible for EU/EEA Member States (86), although data are also received from candidate countries and others outside of the EU. Other international actors are involved in data compilation and dissemination; UNHCR routinely collects data on asylum seekers and refugees, while the United Nations Department of Economic and Social Affairs provides regular estimates on international migrant population stocks (2). Migration data are further compiled and disseminated by the Organisation for Economic Co-operation and Development (102), the IOM (103) and the International Labour Organization (101, 104). The ECDC plays an important role in compiling and disseminating data regarding communicable diseases in refugees and migrants, mainly within the EU/EEA (105, 106). However, data collection may extend past the group of EU/EEA plus Switzerland, as with COVID-19 where the ECDC is compiling data from 196 countries by screening over 500 primary sources daily (107), although migratory status is not consistently captured and reported by all countries. Again, this creates challenges with comparability and, as a highly mobile population, refugees and migrants are at high risk for infectious diseases.

Key points: overview of HIS in the WHO European Region

- HIS differ greatly across the WHO European Region.
- Migration health data is collected in some form by 25 of the 53 Member States.
- National statistical offices are key stakeholders.

Main challenges for collecting migration health data

Collecting migration health data is complex for a variety of reasons and is indicative of the political and historical context surrounding migration (96). There are also different conceptual and methodological challenges, as well as technical barriers, that must be overcome. These can include variations in the subgroups used for migrants, understanding what constitutes a migrant, difficulty in accessing certain migrant subgroups (96) and barriers related to language and mistrust (108). Various initiatives over the years have tried to solve the challenges surrounding migration health data collection (101, 109, 110). One such project set up an information network to “promote exchange of best practices for migrant health care” on a regional level (110). Another

developed criteria and indicators to monitor the health status of migrants in the EU (61). However, challenges still persist.

The lack of internationally accepted definitions for what constitutes a migrant has meant that the specificity of the data collected, defined and decided is only relevant at that national level, if defined at all (48,96). Each individual country collects migration data relative to the legislative, policy and administrative needs of the country (111). This variance in terminology, and what is deemed acceptable and necessary, is essentially a reflection of the historical context, welfare structures and immigration histories of each nation state (63). While some Member States in the Region collect data on ethnic minorities, often as a proxy for migratory status, others find it unnecessary or refuse based on ideological, ethical and security concerns regarding data protection (112, 113). Furthermore, the traditional sense of migration as being only unidirectional has shifted (96). The need to take into account circular, temporary and return migration will affect the classifications that are employed, and subsequently the data collected to reflect these variations (96). The migration journey itself may last several months and may expose refugees and migrants to human rights abuses as well as health risks (114). Periodically, definitions on migration are altered for historical and political reasons, which also leads to decreased comparability of migration data over time both nationally and regionally. This can be seen when countries join the EU and must follow the EU's legal regulations, which will have an impact on their data collection for population statistics (101). Finally, when is a migrant no longer considered a migrant within a nation? At some point, a migrant will formally become part of the host population and will no longer be considered a migrant (115). The existence of a commonly agreed definition of the term migrant would address the challenges arising currently in classifying the appropriate group, identifying risk and making cross-country and regional comparisons and analysis. Such a universally accepted definition for migration does not currently exist.

In terms of collecting data, it must be understood that migrants themselves are a heterogeneous group with a wide range of subpopulations such as irregular migrants, international students, unaccompanied minors and regular migrants (48,96). This is particularly important since such subpopulations will have distinct health concerns (48,96) and even within subpopulations there will be a wide variation in vulnerabilities (5,48,96). HEN 46 examined the impact that variations in the definitions used for the term migrant had on access to health care and found that studies often highlighted the need for more data collection on the subgroups of migratory status to better understand differences in delivery and access of health care (19).

When analysing migration health data collected through surveys and clinical studies, it can be difficult to identify relevant results for migrant and refugee populations (63,96, 101) because of a number of issues.

- Disaggregated lists (variables on migratory status) are often not available to researchers who wish to build a proper sampling frame for refugee and migrant populations, and if such lists are available, they may not have reliable ways in which to contact individuals (108). A study in Denmark found that refugee and

migrant populations had lower response rates than the Danish host population and that this was specifically related to the contact phase (reaching out and enrolling individuals into a survey/interview) (115).

- Failure to adapt methodologies to people's language needs can also inhibit data collection. For example, in the Netherlands, refugees and migrants formed a smaller proportion of respondents to questionnaires written only in Dutch than for those translated into multiple languages (63). In Germany, health monitoring surveys were translated into four languages (English, Russian, Serbo-Croatian and Turkish) but in spite of this the only reliable data were obtained for Turkish migrants (116), indicating that language is not the only barrier for refugee and migrant participation.
- Terminology used within surveys may also carry different meanings among refugees and migrants (63). For example, the concept of health may differ among different populations.
- Challenges can arise because of the mobility of refugees and migrants as they adjust to settle in their host country (7,108). Some subgroups, such as irregular migrants, are particularly difficult for monitoring and data capture (63).

A systematic review found that these language, literacy and cultural barriers as an entirety create barriers for gathering migration health data and related figures (117). Even when approaches to increase acceptance among refugees and migrants are implemented, they often require additional human and other resources (48). These structural barriers alongside limited participation from local and regional authorities and the burden of collecting additional indicators (70,71) create further obstacles that must be overcome.

The use of electronic personal health records nationally and along cross-border migration routes is a potential solution provided that migration health indicators are integrated or linked to other databases (7,118,120,121). However, this method, which is part of the Re-Health project, will still only capture migrant populations who are utilizing health care. With the sharp increase in the use of mobile phones and wearable devices, new sources of data could be available and, additionally, this might improve follow-up rates and access to health care (120). Such an approach is not without risks, as surveillance through these methods has already been employed by both governments and private contractors (121).

Mortality data for refugees and migrants are often incomplete and are particularly challenging for irregular migrants, who often remain invisible to authorities (122). In general, mortality data cannot be disaggregated by migratory status (123), with wide variations in availability of mortality data across the Region (122). For those who die during the migratory journey, their bodies may never be found or reported because of the remote topography, or the deaths may never be reported to authorities for fear of legal consequences (123). While mortality data are more likely to be available for migrants living in high-income countries, a review of mortality patterns in international migrants found limited data exist for certain subpopulations, such as refugees, asylum seekers and irregular migrants, and this is more likely within low- and middle-income countries (124).

It must also be recognized that many refugees and migrants may be cautious in sharing sensitive data related to their status (48,96). This may stem from the fear of being stigmatized or discriminated against or, for subgroups such as irregular migrants, the fear of detection leading to potential deportation is paramount (64,96). Attempts to access health data by migration agencies for non-health purposes has been reported (Box 1) (7, 125–127). It has been recorded that health records are being used not only to improve the health of refugees and migrants but also to make decisions on migration issues and admissions (128). For example, a policy of deporting migrants who screen positive for TB, HIV and other communicable diseases during compulsory health check-ups causes migrants to avoid the official health system (85). A systematic review of challenges and facilitators for providing primary health care for refugees and asylum seekers in high-income countries discovered that greater disclosure of health and social information occurred when trusting relationships were found between patients and health professionals (117).

Box 1. Health data for non-health purposes

In January 2017, a Memorandum of Understanding between the United Kingdom Home Office and the National Health Service for NHS Digital was signed. It formalized the existing arrangements for the Home Office to make disclosure requests to NHS Digital to trace irregularities connected to individuals' immigration status. Many requests made were used by authorities for the enforcement of immigration law (125).

There have been several requests for these data since 2010, which led to public debates and concerns that these requests and the Memorandum of Understanding would undermine confidence in the public health system, infringe upon the rights of refugees and migrants in accessing health services without been subjected to any legal or social consequences and discourage them from utilizing health services. This could have a negative impact on the health outcomes for this group and the wider public. Health-care providers considered that this agreement to share patient data was not in line with the core principles of the health service since its implementation could adversely affect health care access and patient safety.

As a result, in May 2018, the Government announced a reversal of the policy and narrowed the scope of the Memorandum of Understanding so that it only covers data sharing in cases of criminal investigations in which a person may be a suspect of a serious crime (126, 127).

This example highlights the importance of transparency and clarity in laws governing the sharing of data within HIS in order to avoid a negative impact on the health of refugees and migrants.

These issues call for a reflection on the overall purpose of collecting migration health data, and what steps must be taken to ensure that the purpose is upheld and data are

not misused. The questions on how to proceed with data collection, synthesis, storage and sharing on both a national and regional scale will be taken up in the following sections along with potential solutions to the many challenges that have been raised here.

Key points: main challenges for collecting migration health data

- Refugees and migrants are a heterogeneous group, with no clear terminology of what constitutes a migrant.
- Barriers hamper access to migrant subgroups, including making contact with people who may be on the move, language, cultural and terminology issues (e.g. does health have the same meaning and relevance) and trust issues related to fears of being stigmatized, discriminated against or reported to other agencies.

Challenges in harmonization of migration health data

Health data, particularly when determinants of health are included, are not produced by a single entity. Consequently, any plan to harmonize migration health data must be collaborative and all-encompassing. Migration health data can be produced and used by a variety of institutions at both national and regional levels, including various ministries, national statistic offices, emergency response, private entities, local civic organizations and development assistance organizations, as well as by international agencies (16). The abundance of data sources creates a multitude of challenges, such as incompatible software systems across data sources, limited sharing between ministries and agencies, data protection stipulations and the use of different indicators and definitions; all of these must be considered before harmonization can occur. This collecting of data into silos is a major obstacle to the integration and use of datasets, as is the lack of linkages that currently occur between different datasets within the WHO European Region (129).

Harmonization of migration health data will support calls from Member States within the WHO European Region for comparability of health data (5). Global initiatives (13,57,67,130–133) have already encouraged harmonization of data to support the achievement of agreed goals, and, although data harmonization has been suboptimal, this has resulted in improved comparability of international data (134). The ability to share and compare data across countries is very important for migration health because it not only measures the progress towards global goals. but more importantly, sharing of data for a mobile population such as refugees and migrants between countries is a prerequisite for good public health. The SDGs have a core aim to leave no one behind with emphasis placed by international actors on the need to uphold the health of refugees and migrants within this (135). Comparability across countries further reinforces the ability to explore best practices and improve policy

coherence (136). A comparative analysis of HIS in different countries also supports understanding of how meso and macro features (e.g. how health-care systems are structured, or specific migration policies) can impact refugee and migrant health status (137). Comparable data also support policy-makers in monitoring progress nationally and regionally, while also allowing trends to be identified over time (134).

HEN 66 examined HIS in the WHO European Region and found that the lack of clear regional and national strategies prevented the collection of migration health data and resulted in minimal nationwide datasets. Instead of emphasizing comprehensive public health monitoring, the focus has been instead on infectious disease monitoring (48). Lack of standardized data collection and dissemination practices by international NGOs leads to further problems in harmonizing data for refugee and migrant health as this prevents comprehensive assessment of their work or comparison across the many essential services that are being provided to refugees and migrants through their programmes (138). Adoption of Regulation No. 862/2007 on community statistics on migration and international protection by the European Parliament (59) has led to improvements in the availability of migration statistics (137). Changes and consolidation of definitions (for immigration and migration) have created better cross-border comparability (most notably in Germany and Poland), and the selection of specific migration variables to be reported by all EU Member States to Eurostat has improved data collection, although discrepancies have not been eliminated altogether (137). However, this Regulation focuses on migration data specifically, not health data, so there continues to be a lack of migration health data as a whole.

While the issue of cross-border datasets is not unique to migration health data alone, the ability to create a strong platform that will support such datasets has many implications that must be explored. One of the main challenges identified for migration health data is the wide variety of indicators and definitions being used among countries, which reduces the ability to compare datasets and findings. Shared datasets for certain indicators and diseases do already exist within the EU, the WHO European Region, the Organisation for Economic Co-operation and Development and several other organizations (139–141). However, establishing the regulatory grounds, reporting frameworks and consensus for these databases took many years. It relied on clear policies, regulations and coordinated efforts such as the International Health Regulations (IHR) (142) and WHO's International Classification of Diseases (143) to put national systems into place to support harmonization of variables collected and reported at national, regional and global levels. Obtaining comparable migration health data from HIS will, therefore, take time in order to incorporate national political and historical contexts (101). The first step for an eventual harmonization of collection and reporting of data is the establishment of a common set of well-defined indicators.

A balance must be achieved between the goal of sharing datasets on migration health and the valid concerns surrounding data privacy and ownership (129). Provisions for data privacy have already been implemented within the EU/EEA with the implementation of the General Data Protection Regulation (GDPR), which increases the level of legal protection for personal health data (144). This is the

first data protection law that refers to the humanitarian sector, thus affecting the use of migration health data when humanitarian organizations assist refugees and migrants (145). It has implications extending to the sharing of migration health data with third-party states or international organizations outside the EU, although there are exceptions for research (Art. 89(1)) and appropriate safeguards required from third parties (Art. 46) (146). If migration health data are anonymous, GDPR should not present any obstacle to collecting or sharing of migration health data, although further linkage and use of a database for storage may require explicit consent if data are stored outside the EU/EEA (Art. 39 and Art. 53) (146). By comparison, the IHR focus on the sharing of data with WHO and other Members States in the case of a public health emergency of international concern (142). The main principles of the IHR focus primarily on the need for anonymization of data and informed consent, and they address the concern that data collection can lead to stigmatization and exclusion if not used or shared appropriately (147).

Key points: challenges in harmonization of migration health data

- A wide variety of institutions collect data within countries and there may be limited sharing of data between agencies.
- Incompatible software systems and data protection regulations may make it harder for institutions and countries to share data.
- The use of different indicators and definitions in different datasets impairs comparability of data.

Integration of migration health data into national HIS

As the global push for universal health coverage continues, so too should HIS stay universal. The Lancet Commission on Migration and Health recommends an integrated approach that whenever possible adapts information systems and data sources to include migration data rather than the creation of a completely separate system (7). An integrated approach, therefore, relies on set standards and protocols to help to guide systematic migration health data collection. For existing data collection systems, this would be the ideal option as it would promote implementation, sustainability and increased availability of refugee and migrant health data (48,62).

