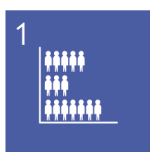
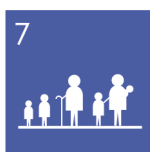


20.



DATA



VULNERABILITIES



BASIC SERVICES

Health information management in the context of forced migration in Europe

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Abstract: This chapter provides an overview of health data among migrants on the Central Mediterranean Route, using a case-based approach. It outlines how data are currently collected and what are the strengths and weaknesses of these health information systems. Examples from Libya, Italy, Germany, the United Kingdom and a transnational electronic health record system show the variety of systems in place. Current health information systems that capture migrant health are very heterogenous, often not harmonized and sometimes time-limited. As a result, information on migrant health is limited. Better recording of migration-relevant information in routine systems, access of migrants to routine care and collection of their data, as well as harmonization of variables and systems, are needed to inform public health policy and health-care delivery.

20.1. Introduction – The challenge of health information in the context of migration

Good population-based and service-based health information is one of the foundations of public health practice. It is the basis of evidence-informed policy and of quality service delivery. In the field of migration, the need for good data, clear and measurable indicators and accurate reporting has been recognized in numerous international key documents, including the World Health Organization (WHO) European Action Plan (WHO, 2016) and the Global Compact for Safe, Orderly and Regular Migration (United Nations General Assembly, 2018). Good health data for migrants are also needed to monitor progress on the Sustainable Development Goals, particularly Goals 3 and 10.7, on ensuring healthy lives and promoting well-being for all (United Nations, n.d.; Ghebreyesus et al., 2018).

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Yet several factors can make the systematic collection, collation, analysis and reporting of migrant health data particularly challenging, especially in the context of forced migration. These include, for example: barriers in access to mainstream health services (preventing recording); concerns about information governance among providers (preventing sharing, for example, for fear of information being used for purposes other than health); or the fact that multiple organizations can be involved in care and data collection in the context of forced migration (a barrier to harmonization). These factors are more pronounced for persons with less secure settlement status, but affect all types of migrants.

As a result of these barriers, described further below – and despite multiple efforts to harmonize definitions, variables or formats – current health information management systems for these populations are often disparate and heterogenous. This means that information on health status, health determinants and access to and costs of health care for these populations is often not readily available, and can be contradictory. Such information gaps can lead to incorrect assumptions or even misconceptions about the need and demand for health care among migrants, which risks causing inadequate preparation, suboptimal health service planning and delivery, and a failure to adequately inform the public debate. This is especially relevant if there are sudden changes in demography or health needs.

This chapter is set in the context of the Central Mediterranean Route (CMR), one of the main routes for mixed migration flows to Europe. Between 2014 and mid-2019, it is estimated that just over 2 million migrants arrived through the Mediterranean, with 82,872 arrivals in 2019 alone (UNHCR, 2018). The vast majority of these arrived via sea and cumulatively almost one third of these via the CMR, between North Africa and Italy (648,117). The route is one of the deadliest, with around 4,100 deaths in 2017–2018, representing almost 77 per cent of total deaths in the Mediterranean.

The current landscape to capture migrants' individual health information and population-based information on migration health is highly heterogenous, particularly in the context of migration along the CMR, making a comprehensive overview of health information systems (HISs)⁷ or the health situation of migrants themselves a challenging task. Therefore, this chapter uses a case study approach to (a) outline the data collection initiatives on migrants' access to health care and health status, (b) describe the practical and ethical barriers these initiatives face, and (c) summarize some generic health status findings.

Most HISs are stand-alone systems, although significant attempts have been made to harmonize health information management and improve interoperability between systems in the European Union (European Commission, 2015). The chapter does not aim to promote one approach over another, nor call for a universal HIS, but rather to improve understanding of existing HISs to promote greater harmonization and more efficient data sharing between providers, as well as more efficient analytical use of data while maintaining or even enhancing individual data security.

20.2. Overview of data sources

Figures 20.1 and 20.2 outline the main data sources available. Broadly, one can distinguish routine sources, such as hospital health records, from dedicated data collection systems, often established for specific operational or sometimes research purposes. Each of these has its own strengths and limitations, often inherent to the purpose of collection or the population in question.

⁷ Defined as any system which allows management of data collected in health care: this can be electronic or paper-based.

