

HEALTH EVIDENCE NETWORK SYNTHESIS REPORT 66

What is the evidence on availability and integration of refugee and migrant health data in health information systems in the WHO European Region?

Themed issues on migration and health, X

Kayvan Bozorgmehr | Louise Biddle | Sven Rohleder | Soorej Jose Puthooppambal | Rosa Jahm



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Abstract

The recent rapid increases in population movements across borders highlight the importance of reliable data on refugee and migrant health for public health planning. This scoping report examined evidence on the availability and integration of refugee and migrant health data in health information systems in the WHO European Region. Refugee and migrant health data were available in 25 of the Region's 53 Member States, but differences existed in the availability, data types and main sources of data collection. Except for countries with population registers, the predominant data sources were medical records, disease-specific records and notification data. Data integration was often limited, and health monitoring surveys and data linkage approaches were underused. Policy considerations include harmonizing migrant definitions, promoting the coordination/governance of data collection, performance monitoring for health information systems, promoting cross-country exchange of experiences, exploiting data linkage, expanding existing health surveillance, reducing health-care barriers and strengthening general health information systems.

Keywords

HEALTH INFORMATION SYSTEM, HEALTH INFORMATION MANAGEMENT, REFUGEES, MIGRANTS, MEDICAL RECORDS, POPULATION SURVEILLANCE

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ABBREVIATIONS

CPR	Civil Personal Registration (number)
DEGS	German Health Interview and Examination Survey for Adults
EEA	European Economic Area
EU	European Union
KiGGS	German Health Interview and Examination Survey for Children and Adolescents
NCD	noncommunicable disease
MeSH	Medical Subject Headings
TB	tuberculosis
TropNetEurop	European Network for Tropical Medicine and Travel Health
tw	textwords

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SUMMARY

The issue

Rapid increases in population movements across borders in recent years have highlighted the importance of reliable data on refugee and migrant health for public health planning. However, such data are not always systematically collected by country health information systems in the WHO European Region. A health information system includes all activities and resources aimed at ensuring the production, analysis, dissemination and reporting of health information for public health monitoring. It also includes some less tangible elements necessary for operating a health information system, such as governance mechanisms and legal frameworks, interinstitutional relationships and values. The *Strategy and action plan for refugee and migrant health in the WHO European Region*, the *Global action plan promoting the health of refugees and migrants* and the *Global compact for safe, orderly and regular migration* all emphasize the need to strengthen health information systems and incorporate refugee and migrant health-related variables into national datasets. To monitor progress towards this goal, and to determine the current status, synthesized information on the various data collection practices is needed. Furthermore, an overview of policy considerations towards refugee- and migrant-sensitive health information systems is required to inform public health decision-making at the national and European levels, taking into account the ethical considerations of collecting, using and disseminating data on refugee and migrant health.

The synthesis question

The objective of this review is to address the question: “What is the evidence on availability and integration of refugee and migrant health data in health information systems in the WHO European Region?”

Types of evidence

Evidence was obtained by conducting a scoping review of peer-reviewed and grey literature published in English, German and Russian between 2000 and 2018. The review considered two types of evidence: (i) theoretical and empirical studies analysing the health information system in one or more countries of the WHO European Region with respect to data on refugee and migrant health and (ii) empirical studies and reports using systematically collected data from such systems to answer a specific question related to refugee and migrant health.

A total of 41 studies analysing elements of country health information systems with respect to data on refugee and migrant health were included in the review. A further 696 studies using data from health information systems were reviewed based on their abstracts to systematically derive information on data sources, data collection practices and available data on health outcomes among refugees and migrants in countries of the WHO European Region.

Results

Research literature on the availability and integration of refugee and migrant health data is fragmented. Most of the studies identified assessed highly specific data sources, disease entities or areas. Studies focusing on more than one data collection source in European countries, or in national health information systems as a whole, were rare. Current knowledge about the different elements of the health information system is disjointed. Although some evidence was found on the availability of refugee and migrant health data, evidence on data quality (a crucial aspect of availability), integration of systems and policy initiatives to strengthen data collection for migrants was much less frequent. Furthermore, the existing evidence was geographically biased towards Scandinavian and central European countries for routinely collected data and towards western and southern European countries for infectious disease surveillance. Very little information is currently available on systematic data collection mechanisms for refugees and migrants in eastern Europe.

Data on refugee and migrant health were available in 25 of the 53 Member States of the WHO European Region, but the extent of availability, type of data and main data sources differed greatly. Data sources that recorded data on refugee and migrant health were diverse and their integration into national health information systems was limited, except for population registers, notification systems and medical records in some countries. Underused strategies to improve data availability are to increase the inclusion of refugees and migrants in health monitoring surveys by means of innovative, refugee- and migrant-sensitive mechanisms for recruitment, sampling and data collection, and to increase the use of data linkage in countries with decentralized, fragmented health systems.

Policy considerations

Based on the findings of the review, the main policy considerations for the WHO European Region are to:

- facilitate the harmonization of indicators and definitions of refugee and migrant status in health information systems in the WHO European Region

to mitigate challenges in cross-border comparability due to heterogeneous definitions;

- designate a supranational body to be responsible for governance, leadership and oversight of data collection on refugee and migrant health to foster better coordination, cross-country exchange and learning, as well as harmonization of data collection strategies (including data quality, integration and protection); and
- regularly monitor the performance of European health information systems regarding the availability and integration of refugee and migrant health data using appropriate assessment tools.

The main policy considerations for improving health information systems at country level are to:

- strengthen existing health information systems for the general population because this is also likely to improve the availability of data on refugee and migrant health;
- integrate key data elements related to refugees and migrants (e.g. country of birth, nationality, length of stay, reason for migration) into existing data collection systems to facilitate stratified data analysis, identify at-risk subgroups and ensure cross-border comparability;
- establish and/or strengthen a tailored, proactive approach to data collection for refugees and migrants that addresses the difficulties in accessing these populations, their limited access to health care, their language barriers and the small sample sizes;
- utilize and scale up national health monitoring surveys to effectively integrate refugees and migrants and facilitate better linkage of survey data with civil/vital registration data; and
- establish and/or strengthen data linkages across records (e.g. population registers, facility-based records and household surveys) in order to:
 - maximize the available health information, particularly in countries where refugee and migrant health data are not routinely collected due to decentralized health information systems and lack of civil registrations; and
 - generate comprehensive information on refugee and migrant health by combining information on health service utilization and migration status.



1. INTRODUCTION

1.1 Background

The number of international migrants has increased substantially in recent decades. In 2017, the WHO European Region was home to around 90.7 million international migrants, corresponding to almost 10% of its total population and 35% of all international migrants (1). There has been a dramatic increase in the number of refugees, both globally and in the WHO European Region. Furthermore, population movements have been characterized by a mixed flow of labour migrants, refugees, asylum seekers, irregular migrants and victims of trafficking. It is acknowledged that all nations are increasingly becoming countries of origin, transit and destination, and that migration has been and will continue to be a reality in every society (2). Therefore, health information systems need to adapt accordingly to collect, analyse and disseminate timely data on health for an increasingly mobile population.

Monitoring refugee and migrant health through relevant data is an important public health strategy. Data on refugee and migrant health, including data on the social determinants of health and on the accessibility and utilization of health services, are essential for monitoring, safeguarding and promoting the health of refugee, migrant and host populations. The need for strong data collection and reporting has been identified in a WHO Health Evidence Network synthesis report (3), the *Strategy and action plan for refugee and migrant health in the WHO European Region* (4), the *Global compact on refugees* (5), the *Global compact for safe, orderly and regular migration* (6), the recent draft WHO global action plan to promote the health of refugees and migrants (7) and the academic literature (8–12).

Studies reviewing health information systems in Europe have found that many countries lack systems to collect data on refugee and migrant health, thus limiting the ability to appropriately respond to current needs and plan for the future (8–10,12). A recent survey conducted by the WHO Regional Office for Europe found that only 20 of the 40 responding Member States routinely collected and included data on migration-related variables in their existing national datasets (1). However, information is not available on the frequency of data collection, the variables included and at the level of data collection (health centre, community, national or regional).

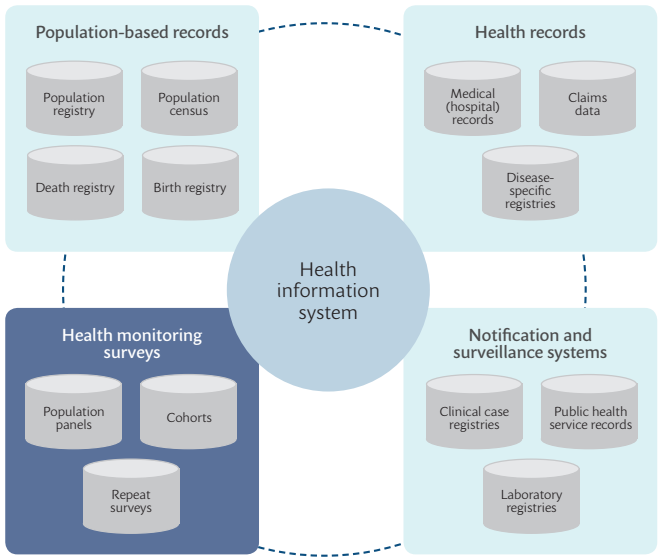
Strong health information systems play an important role for evidence-informed policy-making because timely, reliable data on health status, risks factors and

health determinants, health-care access, quality of care, health-care costs and coverage with required interventions and programmes are required to inform policies and programme implementation. Such data are necessary not only to prevent any potential disease outbreaks but also to protect and promote the health of refugees and migrants and the host population. Such systems will help to mitigate concerns, which are not necessarily based on evidence, that migrants are a threat to public health in countries of the WHO European Region (2). However, developing a robust information system or adapting existing systems to collect health data for refugees and migrants is challenging, because of both the diversity and the mobility of refugee and migrant populations (2). Further challenges include the potential misuse of such data for political stigmatization campaigns against refugees and migrants, as well as the inappropriate access of migration authorities to sensitive health data (2).

The issue of data collection is further complicated by the varying definitions of migrant used in the WHO European Region and how this information is obtained, which compromise the comparability of data across or even within countries (9,13). Guidelines and minimum required datasets have been developed to improve the availability of comparable data at the national (14–16) and European Union (EU)/ European Economic Area (EEA) levels (17), but no processes are yet in place to align indicators or share best practices in refugee- and migrant-sensitive data collection (18).

In order to adequately respond to the health-monitoring needs of refugee and migrant populations, health information systems must not only address these challenges but also generate timely, reliable data from a wide range of sources. Components of a health information system include data sources, but also financial and human resources and less tangible factors such as governance mechanisms, policy frameworks, institutional relationships and values. The task of health information systems is “the production, analysis, dissemination and use of reliable and timely information on health determinants, health systems performance and health status, both on regular basis and in emergencies” (19). To this end, health information systems gather information from a wide range of data sources, including population- and facility-based censuses, household and health monitoring surveys, civil registration systems, public health surveillance and notification systems, medical records, and health services and health system records (e.g. records on human resources, infrastructure or financing) (20). Data are usually generated via different data collection modes either directly from populations or from the operations of health or other institutions. The data sources underlying a health information system can hence be grouped into different data collection categories (20). Fig. 1 gives a simplified overview of relevant data collection categories.

Fig. 1. A simplified overview of a health information system with different data collection categories



Notes: light blue boxes: secondary data, routine statistics; dark blue box: primary data, self-reports based on questionnaires or standardized interviews.

Source: adapted from World Health Organization, 2008 (20).

1.1.1 WHO policies, plans and strategies

In recent years, WHO has adopted several resolutions relevant for refugee and migrant health (21–26). At a global level, the WHO framework of priorities and guiding principles to promote the health of refugees and migrants was presented and approved at the Seventieth World Health Assembly (26) and reaffirmed in the recent draft global action plan (7). One of the priorities in the framework is to strengthen health monitoring and health information systems. Monitoring refugee and migrant health was identified as a key component in implementing resolutions WHA61.17 and WHA70.15 on health of migrants (21,24) and in WHA71.15 on the implementation of the International Health Regulations (25). This resolution highlights the importance of collecting relevant data on refugee and migrant health to substantiate evidence-informed policies and of standardizing and increasing comparability of data on refugee and migrant health. At a regional level, the recently adopted *Strategy and*

action plan for refugee and migrant health in the WHO European Region emphasizes the need to strengthen health information systems and incorporate refugee and migrant health-related variables into national datasets (24). Incorporating such data enables the analysis of population health data to be disaggregated by refugee and migration status, thus substantially contributing to the creation of refugee- and migrant-sensitive health information systems.

1.1.2 Objectives of this report

Synthesized information on data collection practices, including the integration of refugee and migrant health information into nationwide datasets, is needed to monitor progress towards the goal of creating refugee- and migrant-sensitive health information systems in the WHO European Region.

This scoping review systematically examines the evidence base to address the question “What is the evidence on availability and integration of refugee and migrant health in health information systems in the WHO European Region?”

1.2 Methodology

A literature search was carried out of peer-reviewed and grey literature in English and Russian between December 2018 and March 2019 to identify evidence on the availability and integration of refugee and migrant health data in health information systems in the WHO European Region. Studies published from January 2000 to December 2018 in English, German or Russian were included in a scoping review.

The search of peer-reviewed literature identified 14196 articles and the search of grey literature identified 226 articles. Two selection strategies were used to review and synthesize studies reporting evidence on health information systems (strategy 1) and research using routinely collected data (strategy 2). After screening and duplicate removal, 76 abstracts were identified as reporting evidence on routine data sources; of these, 41 were included for narrative synthesis after full-text screening (strategy 1) (9,11,12,26–63). A further 696 abstracts were identified as reporting research using routinely collected data and were included for abstract extraction and quantitative analysis (strategy 2).

See Annex 1 for full details of the methodology, including the inclusion criteria, selection and analysis process of search strategies 1 and 2; Annex 2 for definitions of terms used in the scoping review and Annex 3 for the list of 696 studies identified via strategy 2.



2. RESULTS

The review synthesized evidence obtained through two main strategies. Strategy 1 identified the gaps in the current evidence base on the availability and integration of refugee and migrant health data into health information systems. Strategy 2 identified a large number of studies using routinely collected data in the WHO European Region to study a given scientific question related to refugee and migrant health. Although this second set did not directly answer the synthesis question, the inclusion provided relevant information on the ability of health information systems to collect routine data on refugee and migrant health. Therefore, the combined use of strategies 1 and 2 allowed comprehensive, high-level mapping of the available sources of routine data, as well as a more in-depth consideration of the integration of these data in country health information systems. Particularly informative examples of the approaches used for, and sources of, routine data collection identified by these two strategies were selected as case studies to highlight details of their specific features, characteristics or approaches used.

