INFACT
Joint Action on Health Information

This project is funded by the Health Programme of the European Union

FACT SHEET Health data collection methods and procedures

InfAct WP8: "Tools and methods for health information support"

Key outputs

1. Data collection methods, metadata-reporting standards and usage of data for health monitoring (HM) and health system performance assessment (HSPA) are not uniform in Europe.
2. The objective of Task 8.1 is to identify major gaps and inequalities in health information collection methods, quality assessment, accessibility and availability procedures across EU/EEA Member States (MSs)
3. A scoping review of international organizations and selected EU research networks, and a web-based survey were carried out to identify data collection methods, availability and accessibility of HI in projects/studies performed in Europe.
4. The results of the survey highlight that evidence produced by research is not always available, comparable or usable for research purposes and policy making. Therefore, a research infrastructure providing information on standardized data collection methods and procedures and facilitating sharing and comparability of health data across EU countries is needed.

Background and Rationale

Nationally, health-related data are collected from a variety of sources such as population-based registries, health interview and examination surveys, longitudinal studies, administrative healthcare records, e-health solutions, and more. Data is collected for different purposes, including population health monitoring/public health surveillance and health system performance assessment (HSPA). Most of these data are not included in international databases such as the World Health Organization (WHO), Organization for Economic Co-operation and Development (OECD) or the European Statistical Office (Eurostat), limiting their use for research, policy, international benchmarking and comparisons. Health monitoring data provide the main information for the description of population health status, while performance measurement seeks to monitor, evaluate and communicate the extent to which various aspects of the health system meet the key objectives.

Inequalities and gaps in health data collection methods and in health information availability, accessibility, comparability or reusability are limiting research activities and policy making in EU countries.

To reduce gaps and inequalities of health information across MSs and to facilitate standardization of collection methods, accessibility and availability of health information, Task 8.1 aims:

- to identify European projects/studies providing HM and HSPA data;

- to summarize existing knowledge and definitions of health data, indicators, standardised data collection methods, availability and accessibility procedures covering different health data sources (e.g., population-based registries, surveys, longitudinal studies, health system performance, other administrative sources, data collected through e-health solutions, etc.) across EU/EEA MSs;
- to develop a report on health information collection methods, quality assessment, accessibility and availability procedures in and across MSs.

Proposal

The first phase of T8.1 consisted of a scoping review of international organizations (i.e., WHO-Health For All database, WHO-Health 2020 monitoring framework, WHO-Global non-communicable diseases monitoring framework, OECD, Eurostat) and selected EU research networks (i.e., European Core Health Indicators Monitoring-ECHIM, Joint Assessment Framework on Health-JAF) to identify HI data and metadata characteristics that could be used to develop a questionnaire on health data collection methods and the related harmonization and standardization procedures for health monitoring and HSPA across MSs. The identified data and metadata characteristics were then grouped into five main topics: *Source of information*, *Methodology*, *Quality*, *Data availability*, and *Data accessibility*. In the second phase of T8.1, a questionnaire based on the aforementioned topics was developed to identify data collection methods, availability and accessibility of HI in projects/studies performed in Europe. After a pilot phase, the final version of the questionnaire was administered to all representatives of the InfAct partner countries (28 MSs and 4 associated countries) through the LimeSurvey online platform.
The survey collected information on data related to 91 projects/studies from 18 EU countries. The main results of the survey show that:

- only one-third of the projects share data with EU research networks;
- less than half of the projects follow meta-data reporting standards for data description;
- less than one-third of the projects evaluate all quality criteria defined by Eurostat (i.e., relevance, accuracy, timeliness, punctuality, comparability, coherence, accessibility and clarity) and ECHO (coverage and internal reliability).
- microdata are never accessible in open access; macrodata are accessible in one-third of the projects

Basically, these results demonstrate that evidence produced by research is not always available, comparable or usable for research purposes and policy making.

Recommendations for sustainability

The survey has generated knowledge on standardized health data collection methods and procedures for health monitoring and HSPA in EU; it has also provided information on accessibility and availability of health data across EU countries. The research output will contribute to the development and the sustainability of a research infrastructure by providing information on standardized data collection methods and procedures and facilitating sharing and comparability of health data across EU countries.