However, a separate HIS may be necessary in certain scenarios such as ports of entry or major transit hubs where large numbers of refugees and migrants are crossing through with no intention of staying in the country for a relatively long period of time. Health needs of this mobile population must be met somehow. Separate systems have already been implemented by international organizations such as the IOM and UNHCR (118,126,148,149). Establishment of separate systems should still allow data sharing with national HIS and should uphold the reporting requirements of the nation state in order to be truly effective (148). Other scenarios where separate HIS may be required are discussed in the Core technical content.

Researchers suggest a more comprehensive approach would be obtained through the integration of migration health indicators jointly in data sources such as medical records from health-care facilities and population-based data collection methods (e.g. health monitoring surveys) (62,63,74). The recent Improving Health Monitoring in Migrant Populations project is a good example for integrating migratory status variables within routine collection systems (Box 2) (150–152).

Box 2. The Improving Health Monitoring in Migrant Populations project, Germany

The Robert Koch Institute, the German national public health institute, has shown increased efforts and a strong political will to invest in strengthening the HIS by integrating migration health data into routine data collection (150). The project Improving Health Monitoring in Migrant Populations (2016–2019) contained eight subprojects aiming to improve the integration of refugee and migrant data into the health monitoring carried out at the Robert Koch Institute (151).

A set of 25 key indicators were developed to describe the health of people with a refugee or migrant background and an additional 41 indicators created an extended set (152). The choice of core indicators was based on five principles: (i) a systematic comparison of widely accepted indicator systems, (ii) an assessment of public health relevance, (iii) comprehensibility, (iv) informative value, and (v) the availability of (largely) representative data that could properly account for the diversity of the refugee and migrant populations.

The project has highlighted deficits in data availability particularly on “indicator-based description of health status and the utilization of health services” for refugees and migrants. The results of the project will be used in the next nationwide interview and examination survey of the adult population in Germany. In the future, the indicator set will be incorporated into the overall data collection for regular migration-related health reporting. The reporting will also take into account length of stay, legal status, German skills and region of origin.

Key points: integration of migration health data into national HIS

- Integration using a systematic approach for migration health data collection promotes ease of implementation, sustainability and increased availability of relevant information.
- A separate system may be useful in certain situations such as ports of entry or major transit hubs to ensure that health needs are met for a mobile population with no intention of staying in a country for any length of time.

Core technical content

HIS strengthening and supporting tools

Strengthening national HIS is a continual process because of the nature of technological advances, shifts in political priorities, changing disease patterns and changing health-seeking behaviours (153). Investments made in increasing HIS performance will also contribute to the overall strengthening of a nation's health system, as the other building blocks of a health system depend on reliable data (99). It would also improve health monitoring overall (95). As national HIS are constantly shifting and open to dynamic changes, assessment tools are useful to benchmark the strengths and weaknesses and overall performance (99). Assessments guide the development and strategic plan for HIS strengthening in order to support investments at varying intervals: short (1–2 years), medium (3–5 years) and long term (10 years or more) (154). The objective of assessing national HIS is to provide a baseline for follow-up evaluations, inform stakeholders about all aspects of the HIS, build consensus among all stakeholders involved in the production and use of data, and initiate technical and financial support for the coming strategic plans (154).

A variety of tools and projects already exist to support the general strengthening of HIS, including those from MEASURE Evaluation, through which a HIS strengthening model was developed (153,155,156). The WHO Regional Office for Europe also launched a support tool to assess HIS and develop and strengthen health information strategies (157), which focuses on the development of national HIS strategies to contribute to the implementation of Health 2020 (157). WHO also has a regularly updated package: SCORE for Health Data Technical Package, which addresses data gaps, scalable solutions and informed policy action to strengthen data collection within HIS (158).

There are also tools that specifically support strengthening HIS in the context of migration health data. Member States should assess whether the information of interest (migration health data) is already being collected by routine data collection systems in their country, and whether it is readily available, accessible and sufficient (159). The Toolkit to Assess National Migration Data Capacity facilitates an assessment of national capacity for producing comparable statistics on international migration flow (160). The MIPEX Health Strand is a project within the Migrant Integration Policy Index that assesses the equity of migrants' health-care coverage and ability to access services within national health systems (161). The project has already profiled countries within the EU/EEA, plus Bosnia and Herzegovina, North Macedonia, Switzerland and Turkey. Profiles have also been completed outside of the WHO European Region in traditional countries of immigration (Australia, Canada, New Zealand and the United States of America) (161). Their indicators provide a useful baseline for countries to explore and compare their strengths on policies that support equity. One indicator "collection of data on migrant health" explores if migratory status data are collected or can be linked to national databases (161). Finally, HIATUS (the Health Information Assessment Tool on Asylum Seekers) was built and piloted as an instrument to compare and benchmark

national HIS in relation to asylum seekers' health care needs (99) and could possibly be adapted for refugees and migrants.

The strengthening and implementation of migration health data collection depend on a strong and adaptive HIS and should incorporate measures from all six components outlined in the HMN framework (16): (i) HIS resources, (ii) indicators, (iii) data sources, (iv) data management, (v) information products, and (vi) dissemination and use. These components provide a logical flow from the inputs (resources to ensure a fully functioning HIS and to enable such a system to be functional), via the processes (indicators, data sources and data management) and on to the outputs (production, dissemination and use of information) for HIS. The following sections use this framework to organize and analyse the core technical content in order to explore challenges and opportunities and provide guidance for the collection and processing of migration health data and its integration into national HIS. This will facilitate data harmonization across the WHO European Region.

Key points: overall health system and HIS strengthening

- Strengthening for national HIS is a continual process and will contribute to the strength of the overall health system and support better health monitoring for all populations.
- There are a variety of tools that can be used to support the strengthening of HIS overall as well as more targeted tools to explore migration health equity and inclusion of migration health within health systems and data collection.

HIS resources

The pivotal resources needed to operate a functioning HIS include personnel, financing, logistics support, information and communications technology alongside legislative, regulatory and planning frameworks (16, 156). Functioning HIS rely on the interaction and collaboration of institutions, which can include ministries in charge of health, education, labour or justice; national statistics offices; and disease surveillance programmes (16) as well as international organizations and their programmes (138). As HIS function in different ways across the WHO European Region, the availability of migration health data also differs considerably (159). The HMN suggests that a representative steering committee, composed of representatives of key stakeholders involved within the collection and use of health data, would be useful to guide the development and maintenance of HIS (16). This would extend beyond health institutions because relevant sociodemographic information or determinants of health that are highly relevant for migration data collection may be available through other registries and ministries (e.g. ministries in charge of labour, migration or the interior) (16).

Additionally, not all migrants have the same access to health care, for example irregular migrants and asylum seekers (5,7). Consequently, multiple actors are required to be involved in the process of collecting and synthesizing migration health data and disseminating information. National working groups supported by an international body to assist with technical and liaison capacities would enhance the integration and harmonization of migration health data at national and international levels. This approach has been supported by projects focused on HIS strengthening (153), commissions (7) and academics (95,162). There is also growing evidence supporting the involvement of the end users, the refugees and migrants themselves, in similar committees at local and national levels to ensure that services meet their needs (163–166). Involving refugees and migrants in the decision-making process is important to make health services responsive and needs based.

Legislative regulations already exist, although not in all 53 Member States, to support data collection and sharing efforts. For example, the European Parliament and Council regulate what migration statistics are gathered and shared in the EU through a multitude of regulations (59,167–169). Some regional examples support the collection and sharing of migration statistics, although there is less evidence about the situation in countries other than in the EU/EEA (48).

On a global level, WHO data policy differentiates between sharing data in public health emergencies (170) and outside public health emergencies (147). It encourages the sharing of information by all Member States during a public health emergency, when the IHR come into effect and are binding on all WHO Member States (142). In relation to the processing of personal data (e.g. migratory status), the IHR stipulate that a public health risk (“an extraordinary event which is determined to i constitute a public health risk to other States through the international spread of disease; and ii [t]o potentially require a coordinated international response” (171)) can justify a situation where personal data may not be treated anonymously (Art. 45 IHR) (142). Under Art. 95 of the EU’s GDPR, international agreements made prior to 24 May 2016, and which comply with EU law, would remain in force until amended, replaced or revoked (146). Outside of public health emergencies, the WHO data policy is no longer binding and is managed through a policy statement (147). This data policy gives direction on principles that need to be implemented in the collection and sharing of migration health data, namely anonymization and informed consent (147).

Many global compacts and regional guidelines exist that frame and support the sharing of harmonized data (Box 3).

Box 3. Global compacts and regional guidelines that support harmonized data for refugees and migrants

While global compacts and regional strategies are not binding laws, they are useful in mobilizing countries to actively collect and harmonize migration health data. Two strategies are examples of how such documents could facilitate disaggregation of health data by migratory status and integration with HIS and harmonization.

Global indicator framework for the SDGs

The Inter-Agency and Expert Group on SDG Indicators developed a set of 231 unique indicators in 2017, which would be refined and reviewed annually (172).

- 24 indicators should be disaggregated by migratory status (e.g. 1.1, 3.2, 3.c, and 5.5) (173);
- several indicators are directly related to migration (4.b.1, 10.7.1, 10.7.2, 10.7.3, 10.7.4, 10.c.1 and 16.2.2) (172, 173); and
- two indicators explicitly require disaggregation by migratory status (8.8.1 and 8.8.2) (173).

The WHO Strategy and Action Plan for Refugee and Migrant Health in the WHO European Region

The Strategy and Action Plan was presented to the WHO Regional Committee for Europe in 2016 with the aim of “promote the inclusion of migrant variables in existing data collection systems” (45). A progress report in 2020 found that the majority of Member States that did not currently collect migration-related variables have plans to incorporate such data into their routine HIS (100). This encouraging trend highlights how guidelines can support better integration of migration health data.

The WHO Global Action Plan, Promoting the Health of Refugees and Migrants

The Global Action Plan advises the strengthening of HIS to ensure that standardized and comparable records on refugee and migrant health are available at global, regional and country levels (46).

No EU Member State has laws to fully prohibit the collection of so-called ethnic data, which is defined by the European Commission against Racism and Intolerance (ECRI) as “statistics broken down by citizenship, national origin, language and religion” (113). Yet, in many national contexts ethnic data are not collected because it is deemed highly sensitive and concerns over the potential misuse of such data collection prevail (e.g. eastern Europe and Germany) (96). Even France, which is often seen as a country with complete prohibition on collecting such data, has key exceptions. Public statistics offices are allowed to collect data on origins (e.g. geographical origin, previous citizenship) (113), although the French Constitutional Council prevents the expansion of variables on race or religion within administrative files (174). This example demonstrates how the interpretation and lack of clarification provided by such laws

can create levers and barriers for collecting migration health data, as publicly funded statistical agencies are reluctant to collect data on ethnicity, a proxy for migratory status in many cases, in the national census except for nationality in some secondary studies (113).

There are only a few Member States in the WHO European Region that charge public institutions with the duty of collecting data related to equality in order to support equality planning (113). Obligations to prove equal treatment by public authorities could be used to support arguments for the collection of migration health data. Legal instruments, both nationally and regionally, could support the collection of migration health data under the rationale of equality and fairness (175). The EU Racial Equality Directive could further support the collection of migration health data routinely in order to show compliance with EU law within EU Member States (176). Two examples of best practice were identified in a report by the European Observatory on Health Systems and Policies in 2011: the Swedish annual survey on living conditions and the Health Survey for England (96). The broader antidiscrimination legislation enacted in the United Kingdom provides an example of systematic statistical monitoring to combat discrimination and promote equality, including for access to health care (96). Comprehensive guidance from the Office for National Statistics on how to collect data on ethnicity and national identity ensures that data are collected ethically and are comparable throughout the country (177).

Refugees and migrants themselves are seldom involved in initiatives to increase data collection for their populations (113), although the inclusion of refugee and migrant representatives in the designing, implementing and establishing of migration statistics and policies has been noted as best practice (113,161) and can increase trust and confidence building in the data collection tools (113). Examples where Member States have increased confidence in their data collection by including minority groups in the design process include Ireland, where consultation with NGOs occurred during the design of census categories relating to ethnic and cultural minorities; Spain, where ethnic minorities were involved in collecting data for reports on discrimination; and Hungary, where the 2011 census consulted with the National Alliance of National Minority Self-Governments and involved Roma people as enumerators for the Roma community (113).

Extra resources may be required in order to collect and include migration health data into routine HIS, such as increases in the workforce, training and provision of interpreters and/or cultural mediators (5,7,47,178,179). Cultural mediators often act as both interpreters and as advocates for refugees and migrants while also supporting medical staff to solve cultural conflicts during care (47,178,179). Training of staff in cultural competence can boost understanding and trust and provide further support for collection of migration health data (7,178,180).

Migration data extend beyond health-care facilities and the health sector, and individuals responsible for collecting data on migration health need to be trained on the unique challenges in collecting these data. It has been suggested that data on certain migration variables such as legal status and duration of stay should not

be collected at the point of care by health-care providers since that may adversely affect trust between the health-care provider and the refugees and migrants seeking care (48). Instead, the use of data linkage to gather these data from other routinely collected data sources would allow these important determinants to be analysed and disaggregated while still protecting the trust and utilization of health care for refugees and migrants (in Denmark a personal identifier number allows a protective data linkage between registers).

The extra resources needed for migration health data collection can be a financial burden for hospitals, points of care and other routine data collection systems yet such data are integral in ensuring equity of care for refugee and migrant populations (7). Translation services may also be necessary to enhance the participation of migration groups within national and targeted surveys, although again this may create additional financial and time-related issues (181).

Key points: HIS resources

- The pivotal resources needed to operate a functioning HIS include personnel, financing, logistics support and information and communications technology.
- The collaboration of multiple ministries and organizations is necessary for the collection of migration health data. Furthermore, migrants themselves or proxies (such as NGOs) should be involved in the structuring and integration of migration health data into national HIS.
- Regulatory and legal frameworks structure how and when data should be collected and can encourage the collection of data that can be disaggregated by migratory status (e.g. the Global Compacts, IHR, GDPR).

HIS indicators

The HMN framework outlined three major domains for the assessment of HIS: determinants of health (socioeconomic, environmental, behavioural and demographic), health system and health status (16). Information on indicators for the determinants of health is generated not only through the health system but also through multiple sectors such as labour, agriculture and administrative registries that can be linked to HIS (16). Health system indicators include inputs, outputs and outcomes of health service, while health status refers to mortality, morbidity and well-being (16).