2.1 Evidence on health information systems

Strategy 1 identified a total of 41 peer-reviewed studies on the availability and integration of refugees and migrants in data collection. These studies are highly diverse, reflecting the availability, quality and attributes of the varied data collection mechanisms in the WHO European Region. Only three studies took a broader view of health information systems for refugees and migrants, through using literature reviews or expert surveys to assess the availability of data on refugee and migrant health in several countries and in more than one data collection category (9,12,26). All other studies focused on single data collection categories or disease outcomes.

2.1.1 Population-based records

A total of 19 studies considered the availability and quality of population-based records (civil registration, vital registration, census data) for refugee and migrant health. A survey of 27 EU Member States found that 24 had national death registers that enabled disaggregation by migrant status, while 11 recorded migrant status in register data on health service utilization (9). The remaining 18 studies considered registers for refugee and migrant health in one of five European countries: Denmark, Germany, the Netherlands, Sweden and the United Kingdom.

Eight studies described population-based registers routinely used in refugee and migrant health research in Denmark and Sweden (26–33). In both countries, a personal identifier is provided to each person either at birth or at a specified time after entry for refugees and migrants. The data recorded include country of birth, citizenship, date of immigration and nationality of both parents. Refugees and migrants can thus be identified through their personal identifier and their data linked across national registers, including on health and health care, education, and labour (27–31). Swedish and Danish population registers are reported to provide data of high quality (i.e. with respect to completeness, validity of outcomes and national geographical scope) and timeliness (i.e. routine data are readily available) (28,30). These studies highlight the significance and quality of linked national registers because this approach provides large-scale, representative and long-term population samples over time; avoids loss to follow-up; and is easy to execute (28,30–32). The limitations and shortcomings of register data compared with data collected through health monitoring surveys include the scarcity of individual-level data (e.g. reason for migration, self-perceived integration, self-reported health), lack of data on ethnicity and difficulty of access for international researchers (28,33).

A further seven studies were performed in Germany (12,34–39), where routine data are mostly available at a regional level and coding of refugees and migrants is limited to a classification of German versus non-German nationality, if included at all (34,35). One study assessed the overall capacity of the health information system in Germany to capture information on asylum seekers across three dimensions: (i) availability and level of detail across data sources; (ii) resources and monitoring capacity; and (iii) coverage and timeliness of key indicators (12). Capacity was rated on 50 items and transformed to a weighted summary score ranging from zero (minimum capacity, 100% gap) to 97 (maximum capacity, 0% gap). The study found a capacity gap of 90% on data availability for asylum seekers, in stark contrast to a capacity gap of 40% in the Netherlands (12). Two studies commented that routine data collection in Germany has been set up for managerial and financial purposes by health insurance companies; therefore, it does not provide a comprehensive overview of the health needs of refugees and migrants because it precludes important epidemiological considerations such as length of stay or reason for migration (34,35). To improve routine data, the studies suggested that these important factors should be included in official statistics and that data reporting should be harmonized across regions. To address the gaps in data provision on migrant health in Germany, four studies considered the use of innovative identification and linkage approaches. Two used name-based algorithms to identify migrants in regional population registers (36)



or cancer registers (37), concluding that these approaches are a practicable and useful way to identify migrants in official data sources. Two assessed the possibility of data linkage (i.e. a strategy to link individual-level data from different relevant records) between population registers and decentralized death registers to analyse migrant mortality (36,38), showing that these approaches can be reliably used to assess mortality and cause of death (36,38) or establish large population-based cohorts (38), even without centralized population registers. A further study analysed patient complaints to the Office of the Federal Government Commissioner for Patient Issues to assess the quality of care for migrant populations: it found that, although this complaint register can be a useful source of information on quality of care, information on migration status was incomplete and, consequently, not fit for migrant-sensitive data analysis (39).

A feasibility study in the United Kingdom assessed the potential use of Migrant Workers Scan data (which covers all international migrants applying for a national insurance number in the United Kingdom) to improve migration and population statistics. The study concluded that this dataset is of high quality and has the potential to improve population statistics for migrants, including birth and death registers (40).

One study on migrant deaths along the Spanish–African borders explored the reliability of data from surveillance systems and media reports to monitor mortality during migrant journeys (41). The study assessed the feasibility of using data on departures, fatalities and arrivals to calculate migrant mortality rates and showed that caution is required in interpreting these surveillance data because assumptions about uncertainty in numerators and denominators' substantially affect the resulting rates.

2.1.2 Notification and surveillance systems for infectious disease

In all, 14 studies examined the availability, quality and comparability of notification and surveillance systems for infectious diseases. Infectious disease is a long-standing concern of refugee and migrant health research (9) and, therefore, several surveillance systems enable a disaggregated analysis of refugee and migrant health. The available studies can be divided into those that consider specific health issues or diseases at EU/EEA level and those that assess notification systems at a national level.


1. The numerator is the part of a fraction above the line and the denominator is the part of a fraction below the line that functions as the divisor of the numerator. In epidemiology, the numerator is usually the number of cases of a given health outcome or condition and the denominator is usually the population under study or the population at risk of a given health outcome or condition.

2.1.2.1 EU/EEA level

Five articles on the availability of infectious disease surveillance data for specific issues found that data on refugee and migrant health are neither complete nor integrated into the health information systems of Member States (42–46). For example, a study combining a survey approach and literature review to identify policy and surveillance systems for tuberculosis (TB) screening among refugees and migrants in EU/EEA Member States found that databases on TB screening lacked the sociodemographic data essential for epidemiological analysis (42). Another study combining a literature review, survey approach and stakeholder meeting to assess the burden of measles among migrants in the EU/EEA found that data sources about measles did not systematically record migration status (43). A survey study reported that data on immunization coverage in Mediterranean countries were not disaggregated by different mobile population groups (44).

Regarding HIV monitoring, a survey study of EU/EEA countries found that although 13 countries carried out behavioural surveillance (a valuable addition to biological surveillance for HIV and other sexually transmitted diseases), only three include information on migration status (45). Another survey study assessed the availability of national estimates on the continuum of HIV care (including diagnosis, treatment and treatment outcome) in 55 European and central Asian countries (46). Of these, 29 countries reported data for the general population across all four stages of the continuum (living with HIV, being diagnosed, receiving treatment and achieving viral suppression), but only two countries (Austria and France) did this for migrants. Evidence from these two countries highlights the relevance of disaggregated analysis by revealing inequalities in the diagnosis, treatment and outcomes of care for migrants: compared with the host population, migrants living with HIV were less frequently diagnosed (73% vs 84%), received treatment (51% vs 75%) or achieved viral suppression (41% vs 68%). A total of 41 countries were unable to report migrant data for any stage of the care continuum. In contrast, only three countries were unable to report data on any stage of the continuum for the general population, highlighting a lack of integration of HIV monitoring for migrants among systems for routine data collection (46).

The evidence suggests that a European platform for multicountry data collection and analysis, sharing of countries' policies and practices, and harmonization of migrant screening strategies is needed to overcome the heterogeneity in data collection and ensure comparability across countries (42). Primary studies concluded that, to overcome the lack of recording of relevant health data, a designated body with clear responsibility for data coordination, collection, analysis and



dissemination should be set up to harmonize data collection efforts at the level of EU/EEA countries (45).

Finally, three studies considered the varying practices of coding migrant status and the accuracy of reporting in infectious disease surveillance, and their impact on data comparability (11,47,48). One combined a literature review, data analysis and expert interviews to compare the migration status indicators used by national surveillance systems in six European countries (Denmark, Finland, Germany, the Netherlands, Sweden and the United Kingdom) in order to determine the impact of migration status on hepatitis B virus infection. The migration indicators used were diverse (47):

- **allochtonen** (the Netherlands), defined as those who were born outside the Netherlands or who have at least one foreign-born parent;
- **persons with a migration background** (Germany), defined as those who have either migrated into Germany themselves or are the second- or third-generation descendants of migrants;
- **foreign background**, consisting of foreign-born people with foreign citizenship or foreign language as mother tongue (Finland) or a citizen, either foreign-born or born within the country, and having (i) two foreign-born parents, (ii) a foreign citizenship or (iii) asylum seeker status (Sweden);
- **immigrants**, defined as residents born outside the country (United Kingdom) or a person born abroad whose parents both are foreign citizens or were born abroad (Denmark); and
- **descendants** (Denmark), defined as people born in the country whose parents are either migrants or descendants with foreign citizenship.

The study concluded that heterogeneity in migration indicators limited the comparability of surveillance data across different countries, demonstrating the need for harmonized migration status indicators in different notification systems (47). A systematic review concluded that collecting data on multiple dimensions of migration could favour the disaggregated analysis of migrant health data, with infectious diseases used as an example (11). It found that the only variables reported by EU/EEA Member States in notification systems to define an incident case of a given disease as a migrant were “country of birth” or “country of nationality” (citizenship). The study noted a need for further national-level research to explore the reasons for the underreporting of migrant status and suggested consensus meetings involving disease and migration experts to design a set of core variables and indicators to aid comparability. Another review identified several additional factors affecting the accuracy of disease reporting (e.g. language, legislation,

entitlement to health care, screening for asymptomatic disease). It reported that infectious diseases are less likely to be underreported among migrants compared with host populations due to incomplete denominator data, which results in underestimating the population at risk (48).

2.1.2.2 National level

Three studies considering country-specific infectious disease surveillance were conducted in Italy (49–51). Two of these addressed the accuracy and completeness of TB surveillance systems, with inconclusive results: while the first study found inaccurate estimates of the annual incidence of TB among migrants (analysis period of one year) (49), the second concluded that underreporting was significantly greater for Italians than for migrants (analysis period of 10 years) (50). A third case study from Italy described the initiation of an HIV surveillance network, coordinated by the National AIDS Centre. It found that collaboration with clinical centres, laboratories and institutional agencies to monitor the genetic diversity of HIV strains in Italy is affordable and improves data availability, yet suffers from issues of data quality and accuracy (51).

A French case study highlighted the relevance of Marseille's strategic location as a major entry port for international migrants and the importance of the city's participation in regional and international surveillance activities, including EuroTravNet (European Travel Medicine Network) and the European Network for Tropical Medicine and Travel Health (TropNetEurop) (52). Data collection among migrants and other mobile populations is conducted in several tropical medicine units in civilian and military hospitals, contributing to improved surveillance efforts on infectious diseases such as malaria and dengue (52).

A Swiss case study reported on the improved interpretation of routinely collected HIV notification data using a concurrent (permanent) cohort study. It showed that analysis of notification data alone can lead to the misinterpretation of overall incidence and treatment because data quality is not always sufficient, and information on the time from diagnosis to notification is not recorded. The notification systems allowed for the establishment of a designated cohort study comprising all incident cases and included routinely collected patient-reported data on health service access and utilization, prevalence of risk factors and sexual behaviour, disaggregated by nationality (53).

Finally, a German case study discussed the operationalization of migration classifications in German infectious disease surveillance. Currently (2019),



the recommended criterion of country of birth is only routinely collected for TB, while notification systems for HIV and syphilis use citizenship data (54). There were also concerns over data quality because migration status data were incomplete in all three notification systems. The study called for improved harmonization of migrant definitions between datasets by including both country of birth and citizenship indicators.

2.1.3 Medical records and health service utilization data

Five studies considered medical records and health service utilization data (hospital or clinical records in which data are generated on health service utilization at primary, secondary or tertiary level) for migrants (9,12,53,55,56). Of the 11 countries in the EU that record migrant status in their health service utilization data, five collected data on citizenship, one recorded the country of birth and five used both of these indicators (9).

Italy and England (United Kingdom) have data quality and completeness issues related to coding of migrant and ethnicity categories, which affect the availability of disaggregated data (26). One study that quantitatively analysed the agreement between hospital records and maternal reporting of mode of delivery in a representative sample in the United Kingdom found that a lack of agreement was more common for women not born in the United Kingdom (55).

Data quality was reported to be better in the Netherlands and Sweden because of the possibility of data linkage with civil registration systems and regular clinical audits (26). However, one study found evidence of underrecording of mental health problems among irregular migrants in the Netherlands, which affected the availability of data (56). For asylum seekers, the gap in availability of health records was 13% in the Netherlands, in contrast to 88% in Germany (12).

2.1.4 Subgroup-specific data sources

Five studies considered specific sources of routine data collection for asylum seekers and refugees in camp-like medical settings in Germany, Greece and Italy (12,57–60). These studies highlighted the importance of keeping digital medical records rather than paper-based records to improve data availability on general health aspects and medical treatments (57); those specifically related to vaccination, hepatitis, HIV and TB; and syndromic surveillance (58). They further highlighted the challenge of sustaining data collection in the context of rapidly changing policy contexts related to management of reception centres, which

leads to the discontinuation of routine data collection (59) and a lack of adequate, reliable data for the local planning of health-care services for asylum seekers in reception centres (57,59). Even when data collection systems are in place, health data recording may be inaccurate due to the documentation practices of health workers: a quantitative study in Greek refugee camps that prospectively analysed the quality of data capture and adequacy of recorded clinical information found that clinical data on syndromes was accurately documented for only 11% of cases and that disease severity was largely unknown (60). The authors concluded that case records often do not contain all of the information assessed during the consultation, despite clinicians anecdotally reporting information that would be critical for an outbreak assessment (60). An assessment of the health information systems in Germany and the Netherlands found that data availability for specific subgroups (e.g. unaccompanied minors, pregnant asylum seekers and refugees, victims of torture and violence), determined according to the criteria set out to measure capacity gaps, was poor in Germany (100% gap) and somewhat better in the Netherlands (63% gap) (12).

2.1.5 Health monitoring surveys

Four studies focused on health monitoring surveys among migrants. Out of 27 surveyed EU Member States, one study found relevant health monitoring data for migrants in only six countries: Belgium, Denmark, France, Italy, Portugal and the United Kingdom (9). Limitations of health monitoring surveys among migrant populations included low response rates, small sample sizes, a lack of multilingual survey instruments and variation in the indicators of migrant status used across countries.

In Germany, efforts to represent migrants in health monitoring surveys have increased in recent years. A mixed-methods study compared different sampling strategies and tested different approaches to recruit migrants into the German National Cohort Study (61). It used nationality, name and country of birth to query register data to identify people with a history of migration and concluded that the combined use of the three indicators may improve identification of migrants compared with nationality alone. The register-based approach was compared with a community-oriented data collection approach, which required additional human and time resources but increased acceptance among participants. The higher acceptance rate improved the feasibility of conducting surveys, thus increasing the availability of refugee and migrant health data.



In the Netherlands, health monitoring surveys have grouped first- and second-generation migrants, while distinguishing between “western” and “non-western” migrants (26). Problems were identified in the Dutch health monitoring survey relating to internal and external validity² for migrant populations because these tend to be underrepresented (26). A population-based seroprevalence study that aimed to better integrate migrant populations identified the following strategies to improve data collection among this population: oversampling, multilanguage questionnaires and linkage of serological samples to self-reported data (62).