Figure 20.1. Potential data sources which either alone or through data linkage can be used to provide insights on migrant health

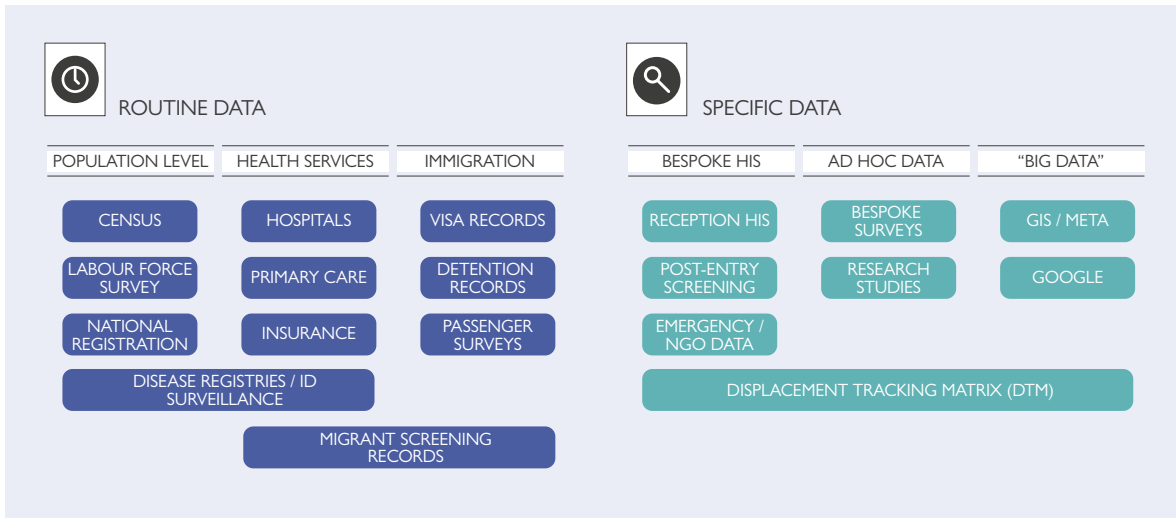


Figure 20.2. Detailed schematic on health data sources



Quantitative health data of migrants who travel along the CMR are often collected through health assessments in reception and detention centres en route or at destination (see Case Studies 1 and 2). The setting and context of these centres means that information recorded in these HISs cannot be seen as representative of migrants along this route (see Case Study 1). These health assessment data are often collected as part of border screening procedures and aimed at detection of public health-relevant diseases or of vulnerabilities, in keeping with respective European Union directives (European Commission, 2016).

One of the most sustainable solutions to ensuring good data on migrant health is to include them in the mainstream health system, but the feasibility of this depends on the setting and on migrants' status. For instance, this can be difficult in less stable settings, such as temporary shelters or reception centres, humanitarian crisis situations, or among migrants who have temporary or no recognized status. A key exercise is therefore to understand why this can be challenging and why data from mainstream health information systems are not routinely available or analysable. The issues are specific to each step of the data cycle – collection, collation, analysis and dissemination.

Reproducible, routine data capture and collation require accessible health-care services and standardized entry of health-care information. A key barrier to data collection on migrants in routine HISs noted above is related to migrants' access to the mainstream health system in countries of transit or destination. Such barriers can include eligibility restrictions, or lack of ability to navigate information needed to access care (IOM, 2017). In addition, existing disease prevention and control programmes at the national level are sometimes restricted or retracted for some migrant groups, particularly those in detention facilities. In Libya, for instance, detention centre management regularly refuses referral of tuberculosis cases to other medical service providers and transport of children to health centres for health-care provisions such as vaccinations (Health Cluster, 2019). Such measures either impede access altogether or prompt consultations with non-State providers. In both cases, records will not be available in the routine system.

New arrivals in Europe may be initially cared for in specialized settings – for example, reception centres, as described in the examples from Italy and Germany (Case Studies 1 and 3). These reception centres can be organized by European Union member States or – particularly in the case of large numbers of irregular arrivals, which may stretch or overwhelm local response capabilities – by humanitarian actors, including non-governmental organizations (NGOs) or United Nations agencies. Sometimes such a reception centre model runs in parallel with the mainstream health-care system, and actors may utilize paper records or stand-alone electronic systems, which are rarely linked to mainstream health information systems. Some humanitarian agencies may prefer separate HISs and restricted data sharing with authorities as a result of practical, humanitarian or ethical reasons.

