INFACT
Joint Action on Health Information

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INTRODUCTION

InfAct is a joint action (JA) on health information (HI). The major outcome expected from the JA is a sustainable solid infrastructure on EU HI through improving the availability of comparable, robust and policy relevant data on health status and health system performance. Through country collaboration, the JA aims to streamline HI activities, reduce the data collection burden and works for a sustainable and robust data collection in Europe that facilitates and supports country knowledge, health research and policy making.

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, etc. Data is collected for different purposes, including population health monitoring (HM)/public health surveillance and health system performance assessment (HSPA). Most of these data are not included in international databases such as WHO, OECD or Eurostat, limiting their use for research and for relevant international benchmarking and comparisons.

Health monitoring data provide the main information for the description of population health status. Monitoring is an intermittent or episodic performance and analysis of measurements aimed at detecting changes in the health status of populations or in the physical or social events [1]. On the contrary, surveillance is a continuous process that requires three functions in this sequence: i) data collection; ii) analysis and interpretations; and iii) decision making. The final phase in the surveillance chain is the application of information to health promotion and to disease prevention and control. Public health surveillance is defined here, as the ongoing systematic collection, analysis, and interpretation of health data, essential to the planning, implementation, and evaluation of public health practice, closely integrated to the dissemination of these data to those who need to know and linked to prevention and control [2].

Performance measurement seeks to monitor, evaluate and communicate the extent to which various aspects of the health system meet the key objectives. There is consensus among members of the Committee on the National Quality Report on Health Care Delivery [3] and clinical experts participating in the OECD Health Care Quality Indicator Project [4] that those objectives can be summarized as: i) health conferred on citizens by the health system; ii) responsiveness to individual needs and preferences of patients; iii) financial protection offered by the health system; and iv) productivity of utilization of health resources. A healthcare system should also fulfil other criteria such as equity on access, effectiveness, quality and safety, and allocative efficiency [5].

For health information systems, standardization for data collection for monitoring/surveillance or HSPA is required to ensure comparability of the results. Comparability is often restricted by differences in definitions, used collection methods and tools, and varying uses of classifications. Standardization procedures ensure that three criteria are met: i) the aims of data collection are made explicit and all necessary and pertinent information are collected; ii) data are collected using the same method; iii) the same definitions are used. Standardization is also time efficient and essential for comparing population groups, geographic areas, or trends over long periods of time [6]. Some examples of standardized data collection are: i) Eurostat health statistics are collected from different sources which are under specific regulations [7]; ii) the countries participating in the European Health Examination Surveys (EHES) research

network also follow standardized data collection methods and procedures [8]. Standardization of metadata is also important in health information systems describing health data. For example, the main reference metadata-reporting standards used by Eurostat [9] are: i) SIMS (Single Integrated Metadata Structure); ii) ESMS (Euro SDMX Metadata Structure); iii) ESMS-IP (Euro SDMX Metadata Structure – Indicator Profile); and iv) ESQRS (ESS Standard Quality Report Structure). There are also other metadata/data reporting standards facilitating the access and reuse of public information, such as:

- Open archival information system (OAIS), specifies how to maintain, transfer and disseminate archival information across institutions, both metadata and data from public archives. The aim of this reference model is to acknowledge the actors, responsibilities/roles and procedures for the long-term maintenance of archival datasets considered public good [10];
- Data Documentation Initiative (also known as DDI or DDI Metadata), an international standard only for metadata standardization in the case of micro data collected because of official statistics (surveys, questionnaires, etc.) conducted in National Statistics bodies [11].

OBJECTIVES and INCLUSION CRITERIA

The objectives of this survey are to identify methods of data collection (and the related harmonization and standardization procedures) for HM and HSPA in projects/studies carried out in EU Member States. These projects/studies could be: **A) part of European research networks** (e.g. EUROCISS, EHES, ECHIM, EUBIROD, ECHO, EuroREACH, EHLEiS, PERISTAT, EuroSafe, euroHOPE, etc.) [12-21], **or B) purely national data collections not yet included in European research networks**. There is no need to report data collections which are already part of existing international organizations databases of WHO, OECD or EUROSTAT. Practical examples for A), regarding HM are: i) the Italian health examination survey [22] is included in EHES; ii) the Italian injury data is included in the European Injury Data Base (IDB) [23]; and iii) the Italian perinatal data is included in PERISTAT [24]; an example for HSPA are hospital-specific indicators from administrative databases and medical records in European countries, including Italy, which are currently being developed and tested as indicators of system performance (e.g. increased survival rates after acute cardiovascular events, including stroke and AMI) [25].

A practical example for B) regarding HM is the Italian longitudinal study 'Osservatorio Epidemiologico Cardiovascolare', which follows standardised data collection methods and procedures, but it is not yet included in European research networks or in databases of international organisations.

In addition, the project/study eligible for the survey should satisfy all the following:

1. health data provided by the project/study should be representative of the population at national or regional level in your country;
2. health data should cover topical areas of population HM and/or HSPA;
3. the project/study should not focus on rare diseases, infectious diseases and cancer;
4. health data should be accessible as micro or macrodata (aggregated results) which are not included in databases of international organizations such as WHO, Eurostat, OECD;
5. the project/study produced scientific outputs (e.g. research papers, reports, etc.).

The sections on availability and accessibility are built taking into account FAIR Data Principles which are a set of guiding principles in order to make data FINDABLE (data and supplementary materials have sufficiently rich metadata and a unique and persistent identifier); ACCESSIBLE (metadata and data are understandable to humans and machines, and data is deposited in a trusted repository); INTEROPERABLE (metadata use a formal, accessible, shared, and broadly applicable language for knowledge representation); and REUSABLE (data and collections have a clear usage license and provide accurate information on provenance) [26].

The health data and related metadata indicated by the member states will be described in terms of:
    i) Source typology of the information/data sources;
    ii) Quality assurance procedures in the methods of data collection;
    iii) Availability and coverage (national/regional) and frequency (the time frequency at which data is collected at regular intervals);
    iv) Accessibility.

The results of the survey will be useful in identifying national data collected for population HM/public health surveillance and HSPA with standardized methods that are not incorporated into existing international datasets. The results will contribute to the development of the European HI Platform, a one-stop-shop for EU HI research.

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