In England (United Kingdom), migrant status (first and subsequent generations) and ethnicity are routinely collected in health monitoring surveys, and analysis of these data has recently been strengthened by the use of designated sampling approaches for migrant populations (26).

2.1.6 Factors affecting the availability and integration of refugee and migrant health data in health information systems

The review also identified articles reporting factors that affect the availability and integration of data on refugee and migrant health in health information systems, at both the political and practical levels.

On a political level, several studies noted the lack of clear national and European strategies for collecting migrant health data, resulting in a lack of nationwide datasets, differing definitions of migrant and an overemphasis on specific diseases rather than comprehensive public health monitoring (9,26,63). For example, Germany and the Netherlands had large shortcomings in data collection capacity (75% gap) related to specified coordination, planning and policy efforts (12). In some European countries, regulatory efforts need to be increased because no data pertaining to refugee and migrant health are currently collected (9). In other European countries, existing routine data sources on the health of migrants have substantial gaps and inconsistencies that could be improved by harmonizing migrant categories and including better questions on migrant status (9). Regarding migrant categories in use, the existing literature shows that indicators on both country of birth and nationality are necessary for high-quality analyses (11,54). In addition, information on factors such as length of stay and reason for migration are essential for rigorous epidemiological analyses (34,35).

² Internal validity is the extent to which a study is well conducted regarding procedures and technical aspects and external validity is the extent to which findings are applicable or transferable to a broader population.

The available literature showed that countries could do more to learn from each other in formulating policy objectives at a European level, which would help to increase the comparability and comprehensiveness of European data collection instruments for refugees and migrants (9,12,26,45,48,63). Suggested actions included designating a body with clear responsibility for European data coordination (9,12,45), establishment of a European data platform to aid the sharing of best practices (42,43) and achieving consensus with experts in the field on a core set of health indicators for refugees and migrants (11).

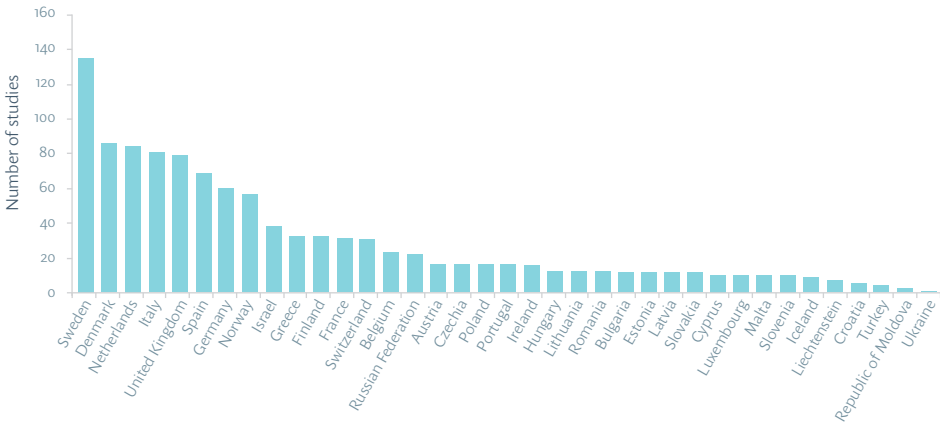
On an operational level, the availability and integration of systems for routine data collection are hampered by poor-quality reporting for migrant subgroups in health service utilization data and associated registers and surveillance systems (48,56,60), lack of denominator data (44) and lack of specific health monitoring approaches to adequately represent migrants in health information surveys (9,26,61,62). Poor-quality medical records for migrants may result from inaccurate disease reporting, which is influenced by factors such as language, legislation, entitlements and access to health care, health service utilization patterns, and attendance for asymptomatic disease screening (48,56). In addition, a lack of understanding among clinicians of the data requirements for epidemiological surveillance could reduce the quality of documentation and limit data availability (60). However, since underreporting is likely to be worse for host populations, one review recommended focusing on improving the existing systems for both host and migrant populations, with specific attention paid to underreporting in host populations, as an approach to improve epidemiological monitoring (48). Existing surveillance systems for the general population could be strengthened towards refugee- and migrant-sensitive health information by including the main risk factors for infectious diseases among refugees and migrants, such as country of origin, length of stay and history of migration (48).

Health monitoring surveys often fail to adequately represent the health needs of refugees and migrants because of low response rates among these populations, small sample sizes and a lack of multilingual survey instruments (9,61). Strategies to overcome these limitations include oversampling strategies among refugees and migrant groups to enable statistically meaningful analyses (9,62) and community-based recruitment strategies to reduce language barriers and increase response rates (61). Overcoming structural barriers to data collection for refugee and migrant populations (including fluidity of the patient population, limited participation of local and regional authorities, closure of temporary accommodation for refugees and the burden of additional data items) requires good coordination with multiple stakeholders and is key to ensuring the sustainability and integration of data collection efforts (59,60).

2.2 Studies using routinely collected data

In strategy 2, a synthesis of abstracts from 696 studies (listed in Annex 3) using data from health information systems to analyse refugee or migrant health found evidence that routine data are systematically collected in only 25 of the 53 Member States of the WHO European Region (Fig. 2). Most studies were identified in Sweden (12.5%), followed by Denmark (8.0%), the Netherlands (7.8%), Italy (7.4%), the United Kingdom (7.3%), Spain (6.3%), Germany (5.6%) and Norway (5.2%), with less than 5% identified in each of the other countries of the WHO European Region. Results for each of the main categories of routine data are given in the following sections.

Fig. 2. Number of studies by country (strategy 2)



Note: total number of studies (1082) includes international studies that are counted more than once depending on the number of countries included.

2.2.1 Stage of migration and data collection

Of the 696 studies, 576 (82.8%) captured data for the routine data collection system at the post-entry stage of migration. Fifteen studies (2.2%) used data sources for which information was obtained at entry to the host countries (e.g. on-arrival screening), while only four (0.6%) used data sources capturing data prior to departure from the country of origin. Determining the migration stage at which data were collected was not possible for 105 (15.1%) studies. In all, 23 of the 53 WHO European Region countries conducted post-entry data collection. Considerably fewer countries conducted at-entry ($n = 9$) and pre-entry ($n = 4$) data collection.

2.2.2 Geographical scope

More than half of the 696 studies ($n = 412$, 59.2%) used data collected in nationwide systems. Most data sources with national coverage were found in Sweden (22.8%), Denmark (14.3%), the Netherlands (11.2%), Norway (8.5%), Israel (6.8%), the United Kingdom (5.8%) and Germany (5.6%). In other countries, the figures were all less than 5%. About one third of the studies identified in the WHO European Region ($n = 226$, 32.5%) used a data source with subnational scope (i.e. covering one or more localities/regions within a country). Most data sources with subnational scope were from Italy (19.0%), followed by Spain and the United Kingdom (both 15.0%), Sweden (8.4%), Germany and the Netherlands (both 7.1%), and Greece (4.9%), with contributions of less than 5% from each of the other countries. The geographical scope could not be categorized in 19 (2.7%) studies.

2.2.3 Data analysis period

Of the 696 studies, 108 (15.5%) covered a period of one year or less in the analysis of refugee and migrant health; 168 (24.1%) covered a period of more than one year to five years, about one fifth covered a period of more than five years to 10 years ($n = 117$, 16.8%) and about one fifth covered more than 10 years ($n = 132$, 19.0%; Table 1). Overall, less than 35% of studies covered a period of five years or longer, which might indicate that the availability of longer data periods is limited in many countries. Information on the data analysis period was not available in the abstracts of about one fifth of studies ($n = 154$, 22.3%).

2.2.4 Sources of routine data by country

Of the 696 studies, 14.0% ($n = 97$) used disease-specific registers that included refugees or migrants (Annex 3 (1–97)), while only 5.3% ($n = 37$) used data obtained from health monitoring surveys among refugees and migrants (Annex 3 (98–134)). About a fifth of the studies ($n = 154$, 22.2%) used data linkage strategies to link the demographic data of migrants with health and/or health service utilization data and socioeconomic variables (Annex 3 (135–288)), and another fifth ($n = 133$, 19.0%) used medical records and health service utilization data to assess refugee and migrant health (Fig. 3; Annex 3 (289–421)). Less than one fifth ($n = 118$, 17.0%) used data from notification systems in the context of infectious disease surveillance (Annex 3 (50,422–538)), 11.9% ($n = 83$) used population-based records (Annex 3 (539–621)), 3.2% ($n = 21$) used subgroup-specific records (Annex 3 (622–642)) and 2.3% ($n = 16$) used other information (e.g. hospitalization data, unemployment) as indicators of refugee or migrant health (Annex 3 (643–658)).

Table 1. Data analysis period by country

Country	<1 year		>1 to 5 years		>5 to 10 years		>10 years		Multiple		Not specified		Total	
	n	%	n	%	n	%	n	%	n	%	n	%	n	%
Austria	1	0.9	1	0.6	0	0.0	0	0.0	0	0.0	0	0.0	2	0.3
Belgium	2	1.9	3	1.8	1	0.9	2	1.5	0	0.0	0	0.0	8	1.1
Czechia	0	0.0	1	0.6	0	0.0	0	0.0	0	0.0	0	0.0	1	0.1
Denmark	8	7.5	9	5.4	17	14.7	22	16.8	2	10.0	10	6.5	68	9.7
Finland	1	0.9	6	3.6	1	0.9	8	6.1	1	5.0	2	1.3	19	2.7
France	2	1.9	3	1.8	4	3.4	0	0.0	0	0.0	1	0.6	10	1.4
Germany	13	12.1	9	5.4	4	3.4	5	3.8	2	10.0	7	4.5	40	5.7
Greece	2	1.9	2	1.2	3	2.6	2	1.5	2	1.5	8	5.2	19	2.7
Hungary	0	0.0	0	0.0	0	0.0	1	0.8	0	0.0	0	0.0	1	0.1
Ireland	0	0.0	1	0.6	1	0.9	0	0.0	0	0.0	0	0.0	2	0.3
Israel	5	4.7	6	3.6	7	6.0	7	5.3	1	5.0	11	7.1	37	5.3
Italy	8	7.5	24	14.3	13	11.2	8	6.1	0	0.0	9	5.8	62	9.8
Malta	0	0.0	1	0.6	0	0.0	0	0.0	0	0.0	0	0.0	1	0.1
Netherlands	4	3.7	19	11.3	12	10.3	12	9.1	2	10.0	14	9.1	63	9.1
Norway	11	10.3	9	5.4	5	4.3	8	6.1	0	0.0	7	4.5	40	5.7
Poland	0	0.0	1	0.6	0	0.0	0	0.0	0	0.0	1	0.6	2	0.3
Portugal	1	0.9	0	0.0	0	0.0	0	0.0	1	5.0	1	0.6	3	0.4
Republic of Moldova	0	0.0	1	0.6	0	0.0	0	0.0	0	0.0	1	0.6	2	0.3
Russian Federation	6	5.6	3	1.8	0	0.0	1	0.8	0	0.0	12	7.8	22	3.2
Spain	12	11.2	9	5.4	8	6.9	9	6.9	0	0.0	11	7.1	49	7.0
Sweden	9	8.4	27	16.1	19	16.4	28	21.4	5	25.0	27	17.5	115	16.5
Switzerland	5	4.7	5	3.0	1	0.9	5	3.8	1	5.0	3	1.9	20	2.9
Turkey	1	0.9	1	0.6	0	0.0	0	0.0	0	0.0	1	0.6	3	0.4
Ukraine	0	0.0	0	0.0	0	0.0	0	0.0	0	0.0	1	0.6	1	0.6
United Kingdom	10	9.3	21	12.5	14	12.1	6	4.6	2	10.0	7	4.5	60	8.6
Europe	4	3.7	6	3.6	5	4.3	6	4.6	1	5.0	19	12.3	41	5.9
International	2	1.9	0	0.0	1	0.9	1	0.8	0	0.0	1	0.6	5	0.7
Total (within groups)	107	100	168	100	116	100	131	100	20	100	154	100	696	100

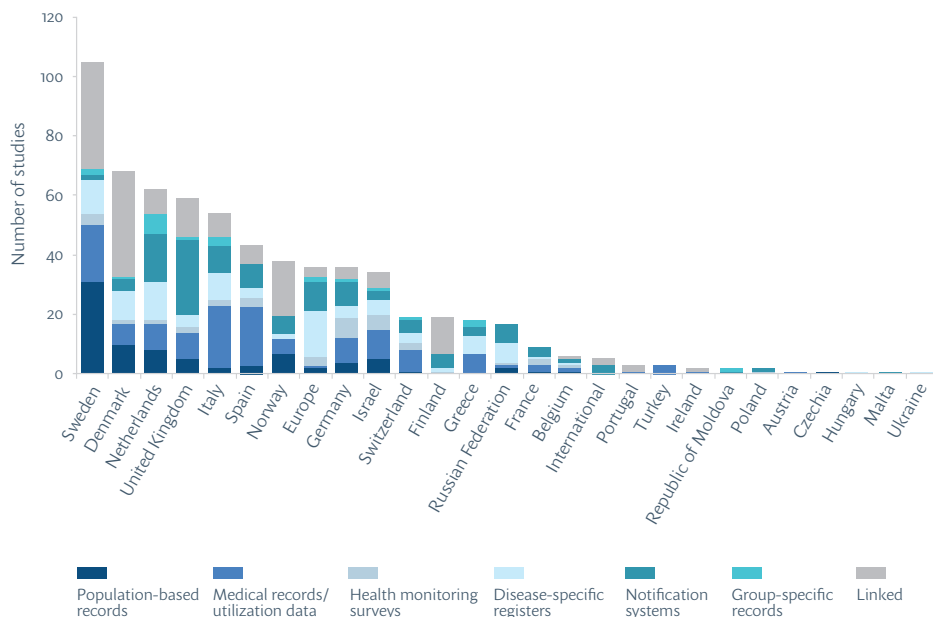
Notes: studies listed under the heading of Europe include more than one country of the WHO European Region; studies listed under the heading of international are comparative international studies from outside Europe that include at least one country of the WHO European Region; percentages refer to column percentages.

Heat map colours indicate quintiles of the total number of studies (darkest being highest).

Specific information on the underlying source(s) of routine data collection was not clear in 5.6% ($n = 39$) of the abstracts, although data were said to be taken from one or more routine data collection mechanisms (Annex 3 (471,659–696)).

Population-based records were most frequently used in Sweden, followed by Denmark, the Netherlands and Norway (Fig. 3). Medical records and health service utilization data were most frequently used to study refugee and migrant health in Italy, Spain and Sweden, followed by Israel, the Netherlands and the United Kingdom. Studies using health monitoring surveys to assess refugee and migrant health were most frequent in Germany, followed by Israel and Sweden.