At the level of analysis and dissemination, issues can be related to poor data quality resulting from the above challenges, or a lack of coordination between actors, particularly between national institutions and others, including NGOs and academia, to the perceived or actual temporary nature of these data collection activities or funding opportunities.

A recent, mostly European-anchored systematic review of health records for migrants and refugees retrieved 33 relevant papers, describing 20 different databases globally. Of these, at least 13 are partially from Europe (Chiesa et al., 2019). The review found a highly heterogeneous field in terms of data collection type, scope, target population and variables of mostly stand-alone health information systems. Only a minority (5 out of 33) could be described as electronic personal health record systems, and interoperability of the systems was limited. Some of the systems had even ceased to exist at the time of writing the review.

Another review performed for the WHO Health Evidence Network (Bozorgmehr et al., 2019) found that data on migrant and refugee health were available in 25 of 53 member States of the WHO European region. The review retrieved 696 studies which used migration health data from routine HISs, but many stemmed from specific disease surveillance systems (often infectious diseases) and from few countries. Systems are highly heterogeneous and often provide patchy insights into migrant health. The issues are well recognized, and recommendations for greater collaboration and harmonization of data collection have been issued (University of Pécs Medical School and WHO Regional Office for Europe, 2019).

Given the complexity of health services in arrival situations, and the fact that newly arriving migrants are initially cared for in specific centres and therefore are less likely to be integrated into routine health-care systems, health data are also much scarcer for people experiencing forced migration. Disjointed health-care and health information situations may persist for years, making routine data collection very challenging.

20.3. Current health information approaches along the Central Mediterranean Route

As outlined in recent systematic reviews (Chiesa et al., 2019; Bozorgmehr et al., 2019), comprehensive, systematic and available routine health information data systems with records on migrant health are not common, and the landscape is dominated by a multitude of stand-alone bespoke systems, often used ad hoc (such as surveys), or in the context of pre- or post-arrival assessments. They vary significantly in nature and scope, and are therefore outlined in a series of “real-life” case studies below.

Case Study 1. Italy – Information systems and arrival screening

In 2018, there were 53,586 asylum seekers in Italy, 3,676 of whom were unaccompanied minors (a 59% reduction since 2017). In the same year, international protection was offered to 31,429 people: 7,096 grants of asylum (7%), 4,319 subsidiary protection (5%), and 20,014 humanitarian protection (21%) (Ministero dell'Interno, Italy, 2018). The number of accepted requests for each form of grant decreased since 2017, and they will probably continue to decrease because of the reduced number of arrivals, demographical changes (different countries of origin) and changes in legal provisions occurring at the end of 2018.

The majority of people who apply for international protection in Italy have crossed borders irregularly (either by sea or through the Balkan route), as humanitarian corridors are a pilot project and accounted for about 2,500 arrivals since 2015 (UNHCR, 2019). For those entering by sea, a systematic health assessment is performed on boats at landing and immediately afterwards in hotspots, which are designated areas where migrants are hosted and undergo security procedures, and where they can start their application for international protection. Health assessments include syndromic surveillance, to identify symptoms and diseases of public health concern (Napoli et al., 2015). These data are transmitted through a web-based platform to the central and national level, from hotspots and selected hosting centres throughout the country, while other records are also kept at local level and paper-printed clinical cards travel together with asylum seekers.

A key challenge to health data management is to establish a verifiable identity, as passports are missing for the majority of asylum seekers. Although identification numbers are assigned to migrants at landings, changes in personal data can lead to difficulties in acquiring previous health records. This can lead to an incomplete health picture for the migrant, and may potentially lead to adverse outcomes – for example, if important medication allergies are missing. Some local, stand-alone HISs were used by agencies working within centres, but data transfer is usually limited to the same provider. Temporary projects tried to improve health data management – including the CARE project, which ended in 2017 (Care for Migrants, n.d.); and the EDETECT-TB project for tuberculosis (Abubakar et al., 2018) – but no systematic implementation is currently ongoing for these two systems (USB flash drive-based and App-based, respectively).