Different subgroups of refugees and migrants are exposed to different social, occupational, cultural, legal and environmental factors that can have short-term and long-term effects on their physical and mental health and well-being (182,183). In addition, the migratory process is itself considered a determinant of health (184), with health risks particularly associated with travel along irregular routes such as the Mediterranean crossing (123). These factors may all cause disparity and inequality in

health outcomes compared with the host population. For example, legal status can affect entitlement to access and utilization of health care (53,85,183). Other factors such as language barriers, low income and low health literacy may also adversely affect utilization of health services (183,185). Occupational risks also seem to be higher for migrant workers, with an increased risk of occupational injuries particularly among low-skilled migrant workers (186).

This TG recommends the integration of two sets of variables into HIS: a core set and a recommended set (Table 1). The core set is based on the United Nations EGMS (197) and are already collected by some Member States for capturing migratory status: country of birth, citizenship, arrival in the host country (year and month of arrival) and country of birth of both parents. The additional set of recommended variables would allow further identification of subgroups such as refugees, international students, as well as returning emigrants, and so would provide a more inclusive assessment of migration health determinants. These recommended variables include the reason for migration, ever resided abroad, knowledge of the official language(s) of the host country and legal status (101,173,188,197). For enhanced disaggregation, comprehensive information and comparability, it is strongly encouraged that the recommended variables are included alongside the core variables in data collection if resources are available for such integration.

Table 1. Core and recommended variables for data collection

Variable	Definition	Description/relevance	Limitations/considerations	Possible sources	Potential use/indicators	Examples collection
Core variables						
Country of birth	The country of residence (in its current borders, if the information is available) of the mother at the time of birth or the country (in its current borders, if the information is available) in which the birth took place (53,59,187)	<ol style="list-style-type: none"> Used to distinguish between native-born and foreign-born residents; foreign-born residents include: <ul style="list-style-type: none"> nationals, individuals who were born abroad but have the citizenship of the host country; includes both individuals born abroad with parents of national background and individuals with foreign background who acquired citizenship of the country of residence (188) foreign individuals born abroad without the citizenship of the country of residence (188) Allows identification of foreign-born population independently of current citizenship (188) It is simple, reproducible and feasible to collect and is commonly included in routine health datasets (189) It is comparable across datasets internationally (189) 	Does not differentiate between subgroups of migrants (e.g. asylum seekers or labour migrants) or identify migration for other reasons (e.g. education, marriage, family reunification or housing) (188,189)	Censuses, population surveys, civil registries, immigration records, labour force surveys (53)	<ul style="list-style-type: none"> OECD: foreign-born population measured as a percentage of the population (190) Eurostat: foreign-born/native-born/unknown (187) 	Eurostat, IOM, OECD, UNDESA, World Bank, Belgium (191), Denmark (192), Georgia (193), Norway (194), Sweden (192), United Kingdom (195)

Variable	Definition	Description/relevance	Limitations/considerations	Possible sources	Potential use/indicators	Examples collection
Citizenship	The legal bond between an individual and the State acquired by birth or naturalization, whether by declaration, choice, marriage or other means according to national legislation (53,59,187)	Defines population as nationals and foreigners irrespective of country of birth (188)	<p>1. In countries where citizenship is conferred based by descent, individuals with foreign parents who were born in the country of residence may be included in the number of international migrants even though they may have never lived abroad (188)</p> <p>2. Individuals who were born abroad and who naturalized in their country of residence are excluded from the stock of international migrants (188)</p> <p>3. For those with dual citizenship, it is recommended that consideration be given to which is the first country of citizenship (reporting country, where the respondent lives) and which the second when collecting information (188); a person with citizenship of the country will not be considered as a migrant (53):</p> <ul style="list-style-type: none"> • dual citizenship creates a problem when using country of citizenship data to measure migration if “mirror” statistics are used to estimate emigration (deriving information from immigration data in destination countries) (196) • option to indicate more than one nationality (to capture information on dual or multiple nationalities) should be provided while collecting data (173,197) 	Censuses, population surveys, civil registries (53,197)	<ul style="list-style-type: none"> • OECD: foreign population: measured as a percentage of the population (190) • Eurostat: nationals/non-nationals/unknown (187) 	Eurostat (59), OECD, UNDESA (2), World Bank (198), Belgium (191), Denmark (192), Georgia (193), Norway (194), Sweden (192), United Kingdom (195)

Variable	Definition	Description/relevance	Limitations/considerations	Possible sources	Potential use/indicators	Examples collection
Year and month of arrival	<p>The year in which the person first established a usual residence in the country (53)</p> <p>1. Usual residence is defined as the place at which a person normally spends the daily period of rest, regardless of temporary absences for purposes of recreation, holiday, visits to friends and relatives, business, medical treatment or religious pilgrimage</p> <p>2. The following individuals alone are considered to be usually residents of the geographical area in question:</p> <ul style="list-style-type: none"> • those who have lived in their place of usual residence for a continuous period of at least 12 months before the reference time • those who arrived in their place of usual residence during the 12 months before the reference time with the intention of staying there for at least 12 months (59) 	<p>1. In which year and month did the person first arrive in the country for whatever reason to live for 12 months or more: answer as year/month/unknown (173, 197)</p> <p>2. The purpose is to measure duration of residence of international migrants in the host country, which helps in analysing and planning for integration programmes and analysing health consequences in relation to duration of stay (53, 188)</p> <p>3. Allows identification of long-term and short-term migrants, which is important in evaluation of policies and measuring migration outcomes, especially in countries where the numbers of short-term migrants exceeding the permanent migrants (53, 188)</p>	<p>1. For multiple migrations, data on the most recent immigration to the country are considered (188)</p> <p>2. Not all countries use the same time threshold to determine a migrant, for example Cyprus, Sweden and the United Kingdom use 12 months (199) and Denmark uses 6 months (192)</p>	<p>Population surveys, immigration registries (53, 197), international passenger survey (United Kingdom (200, 201))</p>	<p>1. Total number of arriving migrants per year</p> <p>2. Duration of stay:</p> <ul style="list-style-type: none"> • OECD: up to 5 years, 5–10 years, >10 years, unknown duration (202) • UNDESA estimation (53): long-term migrants are individuals who move to a country other than that of their usual residence for a period of at least 12 months, so that the country of destination becomes new country of usual residence; short-term migrants are those who move to a country other than their country of usual residence for a period of at least 3 months but less than 12 months 	<p>Eurostat (59), OECD (202), Germany (203), Norway (194), United Kingdom (200)</p>
Country of birth of both parents	<p>The country of residence (in its current borders, if the information is available) of the grandmother at the time of the birth of the father/mother or, in default, the country (in its current borders, if the information is available) in which the birth took place (53, 59)</p>	<p>Allows identification of nationals (native born) with foreign background and foreign born with national background; captures offspring of migrants (second generation) and is useful in countries with a significant number of migrants (188)</p>	<p>Information is not usually available, especially in eastern Europe and central Asia (188)</p>	<p>Population surveys, censuses (191)</p>	<p>Eurostat: native born with foreign origins (with EU and without EU origins); foreign born (born within and without EU) (204)</p>	<p>Eurostat (204), Belgium (191), Norway (194), Sweden (205)</p>

Variable	Definition	Description/relevance	Limitations/considerations	Possible sources	Potential use/indicators	Examples collection
Recommended variables						
Reason for migration	The main reason for undertaking the recent migratory movement (188)	Identifies different sub-groups of migrants (e.g. refugees, students, labour) with varying health needs and risks (188)	<ul style="list-style-type: none"> May be considered as a sensitive topic especially for those with legal and humanitarian reasons Respondent may not disclose the actual reason of migration for fear of discrimination or legal consequences (67) 	Population surveys, immigration registries (173, 188), international passenger survey (United Kingdom (200, 201))	Identifying main reason for coming to live in a country: refugee, asylum seeker, for work or to look for work, for study, simply as a dependent family member, other reason (specify) (173, 197)	Norway (194), United Kingdom (201)
Ever resided abroad	Previously established usual residence in other country (173, 188) (usual residence defined above for year of arrival)	<p>1. Whether a citizen of the country has ever lived outside the country for a period of at least 12 months; if so when did the individual last arrive to live in this country for 12 months or more: year/month/unknown</p> <p>2. In which country did the individual last live (197)</p>	Short-term migrants and circular migration cannot be captured under the threshold period of 12 months (206)	Censuses, population civil registries (191, 193)	Estimation of returned migrants (207)	Belgium (191), Georgia (193)
Knowledge of host country's language(s)	Ability to speak official language(s) of the host country (53)	<p>1. Important variable because the ability to communicate in the host country is considered a key factor for health of refugees and migrants (53)</p> <p>2. Lack of language proficiency can be a major barrier to interaction with other groups, participation in social and civic activities and success in the labour market, and has possibly impact health and access to health care (47, 53)</p>	Self-reporting collection method has the limitation that there would be a tendency to overstate or understate knowledge of language; difficult to verify objectively (47, 53, 208)	Population surveys (193), censuses (53)	<p>1. Incorporation of language data into a patient's file can facilitate timely identification of those requiring interpreter services</p> <p>2. A health system output indicator is the number of health system organizations adding data on patients requiring interpreters to the administrative data in patient files (209)</p> <p>3. Also used to measure integration of migrants into host society (210)</p>	Georgia (193), Ireland (211), Switzerland (209)

Variable	Definition	Description/relevance	Limitations/considerations	Possible sources	Potential use/indicators	Examples collection
Legal status	Status of migrant under the immigration law of the country of destination (210)	<ol style="list-style-type: none"> 1. Terms such as immigration status and residency status are also used (152,212,213) 2. Can capture refugees, asylum seekers and irregular migrants 3. Can give idea on the reason for migration (e.g. labour, student, humanitarian) 4. Legal status may affect entitlement for access and utilization of health services, which, in turn, may affect patterns of disease in a non-random manner (214) 5. Although legal status is important in capturing the subgroups of migrants, it is hard to capture and a sensitive topic with potential to create mistrust and make data collection harder (173,183,214) 6. Before collecting and storing data on legal status, the issue of use of health data for non-health administrative purposes (e.g. detention and deportation) has to be addressed (125,183,215) 	<ol style="list-style-type: none"> 1. Legal status/immigration status may change over time (expiry or rejection of residence/work permit, overstay after authorized entry, rejection of asylum application, etc.) 2. Can be sensitive to disclose (62,216) 3. Hard to capture for irregular migrants (217) 4. UNDESA lists a possible disaggregation: refugees/asylum seekers and internal migrants/internally displaced individuals (173) 	Immigration registries (218), civil registries (53)	–	Germany (152,218)

Notes: OECD: Organisation for Economic Co-operation and Development; UNDESA: United Nations Department of Economic and Social Affairs.

Country of birth

Country of birth is a core migration variable that is widely collected by countries and used in statistical analysis by several international agencies (2,8,53,219,220). This variable has the limitation that it will not capture refugees and subgroups of migrants such as asylum seekers, irregular migrants, labour migrants and migrants who are born in the host country but are not citizens (188,189). Furthermore, migratory patterns are complex and country of birth may not reflect where a person spent most of his/her time living; hence, it is advisable to collect data on all the suggested core variables as these together can account for the complex migratory patterns and allow deeper insight into the relationship between migration and health (173,189).

Country of citizenship

Country of citizenship is widely collected across countries and international agencies and is often combined with country of birth or used as a stand-alone variable (53). For refugees and migrants, acquiring citizenship will grant them several entitlements and services in the new home country that are not available for non-citizens and so functions as one of the many health determinants. However, culture, language and

health-seeking behaviour may still continue to affect their health after acquisition of citizenship (5,47,179). Consequently, it is important to collect data on country of birth for the individual and both parents to shed further light on the significance of specific determinants.

Arrival in the host country (year and month)

The year and month of arrival in country of destination allows accurate calculation of the duration of stay in the country, which is a key variable that impacts the health of refugees and migrants and is a necessary element in evaluation and planning of programmes (5). Newly arrived refugees and migrants often face more challenges in terms of communication and language barriers, while also dealing with unfamiliar health systems. These challenges affect their access and utilization of health care and their health status (221). Data on the first date of arrival in the country are often maintained in immigration registries, which could be linked to the HIS (53).

Country of birth of both parents

The country of birth of both parents is useful particularly in countries with a significant number of migrants. Combined with the country of birth of the individual, it will enable identification of foreign born with a national background (return migration) as well as native born with a foreign background. Defining such groups is important in assessing and planning integration processes as well as for addressing the health risks and needs of these populations (Box 4) (53,188).

Box 4. Questions to capture migratory status data in the national health survey, Belgium

Belgium has adopted a set of questions in their national health survey that captures migratory status (191). These questions allow for further analysis and evidence-informed policy-making and contribute to a refugee- and migrant-sensitive health system.

Composition of the household

Q1. What is your current nationality?

Note. More than one response possible.

Q2. In which country were you born?

Q3. How old were you when you moved to Belgium?

Note 1. For children less than 1 year, indicate 0.

Note 2. Response to be given in years.

Q4. In which country was your mother born?

Q5. In which country was your father born?

Other variables

Adoption of migrant-friendliness as a criterion for service quality assurance, as well as integrating it into staff training programmes, language and communication support services, health literacy and information strategies is key to ensuring that health services are matched to the needs, preferences and expectations of refugees and migrants (182,222,223). User participation in the policy and management system of the health organization will also help to improve service provision. However, although these are important considerations, there are as yet no fully developed and tested indicators to measure these aspects in routine HIS. Frameworks and tools do exist to evaluate these aspects at facility level, such as Standards for equity in health care for migrants and other vulnerable groups, and the International Self-Assessment Tool for Organizational Health Literacy (224–227).

This TG only suggests variables in the domain of determinants of health because it is expected that variables in other domains (health status and health system) already exist in national HIS and are used to monitor and evaluate the health of the host population. As it is often not possible to disaggregate health data by migratory status within HIS, adding the core variables would enable that disaggregation. Variables should be reviewed periodically and new variables could be added and/or existing variables could be strengthened for all three domains for data for the entire population in a country. This should be done as part of routine health system and HIS strengthening processes.