Fig. 3. Number of studies by country and type of data source



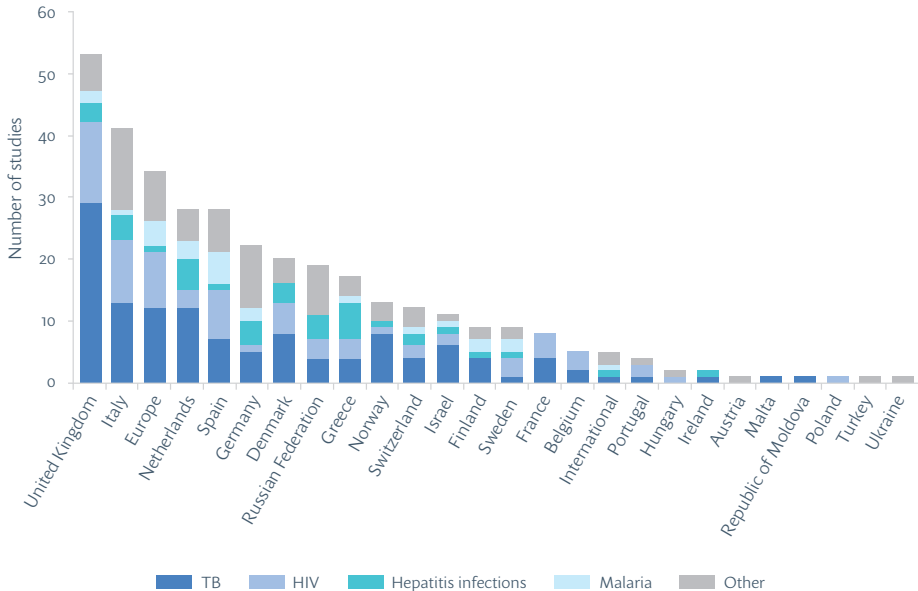
Notes: disease-specific registers: clinical case registers for specific diseases; Europe: Europe-wide studies including more than one country of the WHO European Region; group-specific records: include records for specific groups of refugees and migrants, such as unaccompanied minors and pregnant women; health interview surveys: include population-based household surveys, behavioural surveillance surveys and health monitoring surveys; international: comparative international studies outside Europe, but including at least one country of the WHO European Region; linked: studies reporting data linkage between routine data sources; notification systems: include notification and surveillance systems for infectious diseases.

Countries that often use population-based records are also those that most frequently apply data linkage strategies (Denmark, Finland, Norway and Sweden; 65.6% of studies using linked data sources). About 20% of studies using data linkage were from Italy, the Netherlands and the United Kingdom, while other countries used data linkage considerably less often as a strategy to obtain information on refugee and migrant health.

2.2.5 Health outcome assessed by country

Each study using routine data from health information systems reported one or more health outcomes, depending on its objectives and analysis. Half of the 696 studies assessed an infectious disease outcome ($n = 348, 50.0\%$), one fifth ($n = 140, 20.1\%$) assessed a noncommunicable disease (NCD) other than mental illness and 15.5% ($n = 108$) assessed a mental health outcome (Figs 4–6).

Fig. 4. Number of studies on infectious diseases using routine data by country

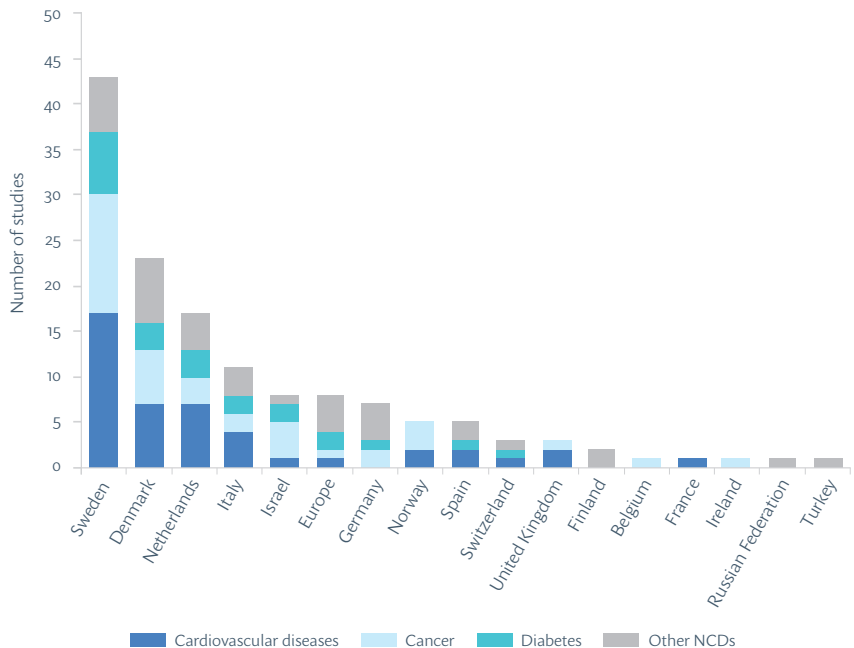


Notes: only countries with studies that reported relevant outcomes are included; Europe: Europe-wide studies including more than one country of the WHO European Region; hepatitis: includes hepatitis A, B and C; international: comparative international studies outside Europe but including at least one country of the WHO European Region.

Other reported health outcomes were maternal health data ($n = 75$, 10.8%), mortality data ($n = 56$, 8.0%), suicide ($n = 23$, 3.3%), injuries ($n = 18$, 2.6%) and other health outcomes ($n = 85$, 12.2%; Fig. 7).

Most studies on infectious diseases were identified in Italy and the United Kingdom, followed by cross-national European studies and then studies from Germany, Greece, the Netherlands and Spain. Studies on NCDs other than mental illness primarily came from Denmark, Italy, the Netherlands and Sweden. Mental health outcomes were also most frequently studied in Denmark and Sweden, followed by France, Israel, the Netherlands and Norway. Maternal health outcomes, as well as general mortality and suicide, were primarily studied in Sweden. Studies on suicide were performed in only nine countries, indicating data gaps in other countries. Similarly, studies on injuries were identified in only 10 countries.

Fig. 5. Number of studies on NCDs using routine data, by disease category and country



Notes: only countries with studies that reported relevant outcomes are included; Europe: Europe-wide studies including more than one country of the WHO European Region.



Fig. 6. Number of studies on mental health problems using routine data, by disease category and country

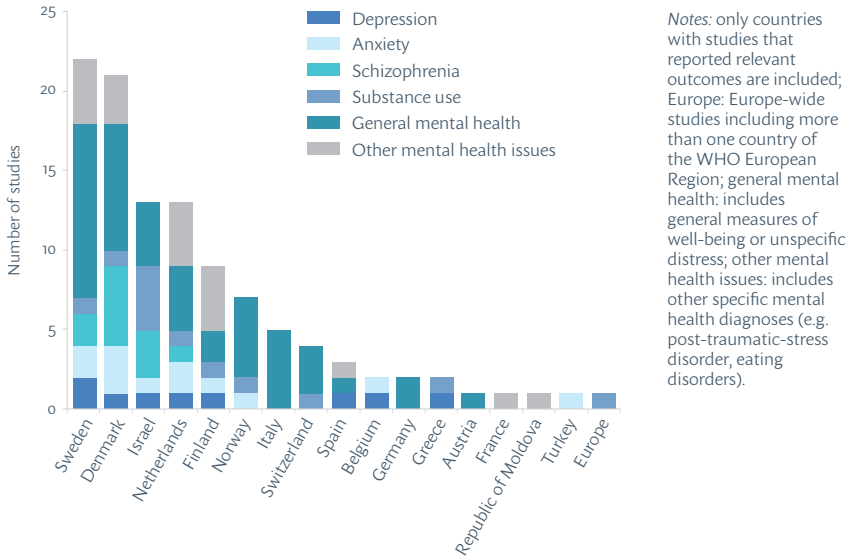
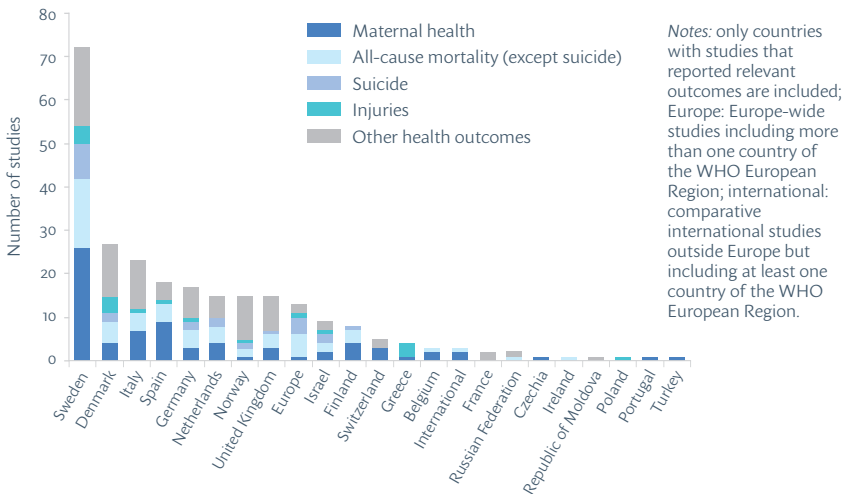


Fig. 7. Number of studies on further health outcomes using routine data, by country



2.2.6 Migrant categories by country

The category of migrants most frequently used by the 696 studies was foreign born (defined by country of birth; $n = 428$, 61.5%), followed by groups characterized by their residence status or experience of displacement (such as refugee and/or asylum seeker; $n = 143$, 20.5%). A total of 129 studies (18.5%) did not further specify the migrant group.

Country of birth was the variable most widely used to identify migrants in routine data sources in Denmark, Finland, Germany, Greece, Israel, Italy, the Netherlands, Norway, Spain, Sweden and the United Kingdom and in European (cross-national) studies. This variable was used in studies from all countries except for Austria and Ukraine. Studies from 17 countries used categories related to residence status or experience of displacement.

2.3 Sources of routinely collected data

This part of the evidence synthesis is based on the abstracts of 696 studies using data from health information systems to analyse refugee or migrant health (Annex 3). Of these, 324 (46.6%) gave the name of the system they had used for routine data collection system, with a total of 242 different routine data sources: 14 (5.8%) were international, 168 (69.4%) were national and 58 (24.0%) were regional. Most of the routine data sources were reported in studies from Sweden ($n = 42$, 17.4%), Italy ($n = 33$, 13.6%), Denmark ($n = 28$, 11.6%) and the United Kingdom ($n = 21$, 8.7%). A full list of the 242 health information systems is given in Annex 4.

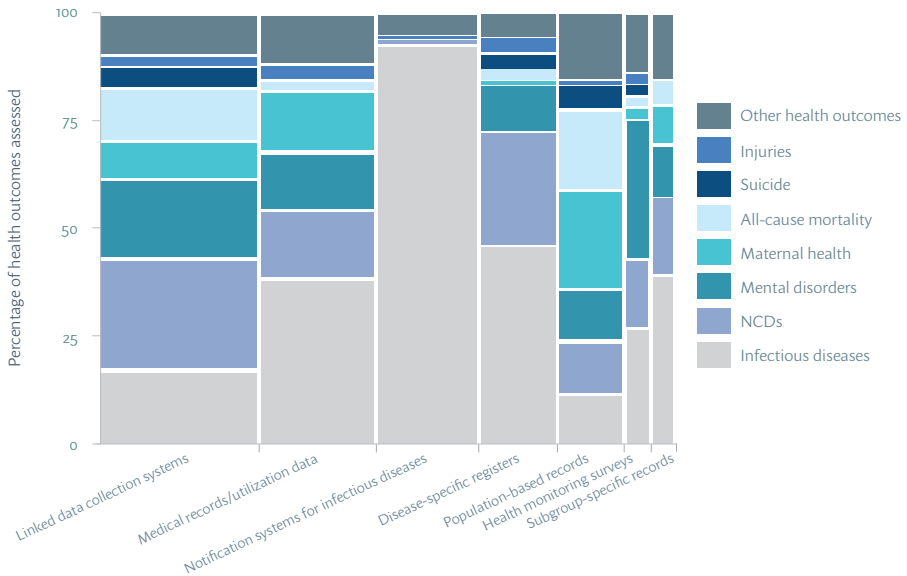
The sources of routine data were found to vary according to the health outcome studied. For example, linked systems and disease-specific registers commonly provided data on NCDs, all-cause mortality and maternal health, while mental health outcomes were particularly prominent in studies using data collected through health monitoring surveys (Fig. 8). Notably, studies based on data from notification systems for infectious disease did not analyse other conditions, suggesting a lack of data availability on comorbidities or other relevant health outcomes among refugees and migrants suffering from infections.

2.3.1 Population-based records

Population-based records were most frequently used in Sweden (37.3% of studies using population-based records) (Case study 1), followed by Denmark (12%), the Netherlands (9.6%), Norway (8.4%), the United Kingdom (6.0%) and Israel (6.0%),

especially for the analysis of maternal health issues, mortality and general mental health problems. A total of 50 unique population-based data sources (20.7% of the 242 data sources) were identified in the reviewed studies (see Annex 4).

Fig. 8. Mosaic graph of sources of routine data and health outcomes



Note: NCDs do not include mental disorders.

Case study 1. The Danish Civil Registration System

The Danish Civil Registration System was launched in 1968 to replace paper-based records in municipal registers with electronic records in a centralized civil register (33). All people born of a mother already registered in the Civil Registration System or who reside legally in Denmark for three months or more are registered in the Civil Registration System with a unique Civil Personal Registration (CPR) number. The CPR number is similar to those of other Nordic countries, consisting of a 10-digit person identifier. A total of 9 484 792 individuals were included in the Civil Registration System in January 2014 (32): information

Case study 1 contd

included the address, date and place of birth, country of citizenship, kinship, civil status and registered partnerships. This information can be accurately and cost-effectively linked via the CPR number to a wide range of individual-level registers (several of these registries were identified in an analysis of reference 32 but are not included in Annex 4): the Danish General Practice Database (since 2007), Danish Cancer Registry (since 1943), Registry of Causes of Death (since 1943), National Patient Registry (since 1977), Danish Breast Cancer Cooperative Group Registry (since 1977), National Prescription Database (since 1995), Danish Pathology Database (since 1997), Western Denmark Heart Registry (since 1999) and the Danish Stroke Registry (since 2003). Further linkages are possible to the Danish Central Psychiatric Research Register, the Danish National Health Service Register, the Danish Injury Register and the Danish Medical Birth Register. Therefore, many studies use the system as a tool in epidemiology, including in refugee and migrant health research, to perform follow-up studies, assess all-cause mortality and establish comparison cohorts, family cohorts, control samples or random samples for population surveys.