Asylum seekers can ask for temporary access to the Italian National Health System (by using a numeric or alphanumeric code), also granted to irregular migrants in case of health emergency or life-threatening conditions. A firewall from the immigration enforcement system is granted by law, as irregular migrants can be reported to legal authorities only in cases of some criminal offences, similarly to Italians (Ministero dell'Interno, Italy, 2009). In emergencies, this code can be assigned upon landing, in order to allow for health assistance that exceeds the one available at hotspots. After resettlement, migrants receive a medical evaluation to assess health needs, immunization and screening for active and latent tuberculosis. Data are registered at the local level. Once a residence permit is received, asylum seekers can regularly be added to the National Health System, with a new permanent alphanumeric code. Inscription needs to be renewed periodically until international protection is obtained. Minors are directly added to the National Health System.

The Italian Health System is organized regionally, and this makes the establishment of a single national data collection system difficult. Several local or regional initiatives have been established to provide better health information, thanks to the work of several NGOs and non-profit migrant medical centres in collaboration with local health systems, either at district or regional level. However, no national system has been developed to date, and data are therefore scarce, especially for non-communicable diseases. At first arrival, from syndromic surveillance and analyses of agencies working in hotspots/harbours in Sicily, the most frequent diagnoses are parasite skin infections, febrile syndromes with rash (mainly chickenpox), respiratory tract infections and trauma-related conditions (Di Meco et al., 2018).

Case Study 2. Libya – Rapid surveys

In 2018, the Libyan health authorities undertook a rapid situational assessment to explore the health status of migrants in 16 detention centres in Libya, in order to provide evidence-based essential health care to detained migrants. A survey was undertaken by a multidisciplinary team, which included medical specialists and public health researchers of the Ministry of Health of Libya, with the aim of surveying self-reported disease conditions and factors affecting the well-being of detainees who lived for at least six months in the detention facilities.

At the time of writing, the survey results were still being finalized and thus data presented here were extracted from a draft report. A total of 427 detainees provided consent to participate in the survey, with only 37 female respondents. Over half of the detainees (62.2%) reported having spent more than one year in the detention centres. One hundred and fifty detainees (35.1%) reported that they were exposed to some form of physical violence, such as physical abuse/ beating. Two fifths reported acute diarrhoea in the six months preceding the survey, and 7 per cent had food poisoning during the same period. One third, 142 (33%) had skin diseases, mainly scabies and/or pediculosis; 14.7 per cent had respiratory infections; and 3 per cent reported snake/scorpion bites. Seventy-three detainees (17.1%) reported having chronic diseases such as hypertension or diabetes mellitus.

Despite methodological and sampling issues, the survey report highlighted that, among other exposures, the migrant journeys and detentions can be fundamental determinants of ill health and disease progression. Ensuring timely and dignified health care to migrants in detention centres is critical. International guidelines and general standards with regard to public health conditions in detention centres need careful consideration, including the rationale for detention (IOM, 2010; United Nations Human Rights Council, 2008). Along with the need for improved health-care services for detainees, the report also highlighted the need to improve disease surveillance and basic HISs in order to better capture and identify disease trends within these settings.

Case Study 3. Germany – Information systems for asylum seeker health in the context of secondary migrations

The health system in Germany is decentralized and fragmented between different sectors of care (primary and tertiary sectors) and levels of governance (local, state and national). The situation is even more complex for asylum seekers, with special considerations of reception, accommodation and entitlements to health care (Bozorgmehr et al., 2018a). Reliable data on health and primary care among asylum seekers in reception centres are an essential prerequisite for the planning and provision of appropriate and needs-based medical services to this vulnerable population.

However, health-care provision in reception centres is often haphazard due to the lack of national standards regarding the infrastructure, equipment, or workforce composition in such settings (Bozorgmehr et al., 2016). As a consequence of decentralization and lack of standardization, HISs in reception centres are either paper-based, improvised and/or incompatible across centres, even in the same federal state. Some centres even use multiple (incompatible) HISs, due to different care providers under contract of the state authority in charge of the facility. These factors significantly preclude routine health monitoring and – while health monitoring for regular migrants is fairly decent – data availability is particularly patchy for asylum seekers (Bozorgmehr et al., 2017). Furthermore, health-care entitlements for asylum seekers in reception centres in Germany are restricted, and only a few federal states issue electronic health cards to newly arrived asylum seekers (Bozorgmehr and Razum, 2019). This means that health data of asylum seekers in the initial 15 to 18 months, even if electronically recorded, are often not accessible through the HIS of the regular health system. All of the above-mentioned barriers apply to the population in these settings and result in information not being recorded, shared or harmonized.