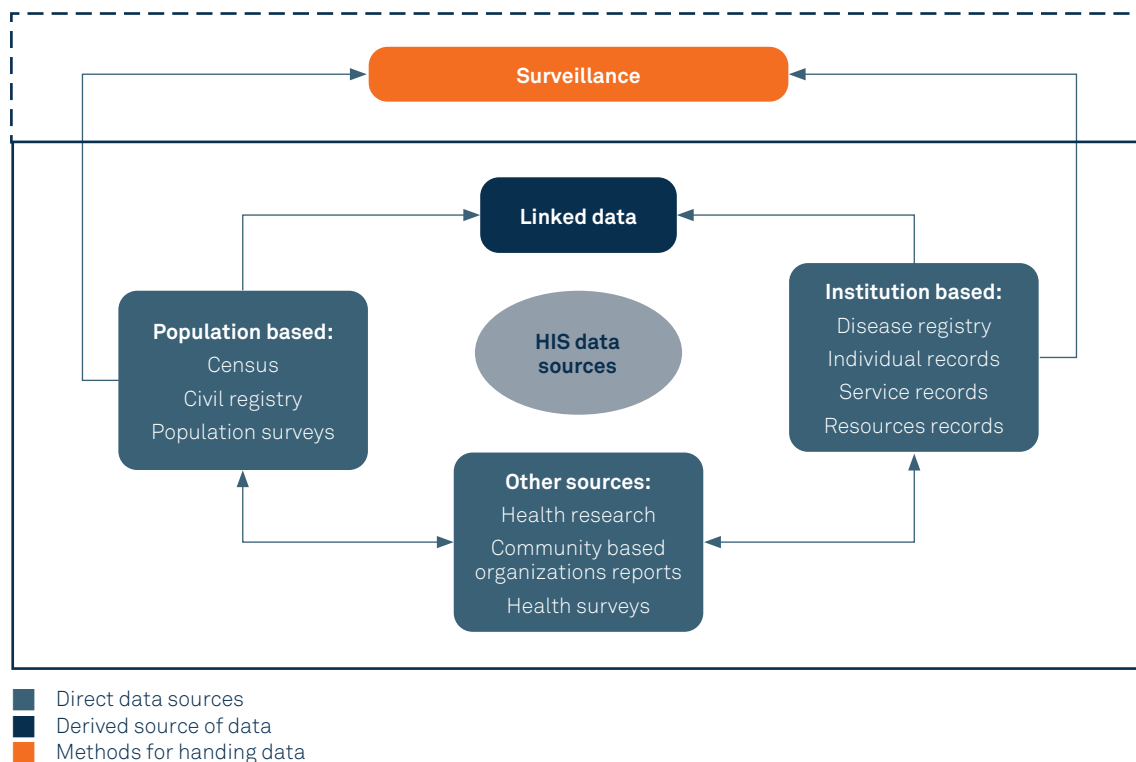
Key points: HIS indicators

- Variables to capture migration health data focus on the collection of key migratory status variables that fall within the domain of determinants of health.
- It is expected that variables in other domains (health status and health system) already exist in national HIS and are used to monitor and evaluate the health of the host population.
- A set of core variables should be integrated in national HIS, some of which are already collected by some Member States, to facilitate disaggregation of HIS data by migratory status: country of birth, country of citizenship, month and year of arrival, and country of birth of both parents.
- Further recommended variables would support further disaggregation of health data by subgroups of migrants: reasons for migration, knowledge of the official language(s) of the host country, ever resided abroad and legal status.
- Variables should be reviewed periodically and new variables could be added and/or existing variables could be strengthened for all three domains in HIS.

HIS data sources

No single data collection source can provide all the information that is necessary for national HIS (16) and consequently the same holds true for migration health. A combination of sources would lead to better-quality information and efficiency if duplication can be avoided (16). Fig.2 details the flow of data sources for HIS from direct and derived data sources. HIS data sources are broadly divided into population-based sources and institution-based sources available at health-care facilities and institutions such as insurance providers (16). Population sources may include censuses, civil registration and population surveys and produce data on all individuals or data on representative populations or subpopulations, not only those utilizing institutional services (16). Institutional sources result from administrative and operational activities where data are only collected on individuals who access a service; the sources could be resource records, service records or individual records and would not be confined to health-based services (e.g. police or occupational reports) (16). Other less-traditional sources are research reports and NGO reports (16, 153). According to the HMN, public health surveillance is a special set of methods rather than a data source in and of itself (16). Surveillance pertains to more than just the tracking of epidemics and will also identify epidemiological trends. Surveillance uses data from population-based sources such as mortality registers, survey methods such as antenatal care surveys and household surveys on tobacco use, and from analyses of health service records (16).

Fig. 2. Flow of data from direct and derived sources for HIS



Source: based on the HMN framework; WHO, 2012 (16).

HEN 66 found that researchers regularly derived migration health-relevant statistics using routinely collected data from sources including linked data collection systems, medical records, notification systems for infectious diseases, disease-specific registers, population-based records, health monitoring surveys and subgroup-specific records (48). Although a wide range of potential sources could be identified, the depth of information provided by each data source on refugee and migrant health was limited, with even less evidence on the quality of data and integration of different data sources (48).

From a data analysis perspective, ideally there could be a unique identifier for each individual in a country, which would facilitate linking of data (Fig. 2) for the same individual from various sources (discussed more under Data management). However, only a handful of Member States in the Region have such unique identifiers in place (48).

Multiple variables, particularly those capturing migratory status (the core variables), might need to be collected by various or all data sources so that effective migration health data could be produced through data linkage.

An alternative approach has used algorithms to create innovative linkages; this has been tested by researchers but still needs to be fully evaluated and implemented at a large scale (228,229). Frequently, data for specific indicators can be produced from multiple sources (16).

Population census

General population censuses can be both traditional (e.g. questionnaires administered by enumerators or self-enumeration methods) or based on administrative or statistical registers, or a combination of the two (101). Censuses can typically allow for identifying a migrant whether through citizenship and country of birth or through other variables such as language, religion or ethnicity (101). Recommendations for the 2010 and 2020 censuses prepared with support from Eurostat called for inclusion of international migration as a core topic of concern (101,188). As censuses cover an entire population, they are robust data sources and allow for analysis of smaller population groups (e.g. refugees and migrants) that may not be distinguishable in smaller surveys (101,159). Disadvantages are that they are not implemented frequently and usually come at a high cost to nation states (101). The United Nations EGMS has proposed that questions capturing data on migration should be included in all national censuses (and general household surveys) in order to improve the quality and comparability of international migration statistics and should use a few core migratory status variables (e.g. citizenship) (197).

Administrative registries

Registers contain information on an individual's current status (e.g. birth, death or disease-specific registries) (101). HEN 66 found that researchers were able to utilize disease-specific registries to perform migration health research, identifying 38 different registries where data disaggregated by migratory status were available, and 50 unique population-based registries (e.g. birth registries) where migratory status identifiers allowed for migration health research (48). Registers can be disease specific (e.g. cancer), based on employment or income (e.g. unemployment, social insurance), education, legal status (e.g. immigration records) or may cover general population issues (48,101). The advantages of registers are that they are regularly updated and are used for multiple administrative purposes while being reasonably inexpensive compared with other data sources (48,101). However, registers may miss certain subpopulations of migrants (e.g. irregular migrants) (159) and do not always analyse conditions outside the purpose of the registry, suggesting that data might be lacking on issues such as comorbidities or other relevant health outcomes among refugees and migrants (48). Another limitation is that there is often minimal integration of these registers into national HIS (48). Suggestions were made in the late 2000s for expansion and establishment of registries and for better harmonization of data collection terminology in order to improve comparability between Member States and the Region (61).

Surveys

Surveys are sample based and involve interviews with an individual or household (101). Large amounts of information can be collected (compared with registries) although a major problem arises from non-representative sampling procedures, failures to response or underrepresentation of key target groups that might be hard to reach, such as refugees and migrants (101). Several international surveys are important for refugee and migrant research, including the European Labour Force Survey, the EU Statistics on Income and Living Conditions, the European Social Survey and the International Social Survey Programme (101). While these international surveys have a high degree of comparability because of harmonization of set indicators, they also have low sample sizes for refugees and migrants (48,101). Underrepresentation of migrant populations in the European Labour Force Survey has been linked to delays in entering recently arrived migrants into sampling frames, higher mobility of migrant groups, poorer response rates for migrants because of language issues and irregular migratory status, and lack of statistical reliability because of small sample sizes (101). Further discussion on solutions to enhancing refugee and migrant participation in surveys is detailed in the section on Data collection.

Medical screening

Relevant information for refugee and migrant health is also collected during medical screenings, which can take place in the country of origin, the transit country and/or the host country.

Many labour migrants are screened predeparture, within so-called migrant health assessments (230). Screening providers usually operate separately and are providing information for determining admissibility for visa issuance (231). Formal linkages with national HIS are lacking, which could be important for public health purposes and the overall improvement of the health of migrants (230,231). There are no global estimates of how many international migrants receive predeparture screening, but it is estimated that about 2 million health screenings for immigration purposes are carried out annually within Australia, Canada, New Zealand, the United Kingdom and the United States combined (161,231).

Predeparture screening is also conducted in the context of resettlement programmes for refugees. For example, all individuals who are part of resettlement programmes in the United States undergo medical screening before entering the country (232). Results are shared with the State and local health departments through the National Notifiable Disease Surveillance System (233). The IOM also conducts predeparture health screening at the request of receiving countries in the context of resettlement, international employment, enrolment in specific migrant assistance programmes or for obtaining a visa (234). Both physical and mental health are assessed, but procedures vary according to the receiving country's own requirements (234). Data are managed through the Migrant Management Operational Systems Application, which is a web-based migrant management software operated by IOM (234). This Application has interfaces with the Worldwide Refugee Admissions Processing System, the United States Centers for Disease Control Electronic Disease Notification system and the eMedical system for Australian migration health assessments (234).

Practices for medical screening for refugees and migrants vary across the WHO European Region and with whether the country is one of transit or a final destination (235). Data which do exist refer mainly to the EU/EEA Member States, with over half of these implementing screening programmes for newly arrived refugees and migrants (236). Several Member States screen for infectious diseases, most commonly tuberculosis, followed by hepatitis B, HIV, hepatitis C, other sexually transmitted infections and vaccine-preventable diseases (235). NCDs are usually not part of the first health assessment (237). In Germany and many eastern European countries, the screening of newly arrived migrant children is mandatory, whereas it is voluntary in the other western and northern Member States of the EU/EEA (238). Mandatory programmes often focus on the screening of communicable diseases, while voluntary programmes include health issues in addition to communicable diseases (238). In Sweden, all newly arriving migrants should be offered voluntary medical screening, with all positive cases of communicable disease being reported to the county medical officer (239).

Qualitative data sources

Migration health data collection should also incorporate qualitative data through interviews and other methods. Although there are limited examples of how this could be done at a national level, examples from research studies show that there is an abundance of good practice and that integration of qualitative data within routine HIS

can occur in several ways. First, qualitative sources can be nested within routine HIS (e.g. censuses or surveys), which entails recruiting respondents for semi-structured interviews (or other methods) from among a census or survey (240). In order to better recruit underrepresented populations (e.g. refugees and migrants), purposive sampling may be more appropriate than random sampling (240). Purposive sampling uses information on specific aspects such as migratory status, gender and education to select key individuals for the qualitative component (240). Additionally, cultural mediators and/or individuals active in the refugee and migrant communities can be used to recruit and ensure a representative sample of refugees and migrants (179,241).

Secondly, qualitative data from a different sample can be used to supplement survey or census data, and this can be done using either a sequential or a parallel design (242). In a sequential design, the interviews are conducted after the census/survey, while in a parallel design they are collected (almost) simultaneously (242). Here again purposive sampling would be the best practice in order to find respondents with similar characteristics to the original survey/census (e.g. migratory status or gender) or other relevant stakeholders (242). Another approach could be adding open-ended questions or free text comments in routine HIS data sources. This could allow for further analysis either in conjunction with quantitative routine HIS data or as a resource on its own (243).

Finally, collection of survey data can be supplemented by the use of qualitative data methods for all respondents, which can be achieved with the inclusion of open-ended questions. This process is used by Doctors of the World for all patients receiving consultation through their health centres across Europe (Box 5) (244).

Box 5. Integrating qualitative sources into routine data collection

The justification for combining qualitative methods with quantitative methods (e.g. the majority of traditional HIS) is for triangulation (to seek corroboration between qualitative and quantitative data sources) (242). The combination of methods can be complementary, in order to seek further clarification, or can support expansion to extend the range of enquiry.

Qualitative data sources (e.g. interviews) can and should be integrated into routine HIS. Different methods can be used for recruiting respondents.

- Recruiting the same respondents for different datasets through:
 - data-linked nesting (240);
 - adding open questions to existing routine HIS; or
 - integrating routine HIS data with qualitative data.
- Different samples can be recruited using routine HIS data and qualitative data as different datasets.

Box 5 contd.

Adding open-ended questions to existing routine systems such as censuses is a viable option. While there are no current examples using this approach for migration health data, other scenarios show its benefits. For example, a recent census (Active Living Census 2014) for the Greater Bendigo municipality in Australia was distributed to all households and included quantitative components (covering sociodemographic data; information on dietary behaviours, smoking and alcohol use; and physical activity) as well as open-ended questions on perceived barriers to fruit and vegetable intake (245). The combination of the qualitative and quantitative data revealed several barriers for having the recommended intake of fruit and vegetables. Disadvantaged households indicated in the open responses that cost and availability of fresh fruits in their region were the highest barriers for intake. As a large sample was surveyed, thematic software was utilized rather than manual coding for the open-ended questions, which may have resulted in uncertain themes. The team mitigated this in the analysis by interpreting the themes and concepts in relation to previous research in the thematic area. The challenge of analysing and coding such large samples needs to be explored further in order to understand the feasibility and usefulness of this mixed-method approach.

Nontraditional data sources

Although traditional data sources provide a strong base for migration health data collection in many countries, time lags and costs may make these sources prohibitive (215). A range of innovative data sources to capture migration data centre around the use of so-called big data, which is usually captured by private companies and may derive from mobile phones, online tools and platforms such as social media, online payment services and use of satellite imagery (215). There is no common definition of what big data entails (215), but it can be understood as data that are anonymized and inadvertently created and stored (246); big data has been described as an “umbrella term referring to the large amounts of digital data continually generated by the global population” (247). Its strength as a data source lies in its timeliness, level of detail and frequency (215). Medical big data can originate from administrative claim records, clinical registries, electronic health records, biometric data, patient-reported data, the Internet, medical imaging, biomarker data, prospective cohort studies and large clinical trials (248). Three broad categories of big data sources for migration-related statistics exist (215):

- cellular calls, texts and transfers activity (e.g. communication services, financial services/mobile money transfers);
- Internet-based activity (e.g. information services/search engines, communication services/emails, social media and financial services/online money transfers); and
- positioning data using satellites and mobile phones.