2.3.2 Medical records and health service utilization data

The evidence synthesis found that medical records or health service utilization data were most frequently used in Italy (15.8%), Spain (15.0%) (Case study 2) and Sweden (14.3%), especially in the analysis of maternal health issues, infectious diseases and general mental health outcomes. Overall, 25 (10.3%) national and 15 (6.2%) subnational medical records or health service utilization data systems could be identified from the reviewed studies among all 242 data sources (see Annex 4).

Case study 2. Use of electronic medical records in refugee and migrant health research in Spain

A total of 20 studies from Spain on refugee and migrant health used electronic, facility-based medical records, indicating that this country predominantly relies on such records for migrant health data. Most of the studies were on infectious diseases, included between one and four facilities and covered time periods of up to two years (64–74).

In the Aragón region, all medical data of patients registered in the public health-care sector are coded and stored in a central electronic medical records



Case study 2 contd

system (OMI©: Computerized Medical Office). After an official request and authorization, researchers are allowed to conduct research using population-based, regional samples. Demographic variables routinely recorded in the system include nationality, which has been used as a variable to assess the health of migrants (75–77). Three studies included in the evidence synthesis have used this data source: they address overall morbidity, primary care utilization and mental health in migrant populations (75–77). In addition, data obtained from OMI© can be linked with other databases through the Aragonese Identification Code. Two studies following this approach linked medical data obtained from OMI© to either a regional prescription register with the health insurance database (77) or the central medical database of the regional health service (76).

2.3.3 Health monitoring surveys

Studies utilizing health monitoring surveys as a data source were most common in Germany (18.0%) (Case study 3), followed by Israel (13.5%) and Sweden (10.8%); they mainly focused on the analysis of HIV, TB and mental health problems. A total of 31 (12.8%) individual health monitoring surveys were identified among all 242 data sources (Annex 4) in the 696 reviewed studies (Annex 3).

Case study 3. Health monitoring surveys in Germany

In Germany, three key data collection surveys were used to monitor the health status and health system accessibility for the population: the German Health Interview and Examination Survey for Adults (DEGS), the German Health Interview and Examination Survey for Children and Adolescents (KiGGS) and the European Union Statistics on Income and Living Conditions (EU-SILC; implemented in Germany as the Living in Europe survey). The first two were carried out by the Robert Koch Institute and the third was conducted by the Federal Office for Statistics (*Statistisches Bundesamt*).

DEGS is the main health monitoring survey in Germany; it has been conducted since 2008 and is based on previous similar health monitoring approaches for the German population. In its current form, it is conducted approximately every four years and combines health interviews (general health, medications, nutrition, anamnesis), using in-person, postal and telephone interviews,

Case study 3 contd

with health examinations (laboratory tests, physical examination) (78,79). The survey has a response rate of 42% and shows good representativeness when compared with the general population (79). The general self-completion health survey includes questions to capture data on self-rated health status, chronic illnesses, health risks, participation in health promotion activities and health service utilization. Migrant status is captured using multiple indicators on citizenship, country of birth of parents, first language and length of residence in Germany (14). The questionnaire has been translated into four languages (English, Russian, Serbo-Croatian and Turkish), but so far the survey has been able to generate reliable data only for specific migrant groups (e.g. Turkish migrants). Therefore, recent initiatives have tried to improve the integration of migrants into existing health monitoring surveys (80).

KiGGS additionally captures residence status, enabling a distinction to be made between migrants with secured residence status and those with insecure status (temporary refugee protection, toleration or asylum seeker status). The availability of a public-use file of the data to researchers and the variety of included health outcomes make it a valuable resource for scientists and policy-makers to monitor the health status and access to health care for migrants. The evidence synthesis identified three studies that used the survey data: one on access to physical therapy services (81), another on the prevalence of osteoporosis (82) and a third on subjective health status (83). Four further studies used KiGGS to examine the prevalence of hepatitis B (84), varicella (85) and the use of herbal medicinal products (86) among migrant children and adolescents, and inequalities in health and access to health care between children with insecure residence status and those with secured status (87).

2.3.4 Disease-specific registers

In the 696 reviewed studies, disease-specific registers were most frequently used as a data source in the Netherlands (13.4%), Sweden (11.3%), Denmark (10.3%) and Italy (9.3%). In addition, 15.5% of those studies using disease-specific registers analysed data from multiple European countries. The health outcomes analysed most frequently were NCDs (diabetes, cancer and cardiovascular disease) and infectious diseases (especially HIV) (Case study 4). A total of 38 (15.7%) different disease-specific registers were identified among all data sources (Annex 4) in the reviewed studies.



Case study 4. Cancer registers in the WHO European Region

Cancer registers were the most common type of disease-specific register used by studies on migrant health in the WHO European Region. A survey study in 2007 identified several European cancer registers that routinely collect and integrate migrant status but noted that, although the data were available and allowed disaggregation, the registers were rarely used in epidemiological research (88). The evidence synthesis identified a total of nine empirical studies using information from cancer registers: four from Sweden (89–92), two from Israel (93,94), one from Germany (95), one from the Netherlands (96) and one from Norway (96).

Most of these registers cover cancer in general (the German Centre for Cancer Registry Data at the Robert Koch Institute, the Israel National Cancer Registry, the Netherlands Cancer Registry and the Cancer Registry of Norway), while others focus on a specific type of cancer (the Swedish Melanoma Registry and the National Quality Register on Prostate Cancer of Sweden) or other aspects, such as familial risks (the Swedish Family-Cancer Database (90,91)). Datasets from these registers are available to researchers upon request, but the availability of data on migration variables differs between registers.

The Netherlands Cancer Registry routinely includes data on country of birth within its datasets, while the Israeli counterpart retrieves such data from the national population register via a personal identifier (93,94,96). In Norway and Sweden, the national cancer registers do not include sociodemographic data beyond age, sex and place of residence. However, the data can be linked to datasets available from other population-based registers such as Statistics Norway or the Swedish Population Register via a personal identification number (89–92,97). Data in Statistics Norway include country of birth, migration status and age at immigration and in the Swedish Population Register include country of origin and date of immigration; consequently, their datasets provide important variables related to migration (97).

In contrast, German cancer registers are fragmented, regionally governed and do not include data on country of birth or other variables related to migration, making their data less readily available for migrant health research. In the only German study identified in the review to use data from a cancer register, researchers used a cohort of re-settlers from the former Soviet Union that was established in 1990 based on information on country of birth obtained from local population registers. Records from this cohort were then linked to the cancer register through name recognition (95).

2.3.5 Notification and surveillance systems for infectious diseases

Of the 696 reviewed studies, data from notifications systems for infectious diseases were most frequently used in studies from the United Kingdom (21%), followed by the Netherlands (13.4%), Italy (7.6%), Germany and Spain (both 6.7%) for the analysis of hepatitis, HIV, malaria and TB, infections. In addition, around 8% of reviewed studies used notification data from multiple European countries (Case study 5). A total of 61 different notification systems for infectious diseases in WHO European countries could be identified in the reviewed studies, comprising 25.2% of the 242 identified sources of routine data collection (Annex 4).

Case study 5. TropNetEurop

TropNetEurop is currently the largest European network on imported infectious disease surveillance, involving 75 specialized clinical sites in 18 European countries and focusing on infectiology and tropical medicine. TropNetEurop is coordinated by the Department of Medical and Diagnostic Services of the Swiss Tropical and Public Health Institute in Basel and is structured into three committees: a steering committee, a network committee and a research committee. Its objectives are to establish and sustain a sentinel surveillance of imported infectious diseases in Europe and to identify emerging infections in returning international travellers, refugees, migrant workers, business travellers and foreign visitors. TropNetEurop provides a platform for collaborative research on travel-related infectious diseases for evidence-informed recommendations and strategy development in European countries (98,99). It collects data from patients with travel or migrant history who have presented for treatment at one of the participating clinical sites in Europe.

This evidence synthesis identified four studies using surveillance data from TropNetEurop. Two studies analysed features of incident schistosomiasis cases in Europe regarding patient origin, type of travel and potential risk factors associated with infection (100,101). Another two further examined the epidemiological characteristics of migration-related malaria cases in Europe (102,103). However, surveillance via specialized clinics and departments for infectious diseases entails limited external validity for the overall population of refugees and migrants because of the facility-based nature of the data, which rely on referrals and self-referrals (entailing the possibility of hospital bias through lack of population-level data and samples).



2.4 Overall evidence on refugee and migrant health data

The combined evidence synthesis found that research on the availability and integration of refugee and migrant health data is fragmentary across the WHO European Region. Most studies assessed specific data collection sources, diseases or aspects of health data. Only very few studies focused on more than one data collection category or on the health information system as a whole (9,12,26). Even less evidence was found on data quality (a crucial aspect of availability), integration of systems and policy initiatives to strengthen data collection for refugees and migrants.

The evidence also showed that even when refugees and migrants are formally included in health monitoring surveys, proactive strategies are required to adequately reflect their health concerns, including the accurate translation of survey instruments into multiple languages, specific sampling approaches and innovative fieldwork approaches (9,14,26,61). Strategies identified to include refugees and migrants in health monitoring surveys comprised community-based approaches to recruitment, identification of individuals in population-based registers, oversampling and tailored sampling approaches, and multilingual survey techniques (9,26,61,62). These are consistent with existing research and guidelines on the inclusion of refugees and migrants in national health monitoring approaches (14,15).

3. DISCUSSION

3.1 Strengths and limitations of the review

The main strength of this review is its comprehensive approach to the analysis of health information systems. The inclusion of both empirical studies on health information systems and studies using data from such systems provides an overview of the research landscape, complementing previously conducted reviews in this area (9,11). The blend of narrative and quantitative synthesis allowed conclusions to be drawn on the availability and integration of refugee and migrant health data, either from studies directly focused on this question or as deduced from research using existing data sources across the WHO European Region. The review identified more than 240 data sources for refugee and migrant health, which can be used as resources for future studies. While insights were gained into data collection systems and country practices analysing refugee and migrant health, it is important to note that a cross-national assessment of health information systems would be better suited to assess the availability and integration of data. Nevertheless, the review provides a comprehensive foundation for future undertakings.

The strict definitions of refugees and migrants used in this report (Annex 2) excluded studies focused on ethnicity. This may have led to the exclusion of studies and data sources for refugee and migrant groups, as studies from some countries (e.g. the Netherlands) appear to use these terms interchangeably to refer to both migrants and to non-ethnic Dutch people. The differentiation of ethnicity and migration is very important and has been a matter of controversy (33,104,105). Several papers recommended coding for ethnicity alongside migration (or migration status alongside ethnicity) so as to distinguish the effects of each (9,33,104), as capturing these variables for health monitoring purposes has different objectives (e.g. measurement of inequalities in health attributable to discrimination based on ascriptive factors and physical appearance vs inequalities attributable to pre-, peri- and post-migration factors).

This report is based on a review of 41 full-text articles on health information systems, but another 696 studies using data from routine data sources were included in the synthesis based on their abstracts only in order to keep the amount of work manageable. This approach is commonly used in bibliometric studies (106) but entails the possibility of misclassification, especially in the migration stage in which data are collected and the migrant groups categorized. However, the risk of misclassification in other primary or secondary outcomes was low because only



a few studies did not provide these details in the abstract (5% or less). The review approach provided sufficient information to judge the use of routine data sources, the geographical scope and type of system, the available health outcomes and the data analysis periods. It did not, however, allow for an in-depth analysis and mapping of how refugee and migrant groups were specifically defined, especially for terms such as refugee, which can be used in both the colloquial and legal senses.

The use of scoping review methodology means relevant studies may have been missed. Searches were conducted in English and Russian (and included studies in English, German and Russian), and so studies, national documents, guidelines, standardized operating procedures and manuals detailing the procedure for data collection, storage and dissemination in other languages of the 53 Member States may, therefore, have been missed. Moreover, countries not represented in this report may have captured data on refugee and migrant health in their health that have not been published. However, the aim of this review was not to give a complete picture but rather to explore the patterns, gaps and approaches used for data collection.

3.2 Availability and integration of refugee and migrant health data

Overall, evidence found in the review was geographically biased towards the Scandinavian and central European countries for routine data collection and towards western and southern European countries for infectious disease surveillance. Very little information was found on data collection mechanisms for refugees and migrants in eastern Europe and central Asia. The literature was strongly focused towards evidence on routinely collected secondary data and infectious disease surveillance, with much less information found on important data collection mechanisms such as health monitoring surveys and health service utilization data. Furthermore, notification systems for infectious diseases were disease centred, poorly integrated and often lacked data on comorbidities or other relevant health outcomes. Overall, longer time periods were analysed predominantly by studies in countries with nationwide population registries (indicating good data availability), while single and scattered time frames were more often found in studies relying on fragmented health information systems, indicating limitations in availability of time series data on refugee and migrant health.

Numerous factors were shown to affect the availability and integration of refugee- and migrant-sensitive data in health information systems operating at both regional and national levels in countries across WHO European Region.

3.2.1 WHO European Region level

Within the WHO European Region, countries could benefit by increased collaboration to identify potential strategies, build partnerships, harmonize indicators and promote the sharing of best practices as they move towards refugee- and migrant-sensitive health information systems (9,12,45,48,63). Differing definitions of migrant throughout the health information systems limit the potential for comparisons of data across countries of the Region (1,9,26,44,47). Furthermore, the binary classification of migrant/non-migrant substantially limits the analysis potential for this highly heterogeneous population and reduces the validity of the overall conclusions of any analysis on health and access to health care (13). Therefore, routine data collection could benefit from including multiple migration indicators to capture country of birth, nationality, length of residence and legal status (11,14,15,48,54,107). These indicators should distinguish between refugees/migrants and their offspring (often referred to as second- or third-generation migrants), for example by considering both country of birth and nationality. Health risks are likely to vary substantially between these groups (33,107), so ethnicity categories that fail to consider migration status and length of stay can hide large within-group variations in outcomes. To avoid discouraging individuals from seeking health care through fear of stigmatization or deportation, the migration indicators should ideally not be captured at the point of care but rather made available through linkage of systems or other routinely collected indicators for monitoring purposes (26,33,36).

Initiatives to improve refugee- and migrant-sensitive systems for routine data collection on specific issues exist throughout the EU/EEA, but stronger collaboration, for example by designating a body responsible for coordinating data collection efforts (48), could ensure that the lessons learned are integrated into systematic improvements throughout the Region. As the lead public health agency and with extensive technical expertise in designing and strengthening health information systems at the regional and national levels, WHO is well positioned to take a coordinating role. Initiatives could incorporate the important ethical considerations related to gathering, storing, analysing and disseminating data on refugee and migrant health. It is important to note that data disaggregated by residence or migration status can help public health monitoring and planning of services but may also be misused for political stigmatization campaigns against refugees and migrants. Attempts of migration authorities to inappropriately access health data have been documented (2); therefore, the health sector would benefit from establishing effective legal, technical and political measures to safeguard sensitive health data against (mis-)use for migration policy purposes. This is particularly



relevant and salient for data linkage approaches of the type where immigration registers are used to determine denominators and establish links to health and/or vital records. A coordinating body at the level of the WHO European Region could guide Member States while implementing such measures and provide a platform to share best practices and experiences from other countries.