In order to improve the availability of timely and reliable data, an electronic medical record (Refugee Care Manager, or RefCare©) was iteratively developed in 2016, and since then tested and implemented in German reception centres with financial support by the German Federal Ministry of Health (Bozorgmehr et al., 2018b). Continuous surveillance in this system is realized through a tailored information technology infrastructure for routine recording of medical care in primary care clinics in reception centres, and through a research network (PRICARE, available at www.pri.care) as a formal framework for sustaining surveillance based on such routinely collected medical records data.

Within the network, 64 health and health-care indicators covering morbidity, care processes, quality of care and syndromic surveillance have been developed. The system builds on a decentralized, harmonized, anonymous and automated analysis of medical records data, which allows the analysis of data without central storage of personal data (Nöst et al., 2019). In November 2019, the network covered 21 reception centres in three federal states, with over 30,000 patients and more than 120,000 patient contacts. The surveillance approach allows calculating single-centre prevalence for 29 morbidity indicators based on individual-level data, and pooled estimates across centres stratified by age and sex. Preliminary data show that the morbidities with the highest prevalence were respiratory, digestive and infectious diseases, followed by trauma and accidents, musculoskeletal and mental health conditions. Furthermore, the system allows the electronic and encrypted exchange of patient records and files between reception centres (upon informed consent of the patient) to ensure continuity of care and medical treatment after transfer.

Experience shows that the system helps professionals to manage their clinical data and provide care to asylum seekers in fragile contexts with repeat contacts and dynamic changes in the population. The approach may inform the development of similar networks in other reception countries, in particular where strict data protection regulations preclude others – for example, cloud-based, health surveillance systems – among migrant populations.

Case Study 4. United Kingdom – Health information in the context of diverse arrivals – resettlement and asylum seekers

The United Kingdom offered protection to 20,703 people in 2019 in the form of 12,565 grants of asylum, 1,241 grants of humanitarian protection, 1,285 grants of an alternative form of protection and 5,612 for refugee resettlement (United Kingdom Home Office, 2019).

Resettlement accounted for just over one quarter (27%) of the people granted humanitarian protection in the United Kingdom between 2013 and 2018. Most resettled refugees to the United Kingdom have escaped the Syrian conflict. Resettled refugees are offered a comprehensive health assessment before they travel to the United Kingdom. The health assessment is commissioned by the United Kingdom Home Office and provided by IOM, and follows guidance agreed between the two organizations and Public Health England, an executive agency of the United Kingdom Government. The health assessment aims to protect and promote the health of the refugee and wider public health before, during and after travel to the United Kingdom. A key aim is to support integration in the United Kingdom, by ensuring the refugee's health needs are appropriately identified and met when he or she arrives to the United Kingdom. Another important aim is to monitor the health of this population. For example, analysis of the yields of infectious diseases among refugees showed that these are strongly associated with epidemiology of the infection in country of origin (Crawshaw et al., 2018). A recent pilot of a mental health assessment tool in the pre-entry health assessment showed fairly low prevalence of mental health issues, but design of the pilot means this was not a representative sample of the population (United Kingdom Home Office, Public Health England, 2019).

People who apply for asylum and other forms of protection within United Kingdom borders face a range of different circumstances: some have been in the United Kingdom for a considerable period, while others have recently arrived; some travel on a visa, while others may have crossed the border irregularly; some have a place to live, while others are destitute. There is no systematic health assessment of all asylum applicants in the United Kingdom; however, those who are destitute and apply for asylum may be offered accommodation in an Initial Accommodation Centre (IAC) by the Home Office. Almost all of those who move into an Initial Accommodation Centre are offered an initial health assessment. These records are kept locally by the health-care team. Asylum seekers may move between Initial Accommodation Centres, but there are challenges in sharing the health data, as health-care teams are commissioned locally and information technology systems may vary.

The United Kingdom Government has mechanisms in place that allow health services (through NHS Digital) to share information with the immigration agency (the Home Office) for immigration enforcement purposes. This has raised concerns – especially among health-care workers, Members of Parliament and third-sector organizations – that migrants would avoid accessing health care for fear of immigration enforcement. These concerns have led the United Kingdom Government to substantially reduce the circumstances under which these data are shared, although sharing still takes place.

