

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

Background

Migration health data comprise information that characterizes the health and the social determinants of health of refugees and migrants. The need to enhance health information systems (HIS) and enable rigorous methodologies and capacities for collection of data on migration health across migrant groups at the national level remains challenging for most Member States of the WHO European Region. An initial barrier is that many Member States lack routine systems to collect these data and, when data are collected, the emphasis is often on infectious diseases. In addition, some national HIS are fragmented and collect data on different, often noncomparable, variables and indicators, which limits data sharing and access across governmental entities at national and global levels.

Reliable, consistent and good-quality data are essential to address health inequality among refugees and migrants and ensure their equitable health status in a population. The ability to disaggregate data by migratory status facilitates identification of vulnerabilities and gaps in care and promotes efforts to address shortcomings and improve their health. Furthermore, these data are needed to achieve the Sustainable Development Goals and other national and international targets and to support endeavours to achieve universal health coverage. Consistent data are also needed to ensure that policies are sound and that operational and legislative responses are efficient and effective.

Key messages

Analysis of the current status of migration health data in the WHO European Region has highlighted the gaps and necessary areas of growth.

Issues identified in the Region include:

- health data are available but cannot be disaggregated by migratory status;
- migratory status data exist but are not linked with health data; and
- the currently available migration health data are not representative of all migrant populations.

Poor-quality migration health data lead to lack of comparability, have the potential for misinterpretation and can hamper the efforts of agencies dealing not only with the health of migrants but also with migration itself. Challenges for collecting migration health data include:

- the heterogeneity of migrants, with varying terminology for what constitutes a migrant;
- lack of trust in the authorities and health institutions that collect data; and
- language barriers and difficulty accessing migrant subgroups.

The harmonization of migration health data is further hampered by incompatible software systems, limited data sharing between agencies and data protection regulations at national and regional levels.

Integration of migration health data into HIS

Ideally national HIS should be the cross-cutting component that provides the basis for policy and regulation of all other areas of the health system. Consequently, the integration of migration health data within national HIS is the logical and more sustainable approach to support availability and utilization of health data for refugees and migrants along with those for the host population. Six components that shape HIS help to frame the challenges, opportunities and guidance needed to integrate migration health data into national HIS: resources, indicators, data sources, data management, information products, and, finally, dissemination and use of collected data.

Resources. Personnel, financing, logistics and information and communications technology are the pivotal resources of a functioning HIS. Regulatory and legislative components guide their usage. Regulatory and legal frameworks (e.g. WHO's International Health Regulations and the European Union's General Data Protection Regulation) and guidelines and agreements (e.g. the Sustainable Development Goals, the global compacts, the WHO Global Action Plan for Promoting Refugee and Migrant Health and the Strategy and Action Plan for Refugee and Migrant Health in the WHO European Region) already exist to structure how and when data should be collected. Collaboration across relevant ministries and organizations is crucial in the purview of migration health data, as well as the inclusion of refugees and migrants themselves.

Indicators. Variables to capture migration health data focus on the collection of key migratory status variables within the domain of determinants of health. Because there are currently issues that prevent health data being disaggregated by migratory status, a set of core variables capturing this and other relevant health determinants for refugees and migrants should be integrated into national HIS. This will not only facilitate the disaggregation of HIS data by migratory status but also link different datasets. The core variables are:

- country of birth
- country of citizenship
- month and year of arrival
- country of birth of both parents.

Integration of a second set of recommended variables will allow further disaggregation of health data by subgroups of migrants:

- reasons for migration
- knowledge of official language(s) of host country
- ever resided abroad
- legal status.

Data sources. A combination of data sources is required as no single source can provide all the migration health information needed. The main data sources for migration health data are institution-based records (e.g. disease registries and individual records), population-based records (e.g. censuses and civil registries) and other records (e.g. nongovernmental reports, big data (anonymized and inadvertently created and stored data) and surveillance).

Data management. Data linkage is possible in a variety of scenarios and will enhance the availability and completeness of migration health data. Principles of informed and explicit consent and anonymization of data should be employed, and steps should be taken to safeguard these sensitive data from being used for non-health purposes.

Information products and their dissemination and use. Raw data are rarely useful and need to be converted into information that can become the baseline for evidence generation and policy-making. Data related to the health of refugees and migrants can then be used to benefit their health. Researchers, planners and analysts should have easy access to these data so that results can be used to inform policy and generate targeted interventions.

Key policy considerations

The following policy considerations support the integration of migration health data into routine national HIS in the WHO European Region and include both national and regional level initiatives.

National level

- Organize a multistakeholder national working group for migration health data collection, processing and sharing. Additional working groups at various agencies with a limited scope and comprising a few selected stakeholders could be set up to support and complement the national working group.
- Develop and implement a national strategy for the collection and integration of migration health data within the national HIS in collaboration with other relevant agencies and stakeholders.
- Modify and clarify regulation to allow for the collection, storage, sharing and safeguarding of relevant data on migration health between data providers and users.
- Integrate the core variables for migration health into routine data collection systems and into any separate HIS that are needed.
- Adapt sampling strategies to increase the response from refugees and migrants in surveys, including purposive sampling, oversampling and disproportionate sampling.
- Use multilingual survey instruments, interpreters and cultural mediators during data collection to ensure informed consent and increase response rates.
- Use data linkage techniques to maximize the availability of migration health data from various data sources and generate more comprehensive information.
- Analyse data at regular intervals, publish available migration health data and facilitate public access whether for increasing awareness, research or policy.

Regional level

- Develop guidelines and resolutions within organizations and expert groups to call upon Member States to collect migration health data.
- Encourage the development of a consensus on the definition of migrants by actions within organizations, national working groups and other international stakeholders.
- Integrate core migration health variables into already existing reporting frameworks, such as the WHO Joint Monitoring Framework, to reduce additional reporting burden and enhance cross-country comparability.

This policy brief summarizes information given in more detail in the 2020 technical guidance *Collection and integration of data on refugee and migrant health in the WHO European Region* (<https://www.euro.who.int/en/health-topics/health-determinants/migration-and-health/publications/2020/collection-and-integration-of-data-on-refugee-and-migrant-health-in-the-who-european-region-2020>).