More cross-country research is needed to (i) provide a more comprehensive picture of the availability and integration of data on refugee and migrant health in health information systems across the Region (12) and (ii) explore whether the identified policy strategies can strengthen existing data collections systems and provide a blueprint for the establishment of new systems (9). Regular performance monitoring of health information systems (12) is needed because these complex and adaptive systems may undergo rapid change. Germany provides a pertinent example: while recent literature confirms that the availability and integration of refugee health data in most routine data sources are limited (108), considerable progress has been made in specifically established systems for routine data collection (e.g. among refugees and asylum seekers using real-time surveillance based on electronic medical records (109), targeted health monitoring surveys (110) or longitudinal socioeconomic household surveys including health data (111)).

3.2.2 National level

There is potential for all countries of the WHO European Region to strengthen their health information systems for the collection of refugee and migrant health data. Even in systems without centralized population registers, national data collection efforts could be improved by streamlining migration indicators and including multiple relevant indicators in all datasets, allowing for linkage between relevant datasets and ensuring improved data quality through stronger collaboration on the issue of migrant health between the government, institutions, medical facilities and clinicians.

The review found a strong focus on studies using secondary data, which are often limited by a lack of sociodemographic information, individual life experiences related to the migration trajectory and self-reported health data (28,33). Lack of information in these areas mean that gaps in current service provision cannot be identified and services cannot be planned accordingly. A more complete picture of refugee and migrant health could be obtained by collecting data in both health-care facilities (through high-quality medical records) and among the population (e.g. through health monitoring surveys) (9,26,33).

Although proactive strategies to include refugees and migrants in health monitoring were identified, health monitoring surveys represented only a small proportion of the included studies using data collection systems for the analysis of refugee and migrant health. There is, therefore, an immense potential to scale up the use of surveys with refugees and migrants as part of routine health monitoring in Member States of the Region (9,26). Inclusion of these populations in national health monitoring surveys via effective recruitment, sampling and data collection mechanisms is crucial to monitor their long-term health status and health service needs.

The ability of routine data to provide information on continuity of care and long-term trends also needs to be harnessed. Only around a third of the identified studies using routine data reported results for periods of over five years, and these data primarily came from centralized data collection systems. The potential of these data systems could be further exploited, for example by enabling health service utilization data from medical records to be linked to migrant registers in population records (which are usually maintained by ministries of interior or migration authorities, including for non-nationals). Data linkage was most frequently observed in Scandinavian countries. However, several countries with decentralized health systems that do not have population-wide health registers (e.g. Germany, Israel, Italy, the Netherlands and Spain) had used a data linkage approach to overcome the fragmentation of their health information systems by linking health data with indicators of refugee or migrant status.

Finally, the existing evidence indicates a need to overcome the factors that negatively affect the quality of routine data (48,56). Quality issues that specifically affect migrants were noted in health service utilization data, which forms the basis of registers and surveillance. Furthermore, incomplete recording of diagnoses specifically affects refugees in reception centres and irregular migrants in primary care settings. The review found evidence that strong collaboration between state institutions, clinicians and management, a sound documentation infrastructure, and an understanding among all actors of the importance of documentation are needed to ensure high-quality data (59,60). A whole-system approach to health information systems is required, acknowledging that factors limiting health system accessibility for refugees and migrants (e.g. language barriers, financial barriers, legislation or restricted legal entitlements) will also impede the collection of comprehensive, high-quality data.



3.3 Policy considerations

Based on the findings of the review, the main policy considerations for the WHO European Region are to:

- facilitate the harmonization of indicators and definitions of refugee and migrant status in health information systems in the WHO European Region to mitigate challenges in cross-border comparability due to heterogeneous definitions;
- designate a supranational body to be responsible for governance, leadership and oversight of data collection on refugee and migrant health to foster better coordination, cross-country exchange and learning, as well as harmonization of data collection strategies (including data quality, integration and protection); and
- regularly monitor the performance of European health information systems regarding the availability and integration of refugee and migrant health data using appropriate assessment tools.

The main policy considerations for improving health information systems at country level are to:

- strengthen existing health information systems for the general population because this is also likely to improve the availability of data on refugee and migrant health;
- integrate key data elements related to refugees and migrants (e.g. country of birth, nationality, length of stay, reason for migration) into existing data collection systems to facilitate stratified data analysis, identify at-risk subgroups and ensure cross-border comparability;
- establish and/or strengthen a tailored, proactive approach to data collection for refugees and migrants that addresses the difficulties in accessing these populations, their limited access to health care, their language barriers and the small sample sizes;
- utilize and scale up national health monitoring surveys to effectively integrate refugees and migrants and facilitate better linkage of survey data with civil/vital registration data; and
- establish and/or strengthen data linkages across records (e.g. population registers, facility-based records and household surveys) in order to:
 - maximize the available health information, particularly in countries where refugee and migrant health data are not routinely collected due to decentralized health information systems and lack of civil registrations; and
 - generate comprehensive information on refugee and migrant health by combining information on health service utilization and migration status.

4. CONCLUSIONS

Data on refugee and migrant health are routinely collected in less than half of the 53 Member States of the WHO European Region. The sources of routinely collected data are diverse and the integration of routine data into national health information systems appears limited, except for population registers, notification systems and medical records in a few countries. The availability of health data for refugees and migrants could be improved by increasing their inclusion in health monitoring surveys via innovative mechanisms for recruitment, sampling and data collection, as well as via data linkage in countries with decentralized and fragmented health systems. The review confirmed that varying definitions and indicators of refugee and migrant groups hamper the comparability of findings between studies, countries and time periods. Research on health information systems in the context of refugee and migrant health is patchy and focuses on a few data sources or specific diseases. In general, current research efforts fail to consider national or European health information systems as a whole. This could be remedied by performing regular cross-country and regional assessments of the availability and integration of refugee and migrant health data into health information systems to generate comparative information for all 53 Member States. Although this report provides important policy considerations, countries interested in improving the availability and integration of refugee and migrant health data in their health information systems should consider that there is no one-size-fits-all approach. Instead, strategic improvements to the existing framework are the key to developing migrant-sensitive health information systems.



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ANNEX 1. SEARCH STRATEGY

Databases and websites

Seven academic databases were searched on 3 December 2018 for peer-reviewed literature in English published between January 2000 and December 2018 on the availability and integration of health data for refugees and migrants into health information systems in the WHO European Region: Bielefeld Academic Search Engine, Cochrane Library, Cumulative Index to Nursing and Allied Health Literature, Health Services Research, MEDLINE (via PubMed), Science Direct and Web of Science Core Collection. Three additional searches by two Russian-speaking members of the review team were performed between 16 January and 30 January 2019: Bielefeld Academic Search Engine, eLibrary.RU and Russian Citation Index.

A complementary search for grey literature in English was conducted in March 2019 in Google Scholar and Health Evidence databases using shortened and modified search terms. The Annual Reviews, European Centre for Disease Prevention and Control, Health Policy Reference Centre, Health System Evidence, International Organization for Migration, Migrant Integration Policy Index and Migration Health Research Portal were hand-searched for relevant articles and additional websites were hand-searched to obtain supplementary case studies on selected routine data sources.

Study selection

Inclusion criteria

The general inclusion criteria were:

- published in English, German or Russian
- focused on refugees or migrants as the study population
- focused on at least one of the 53 Member States of the WHO European Region
- published from January 2000 to December 2018.

These criteria were piloted and iteratively refined to create two complementary strategies to select, review and synthesize relevant studies: strategy 1 focused on studies reporting evidence on health information systems and strategy 2 on studies using routine data.



In strategy 1, abstracts and titles of studies were screened in tandem for general eligibility and the following additional criteria:

- studies that directly reported the availability and integration of data on refugee and migrant health in health information systems; and
- studies based on scientific evidence derived from a quantitative, qualitative, case study or literature review method (or a combination of these).

Studies meeting these criteria were included for full-text review and synthesized narratively after systematic data extraction.

In strategy 2, abstracts were screened to identify:

- primary research studies or outbreak reports with a quantitative method using data from health information systems; and
- studies on any health outcome among refugees and migrants that:
 - used information from one of the defined data collection categories as the main underlying data source; or
 - collected primary data embedded or integrated into a system for routine data collection (e.g. in the scope of a national health monitoring survey).

Exclusion criteria

The exclusion criteria for both strategies were:

- reports with an undefined population or no specific mention of migrant or refugee populations in their abstracts;
- reports focused on ethnicity or travellers without clear reference to refugees and migrants;
- studies based on primary data with one-off data collection efforts (e.g. cross-sectional and cohort studies that did not use routinely collected data);
- longitudinal studies conducted for a fixed period of time purely for research purposes;
- studies that formally fulfilled the inclusion criteria but failed to contain any important information (as agreed by at least two reviewers);
- case studies;
- clinical case series;
- conference proceedings;
- no full-text available (strategy 1) or no abstract available (strategy 2); and
- geographical location of study not specified in the abstract (strategy 2).

Screening and data management

Publication details of the identified documents were collected in Endnote X8 (Clarivate Analytics) and converted to an Excel file for selecting eligible citations. Duplicates were removed automatically and/or manually. In both strategies, article selection was independently conducted by at least two authors, with discrepancies resolved by discussion between at least two reviewers. Peer-reviewed literature in Russian was assessed by a Russian-speaking colleague (AT) in consultation with another member of the review team (SR/RJ/LB).

Of the 9357 titles and abstracts screened from peer-review literature after removal of duplicates, 776 were fulfilled the general eligibility criteria: of these, 76 fulfilled the additional criteria for strategy 1 and 696 fulfilled the additional criteria for strategy 2 (Fig. A1.1).

Data extraction and evidence synthesis

Data extraction was guided by pre-defined primary and secondary outcomes.

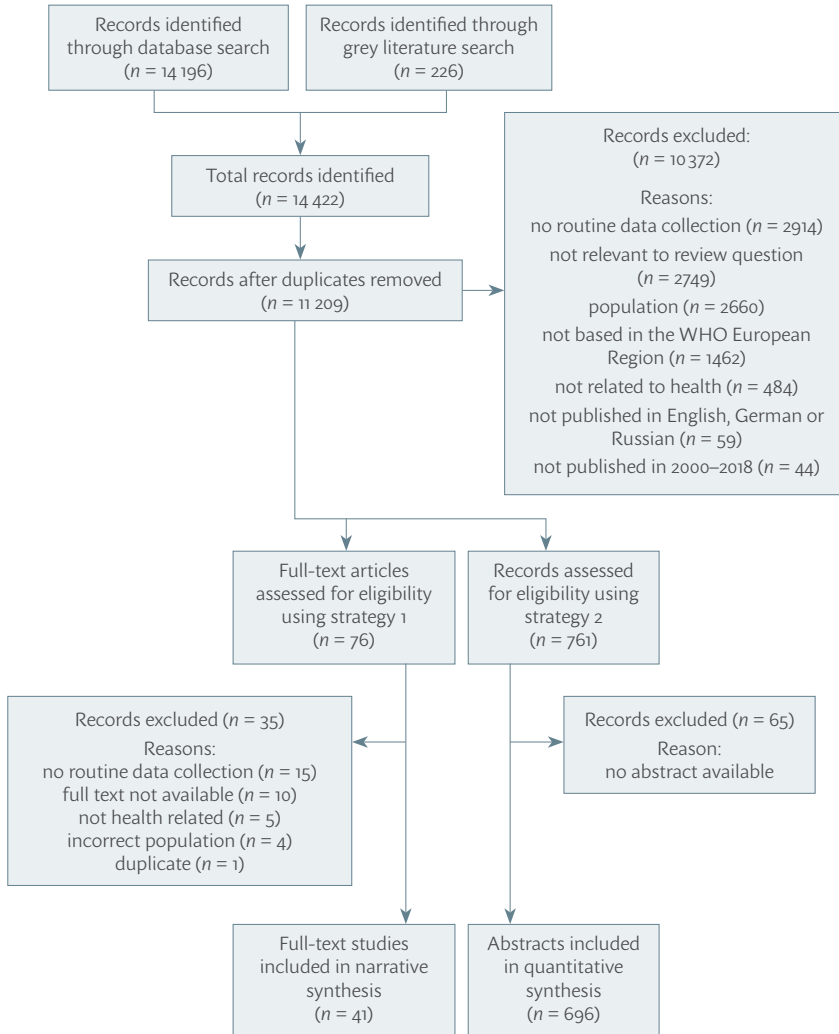
Primary outcomes were:

- availability of refugee and migrant health data in health information systems; and
- integration of data sources covering refugee and migrant health (if any) within national health information systems.

Secondary outcomes were:

- type of data source, based on the data collection categories in the framework of the WHO Health Metrics Network (1);
- types of data (domains, entities, health issues);
- definition of migration;
- stage of migration;
- geographical level (international, national, regional);
- time period covered;
- actors involved in the data collection process;
- policies, arrangements and mechanisms for data collection on migrant health; and
- resources for data collection (financial, physical, administrative, human).


Fig. A1.1. PRISMA flowchart



In **strategy 1**, full-text screening of the 76 articles reporting evidence on the availability and integration of refugee and migrant health data in health information systems identified 41 that directly reported aspects relevant to the review question. These were included in a narrative synthesis approach to extract and present the available evidence on the state of data collection on refugee and migrant health (2). For this, the type of data source, study design, research aim and main findings of each study were first recorded in a data extraction sheet. The articles were then organized by the type of data source and grouped into major themes by at least two members of the review team (KB/LB/RJ) in order to identify the relationships between studies, assess the strength of the results and judge the relevance for answering the review question.