Case Study 5. The IOM electronic personal health record

Based on local needs assessments, prompted by larger numbers of arrivals to Europe in 2015 and 2016 and with co-funding from the European Commission (DG SANTE), a structured health record was developed to support health assessments for newly arriving migrants at points of arrival, including in reception centres in Europe. Subsequently, the system has been developed into a full electronic personal health record system hosted within IOM, which allows recording and secure transfer of this information between health providers in different centres and even between countries. This is important because migrants may be moved between different facilities or may choose to continue their journeys. Currently the system is available in reception facilities of seven countries – including Bulgaria, Croatia, Cyprus, Greece, Italy, Serbia and Slovenia – and there are plans to expand the information system to further sites and countries. With support of the Italian Government, the electronic Personal Health Record has been further developed and tailored to local needs in the Italian region of Sicily. The system has a user-friendly front-end, uses smart technology and easy drop-down menus to support coding (ICD-10), and minimizes manual data entry. It has a back-end business analysis tool, which visualizes the health status and disease categories along with demographic data in real time, and it is highly interoperable by complying with the recommended European exchange format. The system has a business intelligence tool dashboard, which is important to inform health service provision, as well as monitor illness and disease, and allowing it to report according to the International Health Regulations.

Between its inception in January 2017 and July 2019, the system captured 19,733 records of 14,440 individuals, including follow-up records. About half of the records are from Greece, reflecting both the usage of the system as well as arrival numbers. The majority of persons are young (mean age of 27 years) and almost 78 per cent are males. Almost three quarters of individuals did not have any ICD-10 recorded illnesses. Most commonly ICD-10 coded disease categories included respiratory disease (18.7%) and common infections (6.6%), often respiratory tract infections. About 11 per cent of individuals were recorded as having a mental illness in this cohort. This seems to reflect a young, mostly healthy population, who has been exposed to adverse circumstances and overcrowding in reception conditions, and a significant minority who experienced some recent psychological trauma.

From available data, it appears that the majority of migrants following this route are often young and physically healthy, although this varies significantly by setting and many are exposed to significant risks along their journeys, often over a prolonged time. This increases risks of psychological trauma and of diseases of overcrowding, such as some infections, including scabies or more severe ones, such as tuberculosis. The correlation between poor living conditions and certain infections is well established (Chang and Fuller, 2018; Grange and Flynn, 2018; Dhavan et al., 2017).

20.4. Ethical considerations

HISs for migrants raise several ethical considerations. Fundamental to any health intervention, including the storage and transfer of clinical data, is that the patient is provided with appropriate, specific and clear information about his/her records and can freely decide whether or not to have them stored in the system, transferred to others, and for what purposes (informed consent). Health records should serve the interest of the individual, as they facilitate communication between health-care providers, supporting the provision of high-quality care and avoiding clinical risks created by lack of information. However, in the case of migrants, health records are sometimes used for immigration enforcement purposes, as illustrated by the United Kingdom in Case Study 4. This can act as a barrier

in access to health-care services, as migrants may want to avoid immigration enforcement. This can also raise complicated moral dilemmas among front-line health-care practitioners, who want to build trust with their patients and ensure they receive the highest quality care, but also not break the law (by not actively reporting patients to enforcement agencies or by not recording data in clinical records). This has led some organizations and European Union member States to argue for and implement a “firewall” (PICUM, n.d.): a separation between immigration enforcement and the provision of essential services, which allows migrants to access these services without fear.

An important consideration in this area is the balance of data security as an individual right versus the security needs of a society, where some may argue that using data for law enforcement purposes could be acceptable in certain extreme situations, such as prevention of terrorist activity. Conversely, it has been argued that data protection processes created barriers to swift action in humanitarian theatres and may even cause harm. Office of the United Nations High Commissioner for Refugees (UNHCR) data protection principles are seeking to balance robust data protection principles with flexibility in specific situations (UNHCR, 2015). A recent review acknowledged the significant and evident benefits of electronic personal health records for personal and public health, but pointed out some key considerations regarding restricting the type of information that should be stored and who has access to this information to prevent potential misuse of such information (Feeney et al., 2019).

Data from HISs are also often used, at a population level, to plan services and inform policies. This requires collection, analysis and dissemination of data, which can raise several ethical issues with regard to migrants. Particularly in humanitarian situations, data and information can be a key resource, and decision-making and funding can depend on whether data are available and what they show. However, positive uses of data cannot be seen in isolation, and in some contexts, the availability and sharing of such information can have an adverse effect on migrant populations by increasing stigmatization – for example, by selectively reporting high incidences of infectious diseases such as tuberculosis or HIV. The link between donors, humanitarian actors and data collection systems could lead to conflicts of interest, and can also raise ethical issues.