A review of how big data has been used in existing migration studies found potential value in some key areas (215):

- forced displacement (e.g. environmental disasters or conflict);
- remittances or patterns of mobile money transfers;
- estimation and prediction of migration flows; and
- human trafficking.

Big data has been utilized for different public health purposes: in epidemiology, the spread of epidemics could be detected by tracking online queries on disease symptoms using social media sources, in this case through Google Search and Twitter (249). Further, web-based early warning systems for disease tracking already exist, for example HealthMap, BioCaster, Global Public Health Intelligence Network, MedISys and ProMED-mail, which collect disease-specific data from local news and social media (250). Web-based queries and participatory systems are also used for syndromic surveillance; their advantages are timeliness and sensitivity for early disease detection (250). In Zambia, GPS data were used to examine the impact of individual movement patterns on malaria control measures (251).

Additionally, the use of mobile apps has been tested for public health purposes: the Hungarian Government has developed a mobile health app MENTA to monitor patient pathways and to evaluate health interventions (252). The app integrates patient health data from the patient with the electronic health record stored in the national health-care database (252). In Estonia an e-health system was introduced that links information on diagnoses, doctor visits, test results, inpatient treatments and prescriptions (253). The data are utilized for national statistics and tracking health trends, epidemics and efficient use of resources (253). In the context of COVID-19, a study looked at anonymized mobile positioning data in different European countries to assess the impact of COVID-19 confinement measures on mobility in Europe (254). The study also compared mobility data with infection rates (254).

Big data has also been used by different organization for migration management. National border police and the UNHCR use biometric data such as digital fingerprints and eyescans for identification in order to prevent identity fraud and increase efficiency and accuracy (121,255,256). In some European countries, military contractors employ big data such as satellite and drone imagery, as well as big data analytics for surveillance of individual border crossings (121). Since 2016, Europol has made use of social media data to track smugglers (257). Apps such as the IOM's MigApp have been developed to support refugees and migrants in accessing health care, for example through offering information on health guidelines and health services (258). Further, social media data with geo-location (e.g. Facebook and Twitter) have been used to track international migration (259). Mobile phone call records have been used to track internal displacement and the spread of diseases (259). During this COVID-19 pandemic, Facebook launched disease prevention maps, which showed daily updates on population distribution and movement (259). Other social media data such as Facebook advertising can be further disaggregated by sex, age, home country as well as country of residence (259). Online search data can be used to measure migration intentions, for example through Google Trends Index (259).

Integrating big data into public health policy is beset with technical, infrastructural, ethical, legal and societal challenges that must be addressed (Box 6) (260,261). To support big data, a strong platform in which heterogeneous datasets can be collected is necessary to allow real-time analysis, which is the strength of this data source (129). As big data sources are often generated outside the norms of routine data collection for HIS, the potential of these data sources has not been fully recognized or appreciated (129) and there are many concerns and challenges associated with the use of big data (Box 6) (121, 129,215,248,262,263).

Box 6. Concerns with big data

- Most big data sources are private companies:
 - not always easily accessible;
 - data are not easy to clean; and
 - sharing sensitive data collected by private companies with public authorities is seen as particularly risky.
- Although sample sizes are large, they may not necessarily be representative of the population of interest: there is an inherent self-selection bias (who is the data source?).
- There can be issues of oversensitivity with big data:
 - false alarms can occur as spurious correlations and fallacies can multiply; and
 - the strength of big data is in discovering associations, not in whether meaning can be found in these associations.
- The potential of big data may not be realized because of issues such as:
 - challenges with sharing or linking data;
 - poor data quality;
 - safety and privacy concerns;
 - technical challenges (different data formats); or
 - privacy regulations, which often prohibit sharing of big data with governmental organizations, or even within the same organization.
- Medical data are frequently difficult to access:
 - because of concerns over misuse; and
 - the lack of incentives.
- Big data offers unprecedented ways of surveillance of population movements for non-health purposes, collected information from:
 - cell phones
 - mapping services (including location data)
 - social media
 - mobile payments
 - translation software.

Key points: HIS data sources

- No single data collection can provide all the information needed regarding migration health; consequently, a combination of sources is necessary and data linkage.
- Data are mainly derived from:
 - institutions;
 - population studies such as censuses, surveys and disease-specific registries; and
 - other sources such as NGO reports, big data or surveillance.
- Qualitative data sources should also be considered and integrated within routine data collection systems to support further exploration of the health needs of refugees and migrants.

Data management

Anything that involves data handling is considered as data management. This includes the collection, storage, quality assurance and flow all the way to the processing, compilation and analysis of data (16). Data related to migration health are sensitive because of the legal implications that refugees and migrants may face or fear, which may influence the collection, processing and use of these data.

Data protection and informed consent

In the absence of a wider and comparable international law on data protection, the recently adopted GDPR in the EU is widely regarded as a gold standard in data protection. Although the GDPR is a regulation, it also provides a framework for data management. Adopted in 2016, enforcement began in May 2018 and is binding for all EU Member States and the EEA (146). Migration health data is grouped under sensitive data, which the GDPR describes as data that “reveal racial or ethnic origin, political opinions, religion or philosophical beliefs, trade union membership... where the processing of genetic data, data concerning health or data concerning sex life or criminal convictions and offences or related security measures” (Recital 75) (146). Collection of sensitive data is only allowed under strict conditions and special requirements, for example with explicit consent from the data subject or for the management of health or social care systems and services (Art. 9) (146). Further guidance on the collecting of sensitive health data within GDPR states that “Member States may allow processing of personal health data for public health purposes (such as ensuring the quality of health care and protecting against health threats) and more specifically for research purposes as well as statistical and archiving purposes” (264). Effectively this means that safeguards may vary between EU

Member States although the GDPR provides basic safeguards to protect sensitive data that are collected (Box 7) (145, 146, 264, 265).

Box 7. GDPR as a legal framework guiding migration health data collection & reporting

The GDPR can guide collection and reporting of migration health data as it defines standards of

- consent (Art. 4(11) and Art. 7);
- what constitutes sensitive data (e.g. data revealing racial or ethnic origin and data concerning health; Art. 9); and
- processes for pseudonymization (where some additional information could allow an individual to be reidentified from the data) (Art. 4(5)) and anonymization (a person can no longer be identifiable in the data; these data do not fall under the regulations of the GDPR) (Recital 26).

The GDPR sets strict conditions and requirements for the processing of sensitive data (Art. 9), allowing collection of sensitive data:

- for the purpose of managing health systems (Art. 9(2h));
- for research purposes (Art. 9(2j)); and
- in the event of serious cross-border threats to health (Art. 9(2i)).

Challenges

Data linkage: through data linkage pseudonymization might be reversed and individuals identifiable. For pseudonymized data (Art. 4(5)), explicit consent or other exemptions are required for the processing of sensitive data (defined in Art. 9).

Sharing of data: Sharing of personal data with an organization or a third state is possible under certain requirements, for example with appropriate safeguards (Ch. V). The data collector must inform the data subject about the sharing upon the data collection or after a request of the data subject (Art. 13(1) and Art. 15).

Sources: European Parliament, 2016 (146); Hayes, 2017 (145); Kuner, 2020 (265).

The GDPR confirmed ownership of health data by the patients (not the health-care institutions) and, therefore, explicit consent must be obtained for the collection of personal data (266). While the GDPR does not define explicit consent, it can be inferred to mean that consent is received not by someone's actions but rather by written statement or expressly confirmed in words (266). When collecting personal data (e.g. migration health data), the data collector must also justify and explain the use of the data and the person's right to erase the data at any time (Art. 4(13–15); (146)). A few guidelines exist on the process of informed consent (Box 8): general

guidelines from the United Kingdom’s Information Commissioner’s Office (266) and the European Commission’s guidance note on research on refugees, asylum seekers and migrants (267). For particularly vulnerable groups (e.g. refugees living in camps or those in detention centres) the presence of an experienced NGO staff member or a cultural mediator during informed consent procedures helps to ensure that participation is voluntary (267). Another example stresses that translation to the language of the refugee or migrant is essential to guarantee that informed consent is voluntary and fully understood (268). IOM’s Data Protection Manual is comprehensive and provides an overview of national data protection laws enforced by 2010 and can be used as a guide as well for further ethical considerations surrounding migration health data collection (269).

Box 8. Tips on explicit consent

The following tips are derived from the EU (146,267) and the United Kingdom (266).

- A consent is a lawful basis for data collection, processing and usage.
- Explicit consent is not defined in the GDPR but it is not likely to differ from the usual high standard of consent. The key difference is that “explicit” consent must be affirmed in a clear statement (whether oral or written).
- Consent needs to be voluntary, given freely without coercion or fear of any legal consequences.
- The individual should not be denied any benefits.
- Participants must fully understand the implications of data collection, how the data will be used, by whom and for how long.
- The individual should understand clearly the rights of denying data collection, withdrawal from the collection or denying the use of certain personal data by certain authorities at any time.
- Consent should be written in a clear comprehensive style particularly for participants with low level of literacy.
- Explicit consent is not always easily translated into other languages; in this case involvement of independent cultural mediators and/or recognized NGO personnel may facilitate the process.
- For particularly vulnerable groups, such as those in refugee camps and detention centres or unaccompanied minors, careful consideration should be taken to ensure consent is voluntary.
- Consent should be signed by the data subject.
- If signing consent forms may jeopardize the respondent’s anonymity or have any legal or other consequences, an oral consent may be used with the approval of a competent ethics committee.

Data collection

Ideally, migration health data should be collected through routine data collection systems that can be integrated into the HIS of Member States. For HIS that lack migratory status variables, consideration should be given as to which data sources could be added into the HIS and how this would occur (159). Use of the core variables mentioned above are the key to generating comprehensive data on health of refugees and migrants and for harmonized reporting of data within and across Member States. A number of approaches can be used to ensure that data adequately reflect the health concerns of refugees and migrants (62,63,116,270–274). Data collection should include accurate translation of survey instruments into multiple languages (dependent on the country context) (62,63,270), specific sampling approaches (e.g. respondent driven, time, location) and innovative fieldwork approaches (e.g. bilingual enumerators) (181,270), as well as cross-cultural validation of the instruments being used (271,272).

As refugee and migrant populations are a minority in a population and may be hard to reach, traditional sampling methods may not work for collecting survey data (159). Low frequency of responses can be addressed by oversampling if resources are available (159). One strategy for household surveys would be oversampling in geographical areas with a larger proportion of migrants, with a suggested rate of four migrants for every one person sampled from the host population (273). This oversampling may have an adverse effect on overall population estimates; therefore, appropriate weighting may be needed during data analysis (159). Other specialized sampling methods are disproportionate sampling of areas with higher proportions of migrants and two-phase sampling of households (159). The potential to aggregate data by location and/or time can also increase the sample size (159). Further approaches to enhance participation from refugees and migrants in surveys include community-based recruitment and tailored sampling approaches (62,63,270,274). These strategies are supported by existing research and guidelines that reflect best practice for the increased presence of refugees and migrants in national monitoring approaches (116,275). An example of best practice for increasing participation rates in international migrant populations can be found in the recent Finnish Migrant Health and Wellbeing Study (Box 9) (181).

Box 9. Increasing participation rates in international migrant population surveys, Finland

The Finnish Migrant Health and Wellbeing Study (Maamu) was the first large-scale population-based health examination survey among people of migrant origin in Finland (181). Particular attention was paid to enhancing their participation rates because their participation in population-based surveys for the general Finnish population was low. The aim of the Maamu Study was to provide comprehensive information on the health and well-being among those of Kurdish, Russian or Somali origin as these were the largest groups of foreign-born people in Finland.

Box 9 contd.

A representative sample of 3000 individuals of Kurdish, Russian or Somali origin aged 18–64 years was drawn from the National Population Registry. Data were gathered using extensive structured face-to-face interviews and a standardized health examination. A brief questionnaire was provided for those who declined the face-to-face interview. The comparison group constituted of participants of the Health 2011 Study, who were drawn from the general Finnish population of the same age and from the same cities as participants in the Maamu Study. Both groups followed a comparable standardized protocol.

The Maamu Study used several strategies to enhance participation from those of migrant origin, including measures to disseminate information to increase awareness and raise interest in the study, gain trust and reduce barriers to participation. Information about the study was widely disseminated using social media, radio channels targeting migrant groups, television and newspapers. A comprehensive approach to reach the sample population was applied, including sending bilingual invitations by mail, using telephone contact and repeating home visits for those who could not be reached by mail or by telephone. Information was also provided through NGOs working with migrants, mosques and other places regularly visited by migrants to increase trust. Measures aiming at reducing barriers to participation included recruiting bilingual personnel to carry out data collection, translation of all research material into the first language of the participants, offering to conduct interviews at participants' homes or other convenient location, and reimbursement for travel by public transport to health examination centres. Through these measures, participation rates of 70% among Russian, 63% among Kurdish and 52% among Somali origin migrants were obtained.

A number of challenges were identified regarding the fieldwork, including reaching the sampled population, training and supervising fieldworkers and balancing between the use of standardized research methods and adaptation of the questionnaire for specific linguistic or cultural solutions. For example, while interviewers speaking the same language and sharing the same cultural background facilitated interaction and gained trust of the participants, it may have in some cases negatively affected the reliability of answers concerning behaviours that might be viewed as culturally taboo in the migrant origin groups. An extensive training programme and supervision were provided by a large group of experts in migrant ethnic minority health and on conducting of health examination surveys and epidemiology.

Paper or electronic sources can be used for data collection systems dependent on the needs, context, and resources of a nation's HIS (16); some systems may use a mixture of paper and electronic records (126). A review found that electronic systems might be more efficient and effective as tools for registering, monitoring and improving the health of refugees and migrants compared with paper-based systems (126).

