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Road map for the uptake of health indicators: Opportunities and obstacles

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WP9 Lead: Department of Non-Communicable Disease and Injury, Santé Publique France, France
WP9 Co-Lead: Health Information Centre and Institute of Hygiene, Lithuania
Sciensano | Rue Juliette Wytsmanstraat 14 |
1050 Brussels | Belgium | e-mail: infact.coordination@sciensano.be |
Website: www.inf-act.eu | Twitter: @JA_InfAct

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Executive summary

InfAct (Information for Action) is a joint action of EU-Member States and EEA countries aiming to develop a more sustainable EU health information system through improving the availability of comparable, robust, and policy-relevant health status data and health system performance information. The uptake of health indicators into national health information systems is essential to ensure continuous development, quality improvement, comparability, and harmonisation of the various existing approaches in the EU data collection system. We described the uptake of health indicators into the regular EU data collection system and asked the experts from Eurostat and public health institutes for their inputs. The main objective of this report was to highlight the opportunities and obstacles for the uptake of health indicators into a regular EU data collection system by taking into account Eurostat regulations.

The compliance with Eurostat regulations may improve data quality, comparability and harmonise the methodological approaches used to calculate the health indicators. Several constraints may hamper the integration of national health indicators into Eurostat's routine data collection systems, such as different data sources, case definitions, ICD-coding, reference population, statistical methods, reference period, etc.

The outputs of upcoming European projects (i.e., DIPoH [Distributed Infrastructure for Population Health], TEHDaS [Towards a European Health Data Space], PHIRI [Population Health Information Research Infrastructure]) would support the further development of comparable and harmonised approaches for secondary use of data across European countries. Moreover, the integration of health indicators with the use and reuse of data for improved population health and its research would strengthen across European countries.

Key points

- The uptake of health indicators into the regular EU data collection system requires comparable data sources, data collection methods, statistical methods, definition of indicators, ICD-coding, reference population, and reference period.
- Compliance with Eurostat regulations may improve the collection and production of comparable health indicators across European countries.
- The outputs of upcoming European initiatives for a sustainable health information system (i.e., TEHDaS, DIPoH, PHIRI) would support the European countries for the uptake of health indicators into the regular EU data collection system, use and reuse of data, and a harmonised and a comparable health information system.

I. Introduction

InfAct (Information for Action) is a joint action of Member States aiming to develop a more sustainable EU health information system through improving the availability of comparable, robust, and policy-relevant health status data and health system performance information [1]. This project was launched on March 1st, 2018. InfAct gathers 40 national health authorities from 28 Member States (MSs). One of the work packages (WP) was focused on innovation in health information for public health policy development. This WP has identified a set of health indicators estimated in European countries using linked data sets. One of the tasks highlighted the opportunities and obstacles for the uptake of indicators into the EU data collection system.

The integration of health indicators into national health information systems is essential to ensure continuous development, with improvements in quality, comparability, and harmonisation of the various existing approaches in the EU data collection system. The health indicators should be developed using representative population-based health data, comparable between points in time, countries, and areas [2]. Several European standards have been developed to facilitate the integration of health indicators into the EU collection system. However, these standards may not be fully compliant by European countries, and they may encounter certain obstacles to integrate health indicators into the regular EU data collection system.

II. Aim

The main objective of this study was to highlight the opportunities and obstacles for the uptake of health indicators into a regular EU data collection system by taking into account Eurostat regulations.

III. Approach

We performed the following steps to achieve this study's objective: 1. the concept of uptake of health indicators, 2. An overview of Eurostat regulations, and 3. Identifying the opportunities and obstacles for the integration of health outcome indicators into the EU data collection system.

1. The concept of "uptake of health indicators" into the regular EU data collection system

We described the concept of the uptake of health indicators into the regular EU data collection system and asked the experts from Eurostat and public health institutes for their inputs.

2. An overview of Eurostat regulations

Several European regulations have been developed as Eurostat regulations to produce and collect comparable health indicators across various European countries. These regulations facilitate the integration of health outcome indicators into the regular EU data collection system.

3. Identification of opportunities and obstacles for the uptake of health outcome indicators into the regular EU data collection system

We identified the opportunities and obstacles for the uptake of health indicators into the regular EU data collection system from various reports and asked the experts from Eurostat and national public health institutes for their inputs.

IV. Results

4. The uptake of health indicators into the regular EU data collection system

The uptake of health indicators is a systematic process of including comparable and coherent health indicators into the regular EU data collection system that complies with the Eurostat regulations.