Strategy 2 yielded a high number of studies using data from health information systems ($n = 696$). To balance academic rigour against the feasibility of managing and reviewing such a large body of literature, bibliometric research methodologies were applied to perform a quantitative synthesis of information provided in the abstracts. Bibliometric literature review is considered an efficient method for gaining an understanding of themes in areas with a large number of publications (3). The evidence synthesis did not aim to assess the quality or content of the studies themselves but instead to understand on a meta-level which routine data sources have been used to study refugee and migrant health. Relevant information in the following categories was systematically extracted from the 696 abstracts using structured spreadsheets:

- source of routine data:
 - data system;
 - country;
 - type of data source (categorized according to the WHO Health Metrics Network: population-based records, medical records, health interview surveys, disease-specific registers, notification systems, group-specific records, data linkage approaches, data sources that do not fit into these categories, unspecified);
 - type of migrant (country of birth, residence status including refugees and asylum seekers, other);
 - migration stage for data collection (pre-entry, upon entry, post-entry, unspecified);
 - geographical scope of the data source (international, national, subnational, unspecified); and
 - data analysis period (one year or less, over one year to five years, over five years to 10 years, over 10 years, multiple time periods, unspecified); and

- 
- health condition:
 - infectious diseases (bacteria, virus, parasites, fungi, no agent specified);
 - NCDs and chronic diseases (cardiovascular disease, cancer, respiratory, diabetes, allergy, other);
 - mental disorders (cognitive disorders, mood disorders, anxiety disorders, personality disorders, substance-related disorders, sexual disorders, psychotic disorders, developmental disorders, general distress/well-being);
 - maternal health;
 - health risks;
 - mortality;
 - injuries; and
 - health service utilization.

This information was converted into binary codes, with country as the unit of analysis, and then summarized quantitatively by preparing tables of absolute and relative frequencies. Heat maps or bar charts were then prepared using the following variables: information on data source; health conditions; number of studies by country; geographical scope by country; data analysis period by country; type of routine data source by country; health outcomes by country; and type of migrant by country. The main findings of the heat maps are presented as a narrative summary.

Search terms

Table A1.1 gives an overview of the search blocks and search term categories used in the initial search strategy. These included search terms related to refugee and migrant health adapted from recent Health Evidence Network synthesis reports and the authors' previous reviews, and associated Medical Subject Headings (MeSH) and textwords (tw). Search terms related to the category "availability and integration of health data" were omitted to improve the sensitivity of the search strategy.

An initial search of MEDLINE was performed using MeSH/tw combinations (Table A1.2). Search terms within a search block were combined using the Boolean operator "OR" and then merged with the other blocks using the Boolean operator "AND". Searches were limited by publication date (since 2000), species (human) and language (German, English and Russian). This search strategy was adapted for other databases and websites, using appropriate combinations of search terms.

English search terms were translated into Russian by two Russian-speaking colleagues (Table A1.3) and adapted to the selected Russian databases. The search

strategy used for Russian databases was tailored to meet the technical constraints of the database or the availability of downloadable citations, and included multiple search terms for the population and intervention.

Table A1.1. Search blocks and search term categories

Search block	Search term categories
Refugee and migrants	Refugees (MeSH) Human migration (MeSH) Asylum seeker(s) Migrant(s) ^a
Sources of routinely collected data	Population surveillance (MeSH; including public health surveillance and sentinel surveillance) Health information systems (MeSH) Epidemiological monitoring (MeSH) Routine data Facility integrated National, local or nationwide surveillance or monitoring systems
Member States of the WHO European Region	Europe (MeSH; owing to the wide geographical spread, MeSH terms/tw, title/abstract combinations were included for each of the 53 WHO Member States)

^a Further variations were included while testing the initial search strategy.

Table A1.2. English search terms and combinations for the search in MEDLINE

ID	Query	Number of hits
19	ID 5 AND 10 AND 15 Filters: publication date from 1 January 2000; humans; English; German; Russian	3 430
18	ID 5 AND 10 AND 15 Filters: publication date from 1 January 2000; humans; English; Russian	3 331
17	ID 5 AND 10 AND 15 Filters: publication date from 1 January 2000; humans	3 773
16	ID 5 AND 10 AND 15 Filter: humans	4 684
15	ID 5 AND 10 AND 14	5 805

Table A1.2 contd

ID	Query	Number of hits
14	ID 11 OR 12 OR 13	1 840 228
13	europe[tw] OR EU[tw] OR "european union"[tw] OR "european economic area"[tw] OR EEA[tw] OR "WHO European Region" [tw] OR "european region"[tw] OR "eastern Europe"[tw] OR "Baltic States"[tw] OR "CIS"[tw] OR "Czechoslovakia"[tw]	332 900
12	"Albania"[tw] OR "Andorra"[tw] OR "Armenia"[tw] OR "Austria"[tw] OR "Azerbaijan"[tw] OR "Republic of Belarus"[tw] OR "Belgium"[tw] OR "Bosnia and Herzegovina"[tw] OR "Bulgaria"[tw] OR "Croatia"[tw] OR "Czech Republic"[tw] OR "Denmark"[tw] OR "Finland"[tw] OR "France"[tw] OR "Georgia (Republic)" [tw] OR "Germany"[tw] OR "Greece"[tw] OR "Hungary"[tw] OR "Iceland"[tw] OR "Ireland"[tw] OR "Italy"[tw] OR "Luxembourg"[tw] OR "Macedonia"[tw] OR "Monaco"[tw] OR "Montenegro"[tw] OR "Netherlands"[tw] OR "Norway"[tw] OR "Poland"[tw] OR "Portugal"[tw] OR "Moldova"[tw] OR "Romania"[tw] OR "the Russian Federation"[tw] OR "San Marino"[tw] OR "Serbia"[tw] OR "Slovakia"[tw] OR "Slovenia"[tw] OR "Spain"[tw] OR "Sweden"[tw] OR "Switzerland"[tw] OR "Ukraine"[tw] OR "United Kingdom"[tw] OR Cyprus[tw] OR Estonia[tw] OR Israel[tw] OR Kazakhstan[tw] OR Kyrgyzstan[tw] OR Latvia[tw] OR Lithuania[tw] OR Malta[tw] OR Tajikistan[tw] OR Turkey[tw] OR Turkmenistan[tw]	1 402 805
11	"Albania"[MeSH] OR "Andorra"[MeSH] OR "Armenia"[MeSH] OR "Austria"[MeSH] OR "Azerbaijan"[MeSH] OR "Republic of Belarus"[MeSH] OR "Belgium"[MeSH] OR "Bosnia and Herzegovina"[MeSH] OR "Bulgaria"[MeSH] OR "Croatia"[MeSH] OR "Czech Republic"[MeSH] OR "Denmark"[MeSH] OR "Finland"[MeSH] OR "France"[MeSH] OR "Georgia (Republic)" [MeSH] OR "Germany"[MeSH] OR "Greece"[MeSH] OR "Hungary"[MeSH] OR "Iceland"[MeSH] OR "Ireland"[MeSH] OR "Italy"[MeSH] OR "Luxembourg"[MeSH] OR "Monaco"[MeSH] OR "Montenegro"[MeSH] OR "Netherlands"[MeSH] OR "Norway"[MeSH] OR "Poland"[MeSH] OR "Portugal"[MeSH] OR "Moldova"[MeSH] OR "Romania"[MeSH] OR "the Russian Federation"[MeSH] OR "San Marino"[MeSH] OR "Serbia"[MeSH] OR "Slovakia"[MeSH] OR "Slovenia"[MeSH] OR "Spain"[MeSH] OR "Sweden"[MeSH] OR "Switzerland"[MeSH] OR "Macedonia (Republic)"[MeSH] OR "Ukraine"[MeSH] OR "United Kingdom"[MeSH]	1 234 217
10	ID 6 OR 7 OR 8 OR 9	1 319 347

Table A1.2 contd

ID	Query	Number of hits
9	surveillance[tw] OR "surveillance system"[tw] OR "surveillance-system"[tw] OR monitoring[tw] OR "monitoring system"[tw] OR "monitoring-system"[tw] OR "sentinel surveillance"[tw] OR "syndromic surveillance" OR ((hospital[tw] OR clinic[tw]) and (monitoring[tw] OR surveillance[tw])) OR ((hospital[tw] OR clinic[tw]) and ("monitoring system"[tw] OR "surveillance system"[tw] OR "alert system"[tw] OR "records"[tw])) OR ((national[tw] OR regional[tw] OR local[tw] OR international[tw] OR government[tw] OR privat[tw] OR facility[tw]) AND ("monitoring system"[tw] OR "surveillance system"[tw])) OR "data collection system"[tw] OR "health information system"[tw] OR "HIS"[tw] OR "register data"[tw] OR "medical records"[tw] OR ("Public Health"[tw] OR "Public Health"[MeSH]) AND ("monitoring"[tw] OR "surveillance"[tw] OR "data collection"[tw] OR "register" OR "data system"[tw])) OR ("data collection system"[tw] OR "monitoring"[tw] OR "surveillance"[tw] OR "health information system"[tw] OR "HIS"[tw]) AND ("health services"[tw] OR "emergency"[tw] OR "health system"[tw] OR "system resources"[tw] OR "infrastructure"[tw] OR "human resources"[tw] OR "financing"[tw] OR "development"[tw] OR "system performance"[tw]))	1 319 070
8	"Community Integration"[MeSH]	255
7	"Epidemiological Monitoring"[MeSH]	6 216
6	"Population Surveillance"[MeSH]	63 474
5	ID 1 OR 2 OR 3 OR 4	672 868
4	refugee[tw] OR "asylum seeker"[tw] OR "asyl"[tw] OR (displaced[tw] AND (person*[tw] OR people[tw])) OR "migra*[tw] OR "forced migra*[tw] OR migration[tw] OR immigra*[tw] OR "human migration"[tw] OR stateless[tw] OR "state-less"[tw] OR "irregular migra*[tw] OR "regular migra*[tw] OR "undocumented migra*[tw] OR "internally displaced"[tw] OR "detainees"[tw] OR "residence status"[tw] OR "foreign-born"[tw] OR "displaced person"[tw] OR "non-citizen"[tw] OR "outsider"[tw] OR "newcomer"[tw] OR "newly arrived"[tw] OR "new arrival"[tw] OR "recent entrant"[tw] OR "non national"[tw] OR "non-national"[tw] OR "transient"[tw] OR "minorities"[tw] OR "ethnic"[tw]	665 130
3	"Transients and Migrants"[MeSH]	10 400
2	"Human Migration"[MeSH]	25 368
1	"Refugees"[MeSH]	8 929

Table A1.3. Search terms and synonyms: translation from English to Russian

ID search blocks	English	Russian
1	refugees	беженцы
1	refugee	беженец
2	human migration	миграция
2	human migration	переселение
3	transients and migrants	временно пребывающие и мигранты
4	asylum seeker	ищущий убежище
4	asylum seeker	заявителя на получение статуса беженца
4	displaced	перемещённое лицо
4	person	лицо
4	person	персона
4	people	население
4	people	люди
4	people	народ
4	migration	миграция
4	forced migration	принудительная миграция
4	forced migration	высылка
4	forced migration	изгнание
4	immigration	иммиграция
4	immigration	иммиграция населения
4	stateless	лицо без гражданства
4	stateless	лица без гражданства
4	stateless	апатри д
4	irregular migration	нелегальная миграция
4	irregular migration	незаконная миграция
4	regular migration	легальная миграция
4	regular migration	законная миграция
4	undocumented migration	незадокументированная миграция
4	internally displaced	внутренне перемещённые лица
4	detainees	задержанные
4	detainees	задержанный
4	detainees	арестованный
4	detainees	арестованные
4	detainees	арестанты
4	detainees	арестант
4	detainees	заключённые

Table A1.3 contd

ID search blocks	English	Russian
4	detainees	заключенный
4	detainees	осужденный
4	detainees	осужденные
4	detainees	приговоренные
4	detainees	приговоренный
4	residence status	статус резидента
4	residence status	резидент
4	foreign-born	родившиеся за границей
4	foreign-born	родившиеся за рубежом
4	displaced person	перемещённое лицо
4	non-citizen	негражданин
4	non-citizen	неграждане
4	outsider	иностранец
4	newcomer/newly arrived/recent entrant	вновь прибывший
4	newcomer/newly arrived/recent entrant	недавно прибывший
4	newcomer/newly arrived/recent entrant	новоприбывший
4	non-national	иностраннный гражданин
4	non-national	иностраннные граждане
4	transient	временно пребывающий
4	minorities	меньшинства
4	minorities	группа меньшинств
4	ethnic	этнический
4	ethnic	этнос
4	ethnic	малые народы
4	ethnic	народность
7	epidemiological monitoring	эпидемиологический мониторинг
7	epidemiological monitoring	эпидемиологический надзор
7	epidemiological monitoring	Социально-гигиенический мониторинг
7	epidemiological monitoring	Санитарно-эпидемиологический контроль

Table A1.3 contd

ID search blocks	English	Russian
7	epidemiological monitoring	Санитарно-эпидемиологический надзор
7	epidemiological monitoring	эпиднадзор
8	community integration	социальная интеграция
8	community integration	интеграция в социум
9	surveillance	надзор
9	surveillance	наблюдение
9	surveillance system	система надзора
9	surveillance system	система наблюдения
9	monitoring	мониторинг
9	monitoring	наблюдение
9	monitoring	надзор
9	monitoring	контроль
9	monitoring system	система мониторинга
9	monitoring system	система наблюдения
9	monitoring system	система надзора
9	monitoring system	система контроля
9	sentinel surveillance	дозорный надзор
9	syndromic surveillance	синдром надзор
9	hospital/clinic	больница
9	hospital/clinic	клиника
9	hospital/clinic	госпиталь
9	alert system	Автоматизированная система централизованного оповещения
9	alert system	Система экстренного оповещения
9	records	записи
9	national	национальный
9	national	федеральный
9	regional	региональный
9	local	местный
9	international	интернациональный
9	international	международный
9	government	правительство
9	government	кабинет министров

Table A1.3 contd

ID search blocks	English	Russian
9	government	исполнительный орган
9	government	исполнительная власть
9	private	приватный
9	private	личный
9	private	частный
9	facility	организация
9	facility	учреждение
9	facility	институт
9	data collection system	система коллекции данных
9	health information system	Медицинская информационная система
9	register data	регистр данные
9	medical records	Медицинская карта
9	medical records	история болезни
9	public health	Общественное здоровье
9	health services	службы здравоохранения
9	emergency	Скорая медицинская помощь
9	emergency	Скорая помощь
9	emergency	Неотложная помощь
9	infrastructure	инфраструктура
9	human resources	человеческие ресурсы
9	human resources	людские ресурсы
9	human resources	кадровая служба
9	financing	финансирование
9	development	развитие
9	improvement	усовершенствование
9	improvement	совершенствование



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ANNEX 2. DEFINITIONS OF TERMS USED IN THE REVIEW

Definition of terms used in this synthesis report were developed based on the PICO approach, which has the following components: population (P), phenomenon of interest (I), context (Co) (1). In this review, the population is refugees and migrants, the phenomenon of interest is the availability and integration of health data in health information systems, and the context is the Member States of the WHO European Region (2).

Population

Migrant. Based on the International Organization for Migration's definition (3), this report defines migrant as a person who is moving or has moved across an international border or within a country away from their habitual place of residence, regardless of (i) their legal status, (ii) whether the movement is voluntary or involuntary, (iii) the reason(s) for movement, or (iv) the length of stay.