It also found that electronic health records were good for mobile populations and might decrease the gaps in continuity of care and the duplication of diagnostic interventions faced by refugees and migrants, while increasing the access to health services overall (126). Five studies looking at routine data collection for asylum seekers and refugees in camp settings stressed the importance of using electronic medical records, rather than paper-based records to improve the availability of data and continuity (70,71,99,276,277), with similar findings noted in an evaluation of medical records for asylum seekers in Hungary (278). Another study in Italy found that reporting to a web-based platform would have enhanced data collection for refugees and migrants and increase the sustainability of the programme (70). The STEPS survey manual discusses the use of tablet-based electronic data collection, which can be carried out directly in households and at places of work, with immediate transfer of data via mobile Internet to a central database (279). Although electronic records have been found to be more efficient for sharing and collecting data, initial integration of these systems require funding, technical expertise and support as well as training for all users across the system, and this must be considered before implementation (126). If paper-based data collection must occur, the HMN recommends transforming it into digitized data promptly to ensure the data-to-information cycle can progress further (16). For routine data collection within HIS, refugee and migrant data should be collected in the same system as the host population, regardless of the basis used. For separate HIS for refugees and migrants, the use of electronic sources is best practice (126). The CARE project (Common Approach for REFugees and other migrants' health) supported the development of an integrated electronic system for tracking and monitoring the health status of migrants and refugees using the EU/IOM personal health records, which were provided in hard copy format (280).

There are ethical concerns regarding the collection of migration health data because of the potential for stigmatization and discrimination that refugees and migrants face, alongside issues of deportation or revocation of legal residency (215). Migration health data may expose patients or their families to stigmatization and discrimination from clinicians and health-care workers who may have inherent prejudices against refugees and migrants (216). Data that are related to communicable diseases may be of particular concern given occurrences where refugees and migrants have been discriminated against through preconceived fears that they carry and spread infectious diseases (216). If law enforcement agencies have access to health data, these could be used to prevent entry or stay of refugees and migrants (281). To address this issue during data collection, voluntary self-identification could be promoted, whereby the refugee or migrant chooses to identify as belonging to a certain group or not (96). This has been proposed by the ECRI, which is an independent human rights monitoring body specializing in combating racism and racial discrimination in the EU (282). The ECRI has regularly encouraged Member States to collect relevant data that can be disaggregated into categories such as nationality with due respect for the principles of confidentiality, informed consent and voluntary self-identification of people who belong to a particular group (e.g. irregular migrant, nationality or religion) (282). Additionally, clear regulations on who or which authorities could access data within

the HIS should be in place and communicated to patients, since misuse of data has been reported (283).

Data storage and flow

Data should be stored according to national regulations. If migration health data were to be shared (e.g. in a regional database) then again regulations of the GDPR would be in effect for the EU/EEA countries, with transfer and storage outside of EU/EEA governed by Art. 5e and Recital 39, which stipulate that data storage should be limited in time although not stated in terms of explicit numbers (146). The applicability of this would depend on how identifiable the data are, as the GDPR does not concern the processing and storage of anonymous information (Recital 26) including for statistical or research purposes (146). Personal data that is collected for “archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1)” may be stored for longer periods (146).

The IHR also provide guidance on the storage of personal data (under which migration health data falls), stating in Art. 45 that data should not be kept longer than necessary (142). Storing migration health data requires safeguards that must be implemented to ensure rights and freedoms of the individuals as well as their security and protection (146).

Storage of migration health data is a prerequisite for data sharing (284), and improper storage leads to data becoming less accessible over time, referred to as data entropy (285–288). Common best practices for data storage centre on the idea of depositing data in a central data repository (or central data warehouse) as this makes it more available, encourages data collection methods to comply to further best practices and ensures the sustainability and availability of those data over time (284). Such storage of aggregate data makes it feasible to accumulate data from across facilities and from different levels (289). Data could be integrated from other sources if advanced data repositories or warehouses were implemented (289). WHO’s Health Facility & Community Data Toolkit provides a supporting architecture for such a system (289). However, data storage policies differ between repositories (290), and, therefore, it is wise to consider a data management strategy that complies with the specific legal requirements of the Member States as well as regionally (284).

When creating databases or repositories of sensitive data, authorities must be aware of the potential for aiding in surveillance as there is a risk of third parties hacking into or for misuse of the data (145). There is evidence of national authorities using migration health data for non-health purposes (145), with communications intercepted from several international agencies (145). Processing and storing of sensitive data must be handled with care particularly for refugees and migrants fleeing from violent conflict or persecution. Anonymization of data shortly after collection and during storage can help to reduce these risks (145). Furthermore, implementing decentralized, harmonized systems with automated analysis could be of use as explored further in Box 10.

Box 10. Health monitoring in reception centres for asylum seekers using a decentralized, harmonized surveillance system with automated analysis, Germany

In Germany, access of asylum seekers to routine health services is limited while they reside in reception centres. This contributes to their underrepresentation in the country's national HIS. In reception centres, asylum seekers usually receive medical care in onsite, walk-in clinics, which are often administratively separated from the routine health system. As a result, the use of medical records varies widely between centres and impedes the use of routine medical data as a data source within the HIS. Furthermore, data protection laws in the decentralized German health and asylum system constitute a barrier for centralized electronic health records across centres, regions and federal states.

Within the PriCare project a tailored electronic medical record system (Refuge Care Manager) was established as a routine health monitoring system in reception centres for asylum seekers (291). Through an iterative development process, the electronic medical record was implemented in a total of 29 walk-in clinics within reception centres. In order to utilize the harmonized and digitalized, but still decentralized, medical records as a basis for routine health surveillance, the project adapted a so-called hive approach. This approach maintains comparability across time and centres with automated analysis of harmonized medical records to give anonymized results. The approach comprises three elements.

1. A surveillance network (PriCarenet) with members from all participating reception centres discuss and agree upon indicators for routine health monitoring. Currently health monitoring is based on a set of 64 agreed indicators from four dimensions of health and health care: morbidity, quality of care, care processes and syndromic surveillance.
2. The indicators are operationalized in an analysis script written at the Heidelberg University Hospital using the freeware R-language for statistical computing. The script is distributed to the facilities through a software update in the electronic medical records system and accessible through an integrated surveillance module. Local administrators can subsequently authorize the local decentralized analysis of their own routine data by the click of a button, and the results are immediately available to the facility.
3. The anonymized tables and figures are then exported to a central surveillance server at Heidelberg University Hospital in encrypted format (through a cryptography-transfer module), where they are pooled by meta-analytic approaches. The results are reported back to the centres on an online reporting platform that allows facilities to access their own indicators as well as benchmark themselves against other institutions.

Box 10 contd.

Experience shows that the system helps professionals manage their clinical data and provide care to asylum seekers in fragile contexts with repeat contacts and dynamic changes in the population. The hive approach implemented by the PriCare project could be used by other reception countries for the development of similar networks, in particular where strict data protection regulations preclude other health monitoring approaches among migrant populations (e.g. cloud-based systems).

While data collected from HIS can be used for management, evaluation and planning purposes, concerns on who has access to personal data and how these data can be shared once collected are of utmost concern for migration health information. A range of examples highlight the concerns surrounding the sharing of migratory status data. A 2017 internal audit found that organizations were handling large amounts of personal data without implementing the proper safeguards; private data were shared with government's, partners and the private sector without the consent or knowledge of those who provided their data (292). Asylum seekers in Lebanon indicated their concern regarding sharing of their data and legally registering with government authorities (292). In Germany, irregular migrants must be reported to immigration authorities by staff from any public institution, including health-care administration (except for emergencies) (293). Several organizations have demanded a so-called firewall, which would prevent immigration authorities from using health data collected by institutions for detection and/or prosecution of irregular migrants (294–297), and health-care providers and staff should be clearly informed that they do not have any duty to report to immigration authorities (298).

Refugees and migrants might also fear the misuse of their health data or migratory status not only by immigration authorities but also in relation to their employment, landlords or others. In 2016, five countries in the EU/EAA plus Switzerland group required professionals and/or organizations to report irregular migrants to the police or immigration authorities; such reporting was explicitly forbidden in law and/or professional codes of conduct in 10 Member States, and in 16 there were no set rules (299). Existing laws on data privacy should be strictly implemented (e.g. GDPR) and supported by national laws that explicitly ban this transfer (299).

Data processing, compilation and analysis

The last step in data management consists of extracting migration health data from the data sources, ensuring consistency and quality, and then transforming the data (e.g. aggregation, calculation, cleaning, translating code values and transposing values) to allow for merging of data sources (16). This can then create a data repository in a format that allows for further analysis, query and extraction by relevant actors (16). The level of disaggregation to protect the data and guarantee confidentiality should be

decided, as should who will be able to access the data. Throughout this process, the flow of data should be tracked and analysed (16).

A guiding principle for ensuring data quality is to reduce the information collected to that of a minimum dataset as reducing the burden on the data collection system(s) can in itself improve the quality of data (16). All data indicators and variables should be assessed for quality by looking at the timeliness, periodicity, consistency, representativeness, disaggregation and confidentiality (16). Migration health indicators and corresponding variables should also be assessed to determine the reliability of the data being captured (300). HEN 66 found that notification systems were incomplete for data on migratory status and this hindered comparability of different notification systems (48). Both Italy and the United Kingdom have noted data quality issues for migrant categories within their health service utilization collection systems (63). The Data Quality Review toolkit provides a series of tools to assess the quality of data being reported in national HIS from the level of health facilities to national data collection (300); further support is provided by the MEASURE Evaluation with its Routine Data Quality Assessment Tool (301).

One approach that could increase the availability of migration health data is the linking of datasets, which could occur across ministries, organizations or institutions nationally and regionally (159). The Wellcome Trust defines data linkage as “the bringing together of two or more sources of information which relate to the same individual, event, institution or place. By combining the information it may be possible to identify relationships between factors which are not evident from the single sources” (302). Linkage and compilation of different datasets can be achieved in a variety of ways; for example exact (or deterministic) linking is possible where a unique identifier is shared between two data sources (e.g. unique personal identifiers) whereas in probabilistic matching identified variables are compared across two or more datasets to determine the likelihood of two records being a true match and related to the same person (48,301). Denmark uses a deterministic approach (Box 11) and the use of similar systems in other Nordic countries allows cross-national data comparisons (178).

Box 11. Registry-linked system in Denmark

In Denmark, a unique 10-digit Civil Personal Register number is assigned to all people in the Civil Registration System including refugees and certain groups of migrants, such as labour migrants. The data recorded include country of birth, citizenship, date of immigration and nationality of both parents, thus allowing identification of refugees and migrants. The personal identifier is linked across national registers, including health, education and labour.

The Civil Registration System is linked with a variety of national disease registries (e.g. the Danish General Practice Registry, Danish Cancer Registry and Registry of Causes of Death), which allows health information to be linked with migration indicators (303). This linkage bypasses the need for health agencies to collect and record data, which decrease the burden on health-care workers.

Box 11 contd.

The use of a unique identifier allows for easy, cost-effective and unambiguous individual-level record linkage of Danish registers. Daily updated information on migration provides large-scale, representative population samples over time as well as follow-up on migration and death. The Civil Registration System facilitates sampling of general population comparison cohorts and identification of controls for case-control studies, family cohorts and target groups in population surveys. The data are high quality in terms of completeness, the validity of the outcomes, national geographical scope and timeliness. Data are available for research purposes while protecting the anonymity of Danish residents. The limitations include the scarcity of individual-level data (e.g. reason for migration or self-perceived health), that is collected through health monitoring surveys, and difficulty of access for international researchers.

Deterministic linking with unique personal identifiers provides high-quality integrated datasets that enable reliable empirical inference, yet this approach may not always be a realistic because of the high demands on data infrastructure (131). The use of probabilistic or statistical matching may then be more appropriate for many countries and researchers (131). The probabilistic approach has been used and tested by Public Health England to examine the accuracy of matching between two public health datasets for TB, finding both high sensitivity and specificity of the method (304).

The final linkage option is the use of statistical matching, although this is yet to be explored in the context of refugee and migrant populations (131). Simplistically, statistical matching works to arrive at an estimate of the relationship between the target variable and the variables in the recipient dataset that were not actually jointly observed (131). Statistical matching has been used for data integration in the context of statistics on labour, income and consumption (305), a microsimulation of a social policy database (306) and for market research.

Data linkage can be used to combine nationwide registers from several countries (e.g. Nordic cohorts) or even for cross-national comparisons (303). Data linkage for migration health data can allow a broader range of questions to be addressed, can help to ensure data consistency, can facilitate re-use of collected data and more timely analysis, and can support interdisciplinary research (302). The potential to link data across countries can increase sample sizes, which is highly relevant for refugee and migrant populations, and also allow measurement of national context effects (302). Integration of core migration variables across all national datasets (even in decentralized HIS) allows for linkage to occur, ensuring improved data quality and possibility for stronger collaboration on the issue of migration health (48).

There are risks with integrated datasets, particularly with collection and compilation of sensitive data such as for tracking migration health, as misuse could lead to stigmatization and exclusion (147). Privacy and confidentiality concerns are

particularly important and serious efforts must be taken to ensure anonymization and pseudonymization of data (see Box 7) (131).

Data linkage requires consent, not only from the individual but also from the different organizations/institutions involved in maintaining datasets and allowing for the sharing of that data (302). Sharing of personal data (i.e. not anonymous data) under the GDPR with an international organization or a third state is possible under certain circumstances (Ch. V) (146). Careful deliberation on this must occur if a regional migration health data repository or database is to be established. This sharing of data can be possible under EU law when the European Commission takes an adequacy decision, meaning that the third country or international organization provides an adequate level of data protection (Art. 45) or appropriate safeguards by third parties are provided (e.g. legally binding instruments, standard data protection clauses; Art. 46) (146). The applicability of the GDPR to WHO is disputed; what is clear is the explicit statement in the GDPR on transfer of personal data from EU/EEA Member States to international organizations (Ch. V) (265). Therefore, even organizations with certain immunities have to demonstrate that they have adequate data protection policies if they plan to share and receive data from governments or organizations within the EU/EEA (145).

Collection, processing and sharing of migration health data could use the GDPR definitions of consent and anonymity as standards, thus fulfilling requirements set by the GDPR (146) and WHO data policy (147). In addition, data controllers (e.g. national statistic offices) should have a duty to disclose any sharing with third parties and to ensure that the purpose of data collection is disclosed to all data subjects (before collection and when requested by data subjects) (146, 147).