A number of HISs are established mainly or exclusively to support member States' border health assessment efforts, often for infectious diseases. Such screening, often done for health security reasons (such as to avoid importation or transmission of infectious diseases), can be beneficial for the recipient in terms of early disease recognition and treatment. However, because many of these activities are not entirely voluntary – sometimes mandated, sometimes linked to benefits or at least perceived to be linked to benefits – such systems can create moral dilemmas (Beeres et al., 2018), and this may be aggravated if providers have mixed or dual accountabilities (to the patient and the member State). It is sometimes not clear whether and to what extent such screenings benefit the individual, and how outcomes (or declining screenings) may interact with their migration status. The absence of such clarity would counter any notion of informed consent (Pacheco et al., 2016).

20.5. Way forward

The case studies illustrate that, while some migration health data are collected in many places, there are vast differences in what is collected, how it is collected and how it is used. Significant work needs to be done if we are to harmonize collection processes and variables, and optimize use of data (Santo Tomas et al., 2009). The Center for Global Development has issued five key steps to improve data collection, and while these are generic, they are highly applicable to migrant health data along the CMR. These steps, adapted to migration health data, would include:

- (a) Introducing key variables such as country of birth or nationality and residence status into routine datasets;
- (b) Maximizing the use of such routine data, while being aware of their limitations;
- (c) Collecting and harmonizing cross-country data;
- (d) Making aggregate data widely available; and
- (e) Encouraging the inclusion of specific standardized migration-related questions in household and population surveys.

In addition, and for migrant groups in vulnerable situations, improving coordination of care, especially upon arrival, and coordination of information of care – through systems such as the IOM electronic Personal Health Record – will be vital to addressing the current heterogeneity of systems.

20.6. Conclusions

This chapter provided an overview of some of the existing data collection systems on migrant health and their findings. These health records show a young, predominantly male and mostly healthy population with an infrequent but expected distribution of diseases (Aldridge et al., 2018). In keeping with the literature (Kien et al., 2019), there is a setting-specific higher rate of common mental illness, such as post-traumatic stress, depression and anxiety. Prevalence can be increased by aggravating circumstances, such as detention (von Werthert et al., 2018) and obviously may be related to previous trauma or current experiences of uncertainty. In specific settings, there is also a higher prevalence of specific infectious diseases, some of which as previously described could be related to mass accommodation, encampment and overcrowding.

This chapter also showed that health data for recently arrived migrants and refugees in Europe are highly heterogeneous and sources are mostly not linked, making it difficult to produce a comprehensive and generalizable overview of the topic. A more coordinated approach to HISs among migrants, mapping and harmonization of variables and definitions and reliable modes for comparison, including to routine HISs, is needed. Significant challenges in doing so persist, given the context of current health data collection for these populations.

Since HISs are usually accompanying health care, much of the variation in the former can be explained by variation of the latter. Access to care can be dependent on legal status, and data on some of the most vulnerable migrants, including those with no legal status, can be scarce, as they may not access care, or may access parallel systems – for example, through NGO providers (Médecins du Monde, 2019). Many data collection systems on arrival are set up to record health assessment data and may be restricted in scope to disease areas of interest. Lastly, the mobility aspect also impedes good data collection; migrants may move or be moved, or may change status (for example, becoming irregular). While progress has been made to mitigate against these aspects, specific migrant cohorts and specific diseases (such as chronic diseases) are likely to be missed.

Recent efforts have been made to improve the collection, collation, analysis and dissemination of migrant health data. These include initiatives to set up monitoring systems (WHO, 2016), create consensus regarding the collection and harmonization of variables (University of Pécs Medical School and WHO Regional Office for Europe, 2019), and training workshops for European Union member States. While these initiatives go in the right direction, more is needed to tackle the acute lack of these important data.

Collecting and sharing migrant health data have serious ethical implications, not least the individual right to privacy (Article 17, International Covenant on Civil and Political Rights) and the balance with security issues. New systems or harmonized systems may be powerful tools to get a better picture of migration and migrant health. Considering the severe protection risks, implementation must be carefully monitored to ensure that all data are anonymized and shared in secure ways across different entities. The issue of interoperability among national and regional databases containing information on migrants is another key consideration in driving action toward better information systems.

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