Refugee. This report uses the legal definition of refugee according to the 1951 *Convention and protocol relating to the status of refugees* as "any person who... owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country" (4).

The studies included in this review did not strictly adhere to these definitions. Therefore, to avoid misinterpretation and maintain scientific rigour, the Results section reports the terms actually used in the studies.

Intervention

Availability. This term refers to the ability of national health information systems to generate reliable data on refugee and migrant health and to ensure its accessibility when and where needed by defining, collecting, processing and (eventually) publishing the data.

Health data. This term encompasses the three domains of health information: health determinants, health status and health system performance.



Health information system. According to WHO, a well-functioning health information system as one consisting of all the activities and resources that ensure “the production, analysis, dissemination and use of reliable and timely information on health determinants, health systems performance and health status”, both on regular basis and in emergencies (5). In this report, a health information system is considered to consist of the following data sources: population- and facility-based data from censuses; household and health monitoring surveys; civil registration data; public health surveillance data; medical records; records on health services; and health system resources (e.g. human resources, health infrastructure, financing) (5). The WHO Health Metrics Network distinguishes population-based records from health service/health facility-based records (administrative records, service records, health and disease records) (6). In accordance with this classification, this report grouped the data sources into the following data collection categories:


- population-based records (population register, vital registration, census);
- health records (medical records, claims data, disease-specific registers);
- notification and surveillance systems (laboratory-based registers, clinical case registers, public health services records); and
- health monitoring surveys (population panels, household surveys).

Integration. This term refers to how integral refugee and migrant health data are to the collections systems for health data of the general population. That is, whether a parallel system for routine data collection on refugee and migrant health has been set up, or whether this has been integrated into the existing data collection system for the general population in order to that ensure comparable, consistent definitions and classification are used for health data.

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ANNEX 3. STUDIES USING DATA OF REFUGEE AND MIGRANT HEALTH FROM HEALTH INFORMATION SYSTEMS

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ANNEX 4. SOURCES OF ROUTINELY COLLECTED DATA

Routine data sources by category and geographical scope are shown in Tables A4.1–A4.7.

Table A4.1. Disease-specific registers

Geographical scope	Sources
International	
Europe	DPV (Diabetes-Patienten-Verlaufsdokumentation) Registry MONSUE (Monitoring Suicidal Behaviour in Europe) WHO Regional Office for Europe Multicentre Study on Suicidal Behaviour
National	
Denmark	Danish Cancer Registry Danish Facial Cleft Database Danish Health Authority's Central Odontology Register (SCOR) Danish Psychiatric Central Research Register National Diabetes Register
Greece	Emergency Department Injury Surveillance System (EDISS)
Israel	Israel National Cancer Registry (INCR) National Psychiatric Case Register
Italy	National Leprosy Register
Netherlands	Netherlands Cancer Registry (NCR) Psychiatric Case Register
Norway	Cancer Registry of Norway Cardiovascular Disease in Norway (CVDNOR) project
Spain	Registry of Non-fatal and Fatal Occupational Injury in Insured Workers (Ministry of Labour and Social Issues)
Sweden	National Quality Register on Prostate Cancer of Sweden (NPCR) Swedish Cancer Registry (IACR) Swedish Family-Cancer Database Swedish Hernia Register Swedish Melanoma Registry (SweMR) Swedish National Diabetes Register The Swedish Stroke Register (Riksstroke)
United Kingdom	UK Obstetric Surveillance System (UKOSS)
United States of America	Childhood Lead Poisoning Prevention Program (Manchester, NH)

Table A4.1 contd

Geographical scope	Sources
Subnational	
Germany	Baden-Württemberg Diabetes Incidence Register (DIARY – EURODIAB TIGER network) Saarland Cancer Registry (IACR)
Italy	Observatory on CO poisonings (Verona) Rare Diseases Registry, Veneto Region Reggio Emilia Diabetes Register Regional Chronic Disease Register (Veneto Region) Regional Mental Health Information System (Bologna) Regional Mental Health Information System (Lombardy)
Netherlands	Psychiatric Case Register Middle Netherlands (PCR-MN)
Russian Federation	Saratov Regional Clinical Dermatovenereologic Dispensary, STI notifications
Spain	Barcelona Birth Defects Registry (Registro de Defectos Congénitos de Barcelona: REDCB)
Sweden	Göteborg Myocardial Infarction Register

Note: CO: carbon monoxide.

Table A4.2. Health monitoring surveys

Geographical scope	Sources
International	
Europe	Community-based Testing (COBATEST) Network European Social Survey (ESS) European Working Conditions Survey (EWCS) WHO Regional Office for Europe Health Behaviour in School-aged Children (HSBC) cross-national survey
National	
Belgium	Belgian Health Interview Survey (BHIS) 2001
Denmark	Danish National Health Survey
Finland	Health 2011 Survey Migrant Health and Wellbeing Study (Maamu)
France	French National Nutrition and Health Survey (ENNS) National Reference Centre for Resistance of Mycobacteria to Antituberculosis Drugs, annual surveys
Germany	Generations and Gender Survey (GGG) German Health Interview and Examination Survey for Adults (DEGS)

Table A4.2 contd

Geographical scope	Sources
Germany (contd)	German Health Interview and Examination Survey for Children and Adolescents (KiGGS)
	German Telephone Health Survey (GSTel03)
Israel	Health Behaviour in School-aged Children (HBSC) survey
	Israeli National Health Interview Survey
Italy	Italian Behavioural Surveillance System (PASSI)
	National Health Interview Survey (NHIS)
Netherlands	National Growth Studies
	Public Health Monitor (PHM)
Poland	General Hospital Morbidity Study
Russian Federation	Russian Longitudinal Monitoring Survey (RLMS)
Spain	Spanish National Health Survey
Sweden	Annual Level-of-Living Survey (LNU)
	Health Monitoring of the Swiss Migrant Population 2010
	Swedish Survey of Living Conditions
	Swiss Health Survey
United Kingdom	Labour Force Survey (LFS)
	National Tuberculosis Survey
Subnational	
Netherlands	Amsterdam Health Monitor Survey
Sweden	Stockholm Public Health Survey 2010 (now Health Stockholm)

Table A4.3. Medical records/utilization data

Geographical scope	Sources
National	
Denmark	Danish Childhood Vaccination Programme
	Danish National Health Service Register
	Danish National Hospital Register
	Danish National Prescription Registry
	Regional Laboratory Database
	Register of Prevention at Statistics Denmark
Finland	Finnish Hospital Discharge Register (FHDR)
	Register of Induced Abortions
Germany	Statutory health insurance records
Israel	National Psychiatric Case Register (PCR)

Table A4.3 contd

Geographical scope	Sources
Netherlands	Netherlands Chlamydia Screening Implementation
	Register of Psychiatric Hospital Admissions
Norway	Health Economics Administration Database
	Norwegian Cervical Cancer Screening Programme (NCCSP)
	Norwegian Immunisation Registry (SYSVAK)
Sweden	National Hospital Discharge Register (SNHDR)
	National hospital records
	National Patient Register (inpatient and outpatient)
	Prescribed Drug Register
	Salut Programme Register (Salut-R)
	Swedish Hip Arthroplasty Register
United Kingdom	Swedish National Cervical Screening Registry (NKCx)
United Kingdom	National Health Service Hospital Episode Statistics (NHS HES)
Subnational	
Italy	Health Services Reimbursement Database (Veneto)
	Hospital Discharge Database (Lazio)
	Hospital Discharge Database (Lombardy)
	Hospital Discharge Database (Turin)
	Hospital Discharge Database (Veneto)
	Information System of Emergency Rooms
	Lazio Region Hospital Information System
Netherlands	Health Insurance Register (Agis)
Russian Federation	Tuberculosis Dispensary Smolensk
Spain	Regional medical database (Valencia Health Agency)
	Regional pharmacy database (Valencia Health Agency)
Sweden	Maternal Health Care Register (MHCR – Västerbotten)
	Regional Hospital Discharge Register (Stockholm County)
	Stockholm County Council administrative databases on healthcare consumption
Switzerland	Methadone Case Register of Canton Zurich (regional opioid maintenance treatment case register)

Table A4.4. Notification systems for infectious diseases

Geographical scope	Sources
International	
Europe	European Centre for Disease Prevention and Control (ECDC)
	European Centre for Epidemiological Monitoring of AIDS
	European Network for Tropical Medicine and Travel Health (TropNetEurop)
	European Surveillance System (TESSy)
	European Travel Medicine Network (EuroTravNet)
	International GeoSentinel Surveillance Network
National	
Denmark	National HIV/AIDS surveillance
	National Surveillance Register
	National TB surveillance system
Finland	National Infectious Disease Register (NIDR)
France	Mandatory HIV notification system at Institut de Veille Sanitaire (InVS)
Germany	Notification system for infectious diseases
Greece	Hellenic Centre for Infectious Diseases Control (HCIDC)
	National surveillance system
Ireland	Tuberculosis notifications at the Irish National Disease Surveillance Centre
Israel	National HIV Register
	National TB Notification (Ministry of Health)
Italy	HIV Surveillance System
	National infectious diseases surveillance
	National STI surveillance system
	TB Notification Register
Malta	National TB surveillance system
Netherlands	National HIV serosurveillance
	Netherlands Tuberculosis Register (NTR)
Norway	Mandatory HIV surveillance system
	National surveillance system for acute and chronic hepatitis B
	National Tuberculosis Register
	Norwegian Surveillance System for Communicable Diseases (MSIS)
Portugal	TB surveillance system
Spain	National Epidemiological Surveillance Service
Sweden	InfCareHIV Database
	National HIV Register

Table A4.4 contd

Geographical scope	Sources
Switzerland	Malaria notification system (Federal Office of Public Health)
	Mandatory HBV notification system
	MDR-TB notifications (Federal Office of Public Health)
	National TB surveillance system
	Public health agency surveillance database
United Kingdom	Enhanced Tuberculosis Surveillance system (TB-ETS)
	GUMCAD STI Surveillance System
	HIV and AIDS Reporting System (HARS)
	HTLV notification at the Communicable Disease Surveillance Centre (CDSC)
	National Register of Malaria Cases
	Surveillance of Infectious Disease
	TB Reporting System at the Health Protection Agency in England and Wales
Subnational	
Greece	Syndromic notification system (Athens)
Italy	Lazio Region HIV Surveillance System
	Modena Region HIV Surveillance System
	Multicentre Study on Resistance to Antituberculosis Drugs (SMIRA) network
	Regional Information System for Infectious Diseases (Umbria)
	Regional TB notification system (Emilia-Romagna)
Spain	AIDS Register, Barcelona
	Catalan Region HIV/AIDS Surveillance System
	Galician Tuberculosis Prevention and Control Programme
	Malaria Register, Barcelona (Public Health Agency of Barcelona)
United Kingdom	East of England enhanced surveillance
	HIV Reporting System, Health Protection Agency (England and Wales)
	London TB Register
	Public Health Laboratory Bristol records
	Regional notification of HIV (England, Wales) at the Health Protection Agency Centre for Infections
	West of England enhanced surveillance
Not specified	
Italy	Syndromic surveillance system for migrant populations

Notes: HBV: hepatitis B virus; HTLV: human T-lymphotropic virus; MDR-TB: multidrug-resistant tuberculosis; STI: sexually transmitted infection.

Table A4.5. Population-based records

Geographical scope	Sources
National	
Belgium	Census of Belgium
	Register of Births (population register system)
Czechia	Czech Republic Birth and Baptism Records
Denmark	Attainment Register
	Central Taxpayers' Register (CSR)
	Civil Registration System (CPR)
	Danish Medical Birth Register
	Danish Register of Causes of Death
	National Patient Register
Finland	Statistics Denmark
	Finnish Causes of Death Register
	Medical Birth Register
	Population Census
Germany	Population Register Centre (VRIK)
	German Death and Burial Index
Germany	German Microcensus 2005
	German Death and Burial Index
Israel	Israel National Civil Census
	Israel National Database on Causes of Death
	Israel Population Registry
Italy	National Cause of Death Register
Netherlands	Netherlands National Cause of Death Register
	Netherlands Population Register
Norway	Cause of Death Register
	Medical Birth Registry of Norway (MBRN)
	National Register (population)
	Norwegian Patient Registry
	Statistics Norway
Portugal	National Cause of Death Register
	Portugal Census
Spain	Birth Register (National Statistics Institute)
	National Cause of Death Register
	Population Registry (National Statistics Institute)
Sweden	National Patient Register
	Swedish Cancer Registry (IACR)
	Swedish Cause of Death Register

Table A4.5 contd

Geographical scope	Sources
Sweden (contd)	Swedish Census
	Swedish Fertility Register
	Swedish Medical Birth Register
	Swedish Multi-generation Register
	Swedish National Income Register
	Swedish Population and Housing Census
	Swedish Population Census
	Swedish Population Register
United Kingdom	National Health Service patient demographic system
Subnational	
Italy	Lazio Region Mortality Register
	Municipal cause of death registers
	Municipal population registers
Netherlands	Municipal Register, Amsterdam
Spain	National Cause of Death Register
	Municipal Population Register, Madrid
Sweden	Swedish Medical Birth Register
	Swedish National Population Register
United Kingdom	Lothian Region Birth Register

Table A4.6. Subgroup-specific records

Geographical scope	Sources
International	
Europe	European Migrant Ethnic Health Observatory (MEHO)
National	
Denmark	Danish Immigration Service Database
	Danish Health Visitor's Child Health Database
Netherlands	Electronic medical records database of the Community Health Services for Asylum Seekers in the Netherlands (MOA)
	Asylum seeker centres mortality notification system
	Netherlands Paediatric Surveillance Unit (NSCK)
Sweden	Swedish Longitudinal Immigrant Database (LISA)
	Swedish National Crime Register
	Swedish Persons Convicted of Offences Register
Not specified	
Italy	Protection System for Refugees and Asylum Seekers (SPRAR)

Table A4.7. Other records

Geographical scope	Sources
National	
Denmark	Danish HIV Cohort Study
	Integrated Database for Labour Market Research (IDA)
Norway	Norwegian Mother and Child Cohort Study
Sweden	Swedish Labour Force Survey (LFS)
	Swedish Longitudinal Integration Database for Health Insurance and Labour Market Studies (LOUISE)
	Swedish nationwide research database at Lund University
United Kingdom	National Study of HIV in Pregnancy and Childhood Surveillance
Subnational	
Denmark	Danish Red Cross database
Germany	Clinical Surveillance of HIV Disease Cohort (ClinSurv)
Italy	Italian Network of Longitudinal Metropolitan Studies (IN-LiMeS)
	Italy Home Care Database
Switzerland	Swiss Hospital Clinic Primary HIV-1 Infection Cohort

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