Key points: HIS data management

- Certain strategies can be employed to increase the representation of refugees and migrants in routine data collection, for example oversampling, purposive sampling, multilingual surveys and the use of cultural mediators.
- Migration health data collection should be integrated into national HIS and should use the tool that is being implemented for the host population (paper or electronic), ideally electronic data collection for all.
- Data repositories for data storage can increase the availability, flow and sustained use of data.
- The principles of informed and explicit consent and anonymization of data should be employed as standards in data collection for refugees and migrants.
- Steps should be taken to safeguard sensitive data from being used in surveillance; some options include firewalls, laws that regulate the use of private data and direct anonymization of sensitive data.
- Data linkage can be implemented in a variety of ways depending on the structure and needs of the national HIS. Linkages enhance the availability and completeness of migration health data.

Information products and dissemination and use

To guide health planning and policy, data must be transformed into information that can become the baseline and guide for evidence and knowledge (16,307). Raw data alone are rarely useful; it is essential to report data and ensure that they can be used later for evidence-informed decision-making (16). Knowledge translation is defined by WHO as “the exchange, synthesis, and effective communication of reliable and relevant research results. The focus is on promoting interaction among the producers and users of research [and] removing the barriers to research use” (308). Standardization of reporting formats, both nationally and regionally, is important for this process (16). Different organizations understand the term data reporting in relatively similar ways: “publishing and disseminating data and statistics on the SDG indicators” (309), activities “necessary to obtain health information and bring this information into the health policy-making process” (310) or “an interpretive description of the population’s health, [which] analyses problems, and highlights areas in need of action” (311).

The WHO Regional Office for Europe has increased its efforts to reduce the burden on Member States for reporting to WHO and other international bodies and, in 2018, joint monitoring framework was agreed (312) with a common set of indicators for reporting on the existing frameworks for the SDGs (172), Health 2020 (313) and the NCD Global Action Plan (314). Reporting on migration health should be in line with these efforts and not increase the reporting burden for Member States by introducing a new separate framework and new indicator sets. A practical solution would be to integrate migration health data into existing reporting frameworks through disaggregation by migratory status within existing indicator sets, for example in the WHO joint monitoring framework (312). The core variables outlined above for Migration health could be included inter alia within the social determinants domain of the joint monitoring framework. For the SDGs, disaggregation by migratory status has already been recommended for 24 of the 232 indicators (173). However, specific measures have to be taken to put these options into practice.

While a wealth of information is already being collected on refugees and migrants, the data are less frequently analysed or disseminated for further use (159). This stems from a number of factors: limited awareness on data that is being collected by those responsible for the data system; researchers unaware about the use/existence of such datasets, limited ability for disaggregation by migrant populations, and restrictive data access policies that discourage use of the data (315,316). Agencies and Member States should analyse and publish available migration health data at regular intervals and facilitate public access either as anonymous individual microdata or, if that is legally not allowed, as disaggregated tables (159). The Integrated Public Use Microdata Series (IPUMS)-International (317), while not on health specifically, is a good example of how data can be harmonized and made more readily available for researchers to use globally (Box 12). Awareness of existing migration health data, the available datasets and how to access them would be increased if Member States or regions provided regular reports that detailed data sources to support researchers and organizations (101,159,318).

Box 12. Practices supporting dissemination and use of data)

IPUMS partners with national statistics offices globally in order to offer harmonized international census and survey data for social science and health research (317,319,320). The project goal is to “collect and preserve data and documentation, harmonize data, and disseminate the harmonized data free of charge”, with 98 countries providing 443 censuses and surveys to the database. In order to ensure that data are available and comparable, IPUMS-International cleans, harmonizes and codes data consistently across countries and over time. The archive is available free of charge to qualified researchers through a web-based system. The samples available include full-count census data or individual-level subsets and the sample can be adjusted to the variables of interest for the researcher. Microdata are integrated using a unified coding scheme to support harmonization and enables comparable analysis across time and space. This process allows over 700 variables to be included in the database and provides a clear example of best practice for dissemination of comparable data. Such a dissemination process enables harmonization of data from different sources, making information widely available for researchers and supporting evidence-informed decision-making through integration of routine data sources into policy and planning.

These widely available datasets have been used to study migration, with IOM conducting a pilot study to explore the SDG indicators disaggregated by migratory status (321). The study used 55 IPUMS-International samples from the 1995–2004 census period in which foreign-born individuals could be identified. Census microdata collected by IPUMS were advantageous in monitoring the SDGs as they provided nationally representative samples that were not always available elsewhere. The majority of indicators are health-related or determinants of health, such as fertility and mortality.

Pragmatically complete harmonization of migration health data will take time for Member States (315). During this gradual process, the specific definitions of categories and the methodology used for migration health data collection by national HIS should be provided for understand of the context until complete harmonization of variables can occur (315). The framework developed by MEASURE Evaluation is a good example of guidance on how to link data with action (322). Migration health data are only useful when disseminated and used to support evidence-informed planning and policies. A variety of communication channels do exist and their applicability depends on who is the decision-maker or stakeholder involved (308,322). Some common methods include dissemination workshops, policy forums, publicly maintained websites (e.g. dashboards, data warehouses), infographics, research reports and presentations (322). The key is to determine the target audience and tailor the information to their needs creating a usable platform that targets the key issues, data, and potential solutions (322). Regardless of the method chosen, data should be provided in formats that are easy to understand by the users (e.g. summary reports

or graphs) (318). The data collected should also support the providers of the data and therefore, include patient and public involvement (323,324). Studies have shown that brief and user-friendly summaries of evidence are preferred by policy-makers (325–327). Some examples of tools to support dissemination of migration health data and knowledge for policy-makers would be WHO’s evidence briefs for policy (328), rapid response syntheses, evidence summaries and media or sound bites. To improve the use of migration health data and to ensure that data are available to all stakeholders, protocols should be clarified for sharing and requesting copies of datasets if direct access is not available (318).

Key points: HIS information products, dissemination and use

- Raw data alone are rarely useful and need to be transformed into information that can become a baseline and guide for evidence and knowledge.
- Reporting on migration health should be included within already existing reporting frameworks (e.g. the joint monitoring framework) and should not create an added burden for Member States.
- A variety of communication channels exist to disseminate migration health data, including workshops, dashboards/data warehouses, infographics, research reports and presentations; the method chosen will depend on the target audience.
- The collection of migration health data should also benefit the health of the refugees and migrants providing the data; this can be supported by allowing researchers easy access to the data and using the results to inform policy and targeted interventions.

Issues associated with separate HIS for refugees and migrants

There are risks with creating separate HIS dedicated to refugees and migrants. Comparisons between datasets, for example that for a refugee and migrant population and that for the host population, are hindered as data collection may have different processes and outcomes in the two systems (7). Setting up a new HIS is a technically complex and resource intensive, which could make it prohibitive for many countries and decrease implementation and, consequently, availability of migration health data (16). Furthermore, setting up a separate system has been found to be unsustainable; for example Italy set up an ad hoc system under the EU CARE project to address the sudden influx of refugees and migrants (280). The system was only able to run for a few years before it was abandoned due to lack of coordination between stakeholders, poor data quality and lack of a web-based secure platform (70). However, a new system has been implemented addressing several of the shortcomings (Box 13).

Box 13. An interoperable HIS for migrants and refugees

The SAVe software is an electronic HIS, separate from the National Health Information System, developed by the Italian National Institute for Health, Migration and Poverty in 2019 (329). The system allows Italian workers in the national health system, including health workers working in the reception system, to manage the health of migrants, including those with an irregular status who are not registered with the National Health Service.

SAVe is compliant with GDPR in relation to personal data protection. Access to the system is via user identification, authentication and authorization. Different user roles exist (e.g. doctor, social worker or psychologist) and each role operates only according to their specific privileges. The platform is designed to work both for rapid initial health assessment (at the very moment of arrival or immediately after) and in the following phases of the reception path, offering the tools to investigate traumas and vulnerabilities. The health record of the single patient can be saved, on demand, on external devices such as a memory stick to ensure continuity of care, even in cases of relocation to another country.

The system is available in both a stand-alone and a web environment. In the stand-alone version, the user can work locally even without a network connection; data are then transferred to the centralized database when connectivity resumes.

Currently the system is being implemented by local health authorities in four Italian regions, where over 28 000 migrants are hosted, and it will be also implemented by the Ministry of Interior in all first reception centres and hotspots. Further implementation across other Italian regions is expected to happen in the following months.

A hybrid feature of the SAVe system is that it can interoperate with the National Electronic Health File, where all Italian citizens are registered. The Ministry of Health and the Conference of the Regions have started the technical analysis to make the two systems interoperate. This will use a unique identifier code that is included within the SAVe system (immigrant unique code), allowing the files to be linked to the National Electronic Health File.

The anonymous data from the SAVe system is available for epidemiological and research purposes, with both data sheets and epidemiological reports on the status of migrants' health being released regularly.

When separate HIS do exist (e.g. disease-specific systems) they can typically overwhelm the resources of that country, with health-care and other resource staff overworked in order to replicate information across multiple subsystems that are not interoperable (16), causing poor data quality overall and lack of motivation to report by producers of data (16,70,330). A separate HIS for refugees and migrants can also decrease data sharing with local health authorities and policy-makers when operated

by outside entities such as international NGOs, limiting the ability for evidence-informed decision-making and stunting the development of a country's own HIS (330). Finally, the low data quality of separate systems can prevent end-users from being able to interpret and, therefore, use the data being collected (148).

While integrating the collection migratory status data within national HIS is the preferable solution, in certain contexts such as ports of entry or transit locations, a separate system for refugees and migrants might be relevant. The flexibility of a separate system may be justified when it needs to be rapidly put in place, may need to be scaled up on short notice, has reporting requirements that differ from the national HIS and must accommodate changes in health services (148). Furthermore, a separate system can, in certain instances, improve monitoring of the needs for refugees and migrants where international standards are not being met by the national HIS (148). Many national health systems in Europe still lack the specific policies, programmes and resources to improve accessibility and entitlement to health care for refugees and migrants (161) with barriers to health care for those who are ineligible for financial or legal reasons (331). This validates the creation of separate services specifically targeted to these population groups.

In some contexts, a separate system might be the only feasible solution provided that interoperability with other national HIS elements is possible, for example the system set up to manage the health of refugees and migrants in Italy (see Box 13). If data collection mechanisms include the core set of variables discussed above, then data linkage becomes possible. If interoperability is not feasible then analyses should be done in a way that supports comparability between refugees and migrants and the host population. Separate health monitoring surveys have been implemented in order to improve responses and participation among hard-to-reach groups, such as refugees and asylum seekers. For example, in Germany, a state-wide, cross-sectional, health monitoring survey was carried out in nine languages among asylum seekers and refugees; respondent for the survey were recruited within collective accommodation centres using a specific sampling and recruitment approach to foster trust relations and improve response rates (332). The strong response rates achieved support the use of this type of approach to source data on the health needs of a linguistically diverse, transient and marginalized population (332).

There are several examples currently within the WHO European Region of separate HIS for refugees and migrants in addition to the Italian system described in Box 13. A separate HIS for migrants was developed in Serbia in 2015, partially supported financially and technically by WHO. This system provides a surveillance and monitoring mechanism for thousands who have an unregulated status in the country (333). Providers of health services for refugees and migrants in Serbia provide weekly reports on predefined templates to the regional institutes of public health, which then enter the data into an electronic platform. Hungary also collects health records on asylum seekers, which are not integrated into the national HIS, with a main focus on vaccinations and communicable diseases; however public standardized migrant health data and statistics are currently not available (278). The Re-health project from

the IOM is structured to enhance knowledge among stakeholders about the health needs of refugees and migrants, as well as to strengthen national and cross-border disease surveillance and responsiveness (118,119,334,335). Through this project, electronic personal records have been implemented in seven Member States (Cyprus, Croatia, Greece, Italy, Romania, Serbia and Slovenia) in order to facilitate the use of personal health records for refugees and migrants in EU Member States (120,335). The electronic database is for external use and only those with permitted access can access at specific levels, although data can be extracted in aggregate form or at national level (336).

Germany has iteratively developed an electronic medical record in reception centres for asylum seekers (Refuge Care Manager) within the PriCare project (291). This approach tracks both individual-level data and pooled estimates, with continuity of care supported by electronic exchange of encrypted patient records between reception centres (see Box 10).

The ECDC has various surveillance mechanisms related to migration health and also provides screening recommendations for migrants newly arrived to the EU/EEA (42). The International Recommendations on Refugee Statistics produced by EGRIS have key variables to measure the health of refugees that could be incorporated into separate HIS which already exist and any forthcoming systems (132). EGRIS recommendations include indicators at three levels.

Level 1, priority indicators:

- self-reported health status; and
- coverage of essential health services.

Level 2 indicators:

- under-5 mortality rate and neonatal mortality rate;
- stunting and malnutrition among children under-5 years and disabilities;
- access to health care and unmet needs; and
- mental health.

Level 3 indicators:

- women's health decisions; and
- suffered violence.

As separate systems for collecting refugee and migrant data may not be evaluated alongside national HIS, assessments should be carried out to understand the barriers faced by refugees and migrants in accessing and utilizing health care.

Key points: separate HIS for refugees and migrants

- The preferred solution is to integrate all migration health data within national HIS. This is not always possible and, in those instances, a separate system for refugees and migrants may be created provided that access and comparability to the national HIS is maintained.
- Scenarios in which separate systems may become useful are at ports of entry, major transit hubs and when national systems are unable to support or adapt quickly to the needs of refugees and migrants.
- Core variables suggested above (see Table 1) are highly recommended to be collected within all HIS for refugees and migrants.
- Resources to support these systems and the variables and indicators to be collected can be found in the tools and handbooks from ECDC, IOM, UNHCR and EGRIS (see Recommended reading).

Policy considerations

Based on the evidence overview on collecting, synthesizing and disseminating data on migration health as part of national HIS, the following policy considerations are put forward for the integration of migration health data into routine national HIS in the WHO European Region.

Policy considerations at the national level

- **Working group for data collection:** a multistakeholder national working group for migration health data is an effective way for providing, collecting, synthesizing, disseminating and using the data (16,62,63,337). Such a group might include representatives from national statistics offices; ministries in charge of health, labour and internal affairs; immigration services; health providers (public and private); NGOs; researchers (academia); fieldworkers (care providers); and also key representatives from the refugee and migrant populations themselves (113,162). Member States may already have a multistakeholder working group supporting the collection and processing of data for national HIS, and, if so, it might be appropriate to integrate this extra objective (migration health data) into the already established group. Further actors should be welcomed into the group if they are identified in order to have a well-versed perspective on the needs of migration health data collection.
- **Supportive working groups:** the national working group could be supported and complemented by subgroups at various agencies/levels with a limited scope and a few selected stakeholders.
- **Inventory of current data sources:** a number of data sources will currently be contributing to national HIS (16,156). An inventory will identify where migration health data are already being collected, the definitions and methodology used in collection and the availability and quality of those data.
- **Incorporation of migration health data within national HIS:** a national strategy could be developed and implemented to allow collection and integration of migration health data within national HIS. in collaboration with other relevant agencies and stakeholders (62,63,337).
- **Regulations and safeguards:** regulations should be clarified and modified if needed to allow for the safe collection, storage and sharing of relevant data on migration health between data providers and users. Safeguards could include the use of firewalls that only allow access to certain levels of data to specific users, encryption procedures to create anonymity and the integration of blockchains (making it difficult or impossible to change or hack the system) to better secure data (294–297). As there has been a history of migratory status data being shared with migration authorities, existing laws on data privacy should be implemented; for EU Member States, the GDPR is binding and could be used as an example of

best practice by other countries. National laws should explicitly ban the transfer of migration health data for non-health purposes (48,299). Misuse of migration health data has potential negative consequences such as deportation or discrimination if data are used for purposes other than safeguarding and promoting health of refugees and migrants (338).

- **Protection against unauthorized use:** specific safeguards are needed to ensure that sensitive data linked to refugee and migrant health cannot be used inappropriately (48). Part of the work of a national working group for migration health data collection, processing and sharing would be to provide a roadmap on how data are collected, processed and shared to ensure data protection, transparency and confidentiality for all stakeholders. Ensuring ethical use of data is essential for all HIS but is particularly important for migration health data because of its sensitive nature.
- **Anonymized data:** easily accessible and usable data can be available for all relevant stakeholders such as service planners, policy-makers, analysts, and researchers if it is anonymized. The data can be stored digitally in community standard repositories that support sustainability and accessibility (145,284). Production of regular or annual reports that detail which data sources (e.g. labour surveys, health monitoring surveys or censuses) are available that contain migration health data, and how to access and use such data, is beneficial for research and policy planning.
- **Integration of core variables:** the core variables (country of birth, country of citizenship, year of arrival and country of birth of both parents) on migratory status should be integrated into routine data collection for HIS and into any separate systems if the need arises (19,69,75,95,116,275,339). As HIS regularly need to be adapted to the changing needs of a population, technological advances/modernization and legal stipulations, adoption of the core variables for migration health could occur during these systemic changes for health system strengthening.
- **Training for data collection:** those who are collecting data may include health-care staff, planners at various agencies such as national public health agencies and staff of statistical offices. Training should aim to increase awareness on the importance of collecting and disseminating migration health data and on how to do this in a way that establishes trust, exhibits cultural competency and ensures informed consent.
- **Electronic data collection:** although electronic data collection is best practice (16) as it allows for better continuity, storage and access for all stakeholders, it may not be feasible in all Member States. Integration of migration variables into the routine data collection system will need to occur through the data collection that is currently in practice for the host population. If paper collection occurs, data should be promptly entered into a digital format as soon as possible. If a separate refugee and migrant system is considered then electronic data collection is highly recommended because of the mobility and needs of the population.

- **Sampling strategies to increase refugee and migrant participation:** increased responses from refugees and migrants during surveys has been achieved with techniques such as purposive sampling, oversampling and disproportionate sampling (62,63,116,159,270). Using multilingual survey instruments, interpreters and cultural mediators during data collection helps to ensure informed consent and increase response rates and data quality by ensuring clear communication, building trust and decreasing cultural conflicts (7,48,178).
- **Data linkage:** migration health data are often collected within various data sources and the use of data linkage techniques can generate more comprehensive information, ease data collection requirements and reduce duplication of efforts (48,178). Unique identifiers, when available, are the best standard for data linkage (48). When unique identifiers are not available, other methods (e.g. probabilistic matching) can be implemented based on the context in which the HIS are situated (132).
- **Qualitative migration health data:** along with statistical/quantitative data, qualitative migration health data can add insights into health status and determinants of health for refugees and migrants. Qualitative data questions can either be nested within or supplemented against routine HIS (e.g. data from censuses or national surveys). Another approach could be to add open-ended questions or free text in routine HIS data collection, which can be analysed together with quantitative sources or as a separate entity (240,242,243).
- **Dissemination of migration health data:** once data have been collected, they need to be analysed and published at regular intervals and public access supported whether for increasing awareness, research or policy. Active measures should be taken to disseminate available information to target groups to facilitate translation of evidence into policies (159).

Policy considerations at the regional level

- **Guidelines and resolutions:** organizations such as the EU, WHO, other United Nations agencies and expert groups (e.g. EGRIS and EGMS) should develop guidelines and resolutions to call upon Member States to collect migration health data and support them in this endeavour (175). Prior commitments to reduce inequality can be used to gather consensus on collecting migration health data. Further guidance could help clarify the obligations and needs for this data.
- **Definitions of migrants:** the lack of an internationally accepted definition of the term migrant of some migrant subgroups makes it difficult to collect and harmonize data on migration. Organizations such as the EU, WHO and other United Nations agencies and international stakeholders should facilitate processes to develop a consensus on the definition of migrant alongside the national working groups.
- **Networking and collaboration:** international and intergovernmental organizations should act as liaising agents, at national, regional and international levels, between researchers, technical institutes, NGOs, refugee and migrant communities,

ministries and the national migration health working groups (7,95,153,162). They should provide technical assistance (100) and facilitate Member States to reach consensus on issues connected to migration health data collection, synthesis and dissemination. WHO, in collaboration with other United Nations agencies and international organizations, is well positioned to support the harmonization of migration health data across the WHO European Region.

- **Core migration health variables:** Integrating the core variables into already existing reporting frameworks such as the WHO Joint Monitoring Framework (312) would avoid the creation of additional reporting requirements and support cross-country comparability and harmonization.
- **Regional dataset for migration health:** a supranational body could initiate the creation of a regional dataset for migration health. Initially this is best done by assisting Member States in defining migrants on a national level. Agreeing upon a definition for international migrants and the initiation of migration health data collection will show the importance and usefulness of disaggregated data and encourage the collection of data on various other population subgroups (e.g. minorities).

Top tips for policy-makers

The following are policy considerations formulated specifically for policy-makers on what their role can be to support the integration of migration health data into routine national HIS in the WHO European Region. These are based on the above Policy considerations, and further details can be found there and in the text.

- **Initiate and advocate for a multistakeholder national working group** for migration health data collection, processing and sharing.
- **Support the creating of additional working groups** at various agencies/levels to complement the work of the national working group.
- **Develop and implement a national strategy for the collection and integration of migration health data within the national HIS.**
- **Develop and help to expedite regulations** to allow for the collection, storage and sharing of relevant data on migration health between data providers and users.
- **Support measures to prevent unauthorized access and use of migration health data** for non-health purposes.
- **Ensure legislation allowing data linkage and sharing between ministries**, which will allow for increased availability of migration health data from a variety of data sources from multiple agencies/organizations.
- **Ensure policies are in place to enable increased dissemination of information** based on the synthesis of migration health data for both the general public and researchers.

Conclusions

Migration health data are already being collected to varying extents by many Member States although the forms of routine data collection systems and data sources vary. However, integration of these data into national HIS and comparability between sources within and across Member States are suboptimal. Currently health data are available but cannot be disaggregated by migratory status and migratory status data exist but are not connected to health data or HIS. The ability to harness and amplify data collection and ensure comparability across the WHO European Region depends on a number of factors, including political will, infrastructure, collaboration, a set of core variables and support on both national and regional levels. In order to harmonize migration health data across countries, national HIS need to use the same core variables for data collection as a first step.

The recommendations here for migration health data collection and dissemination focus on targeted integration of this information into national HIS to support the sustainability, ease, effectiveness and quality of migration health data. If migration health data are routinely collected, data could be disaggregated by migratory status and improve understanding the health needs of this diverse population. If migration health data are integrated into existing reporting frameworks, collection would present no significant additional burden on Member States that are already reporting such information to track progress in achieving national, regional and global goals.

Recommended reading

Reviews on refugee and migrant health

- A European framework to monitor infectious diseases among migrant populations (75)
- Epidemiology of HIV and AIDS in migrant communities and ethnic minorities (40)
- Good practices in migrant health in Europe (178)
- International recommendations on refugee statistics (132)
- Availability and integration of refugee and migrant health data in HIS in the WHO European Region (HEN 66) (48)
- Variations in definitions of migrant and their influence on access to health-care services (HEN 46) (19)

General HIS strengthening tools

- A toolkit for facility data quality assessment (300)
- Assessment of national HIS (307)
- Collection, monitoring and evaluation tools, MEASURE Evaluation (156)
- Health facility and community data toolkit (289)
- HIS strengthening model (155)
- Routine data quality assessment tool, MEASURE Evaluation (301)
- SCORE for health data technical package (158)
- Standards and best practices for data sources for HIS strengthening, MEASURE Evaluation (153)
- Support tool to assess HIS and develop and strengthen health information strategies (158)
- The integrated knowledge translation approach: evidence briefs for policy (328)

Other useful references

- Analysis and use of health facility data: general principles. Geneva: World Health Organization; 2018 (Working document, February 2018; https://www.who.int/healthinfo/FacilityAnalysis_GeneralPrinciples.pdf?ua=1, accessed 9 November 2020).
- Analysis and use of health facility data: core health facility indicators. Geneva: World Health Organization; 2019 (Working Document, January 2019; https://www.who.int/healthinfo/FacilityAnalysisGuidance_Indicators.pdf?ua=1, accessed 9 November 2020).

- Analysis and use of health facility data: guidance for national and district planners and managers. Geneva: World Health Organization; 2019 (Working document, January 2019; https://www.who.int/healthinfo/FacilityAnalysisGuidance_IntegratedHealthServices.pdf?ua=1, accessed 9 November 2020).

Migrant-specific HIS strengthening tools

- Handbook for improving production and use of migration data for development (215)
- Health service organizations' responses to diversity (182)
- HIATUS (the Health Information Assessment Tool on Asylum Seekers) (99)
- International self-assessment tool for organizational health literacy (responsiveness) (227)
- The organizational health literacy responsiveness (Org-HLR) self-assessment tool (226)
- Toolkit to assess national migration data capacity (160)

A further reference

- Indicators of cultural competence in health care delivery organizations: an organizational cultural competence assessment profile. Fall Churches (VA): The Lewin Group; 2002 (<https://www.hrsa.gov/sites/default/files/culturalcompetence/healthdlvr.pdf>, accessed 22 November 2020).

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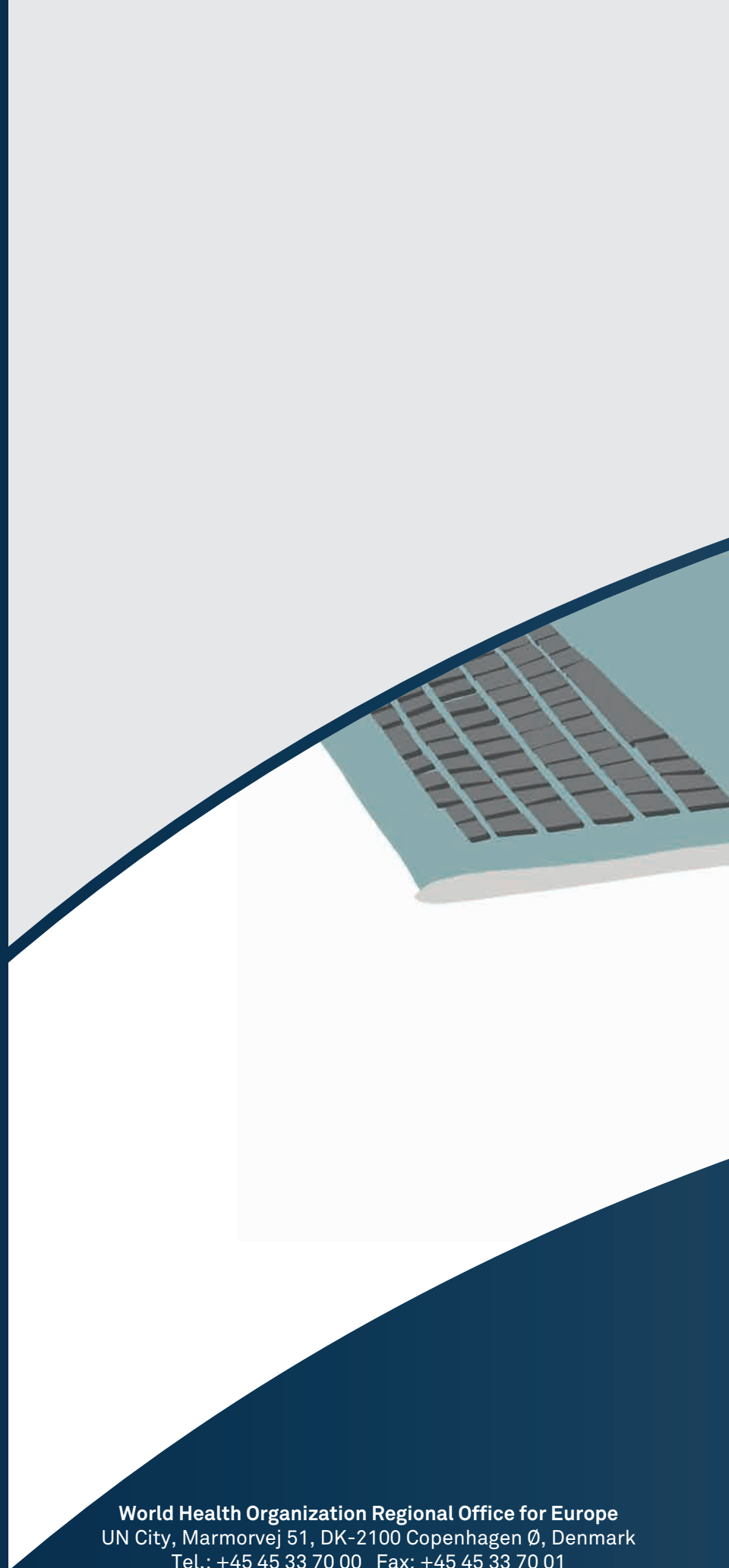
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