5. An overview of Eurostat regulations

Several European regulations have been developed as Eurostat regulations to produce and collect comparable health indicators across various European countries. For example, Council Regulation (EC) No 322/1997 described Community Statistics standards [3]. The decision no 1350/2007/EC of the European Parliament and the Council of October 23rd, 2007 establishing a second programme of Community Action in the field of health (2008 – 2013) indicated its objective of generating and disseminating health information. Moreover, the knowledge would be pursued by actions to develop further a sustainable health monitoring system with mechanisms for the collection of comparable data and information with appropriate indicators [4]. Eurostat regulation (EC) No 1338/2008 was focused on Community statistics on public health and health and safety at work [5]. This regulation includes the following standards: general provisions include subject matter, scope, definitions, data sources, methodology, pilot studies and cost-benefit analysis, transmission, treatment and dissemination of data, and quality assessment. Final provisions include implementing measures, committee, and entry into force. Another regulation (EC) No 223/2009 is detailed on European Statistics standards [6].

These regulations facilitate the integration of health outcome indicators into the EU data collection system, ensure comparability and harmonisation of the used approaches.

6. Opportunities and obstacles for the uptake of health outcome indicators into the regular EU data collection system

We identified some opportunities and obstacles for the uptake of health indicators into the regular EU data collection system from various reports [7]. This information was shared with the experts from Eurostat and national public health institutes for their inputs. We classified the related opportunities and obstacles into the following categories: 1. Data sources, 2. Quality of data, 3. Methodological, 4. Organisational and structural aspects, 5. Legal aspects, and 6. Quality of Eurostat data collection protocol.

Opportunities

The mechanisms of these regulations allow harmonising all steps involved in collecting data, statistical methodologies, definitions of health indicators, ICD-coding, producing information with appropriate indicators, and their dissemination. Consequently, this allows achieving the objective of generating and disseminating health information and knowledge that will be pursued by actions to develop further a more comparable health information system.

1. *Improve the quality of data*: The Eurostat regulations allow improving the quality of data in terms of relevance, accuracy, timeliness, punctuality, accessibility, comparability, and coherence of data [5].

2. *Ensure comparability of methodological aspects*: The compliance with Eurostat regulations allows improving the coordination activities with international organisations to ensure comparability of statistics and consistency of data collection methods and avoid the duplication of effort and deliveries of data by Member states.

3. *Update of existing indicators:* The compliance with Eurostat regulation also supports updating information on specific existing indicators or subgroups is not always possible although relevant, i.e., Gestational age for births.

Obstacles/challenges

We have identified some obstacles that hinder the comparability and, consequently, the uptake of health indicators into the regular EU data collection system. We classified them under the following categories: 1. Data sources, 2. Data gaps, 3. Methodological, 4. Organisational and structural, 5. Legal aspects, and 6. Limitation of Eurostat data collection protocol.

1. *Variability in data sources*: There is variability (in terms of availability, completeness, timeline, punctuality in providing updates, etc.) in national administrative data sources, national or sub-level national surveys, registries, and data collection tools and reporting across the Member States. This variability can challenge the comparability of health indicators.

2. *Data gaps*: some indicators not being available in certain countries, which decreases the likelihood of collection at the EU level if they are difficult to compile or require specific data/linkages that are not common.

3. *Variability in methodological aspects*: There are several methodological aspects, making it challenging to integrate health indicators into the regular EU data collection system, such as the variability in definitions of indicators, ICD-coding, reference population and denominator, statistical methods used to calculate health indicators, reference periods, etc.

4. *Organisational and structural aspects*: Limited resources to compile the health information according to the Eurostat regulations in terms of capacities/skills within national institutes of public health and health information statistics are also barriers for the uptake of health indicators.

5. *Variability in implementation and interpretation of GDPR (General Data Protection Regulations)*: There is variability in implementation and interpretation of GDPR in European countries for data sharing that may challenge the uptake of health indicators into the regular EU data collection system.

6. *<u>Limitation of Eurostat data collection protocol</u>:* To include an indicator in the Eurostat system the agreement is required from all Member States; many of the Euro-Peristat indicators are not available in all countries, and they are not covered by the Regulation (EC) No 1338/2008 of the European Community statistics on public health and health and safety at work

An example of Euro-Peristat indicators for their integration into Eurostat: technical obstacles [7]

Here we report an example of Euro-Peristat indicators for their integration into the Eurostat data collection system and highlight some technical obstacles. This study was performed under the Joint Action (JA) on European Community Health Indicators Monitoring (ECHIM) (2008 – 2013). The main objective of this study was to develop, implement and promote the comparability of health indicators and health monitoring in the EU and all its Member States. In 2010, a study had been performed to report on the legal and technical basis for integrating Euro-Peristat indicators into Eurostat and ECHIM [7].

There are several constraints, which hamper the integration of Euro-Peristat indicators into Eurostat's routine data collection:

(1) Eurostat has one principal partner in each country, while Euro-Peristat often gets data from several sources. (2) The contact people for the two systems are not the same in most cases. (3) To include a new indicator in the Eurostat system the agreement from all Member States is required; many of the Euro-Peristat indicators are not available in all countries, and they are not covered by the Regulation (EC) No 1338/2008 of the European Community statistics on public health and health and safety at work. (4) The negotiation of new regulations is a lengthy process. Eurostat has completed implementation measures for the regulation specifying the rules for collecting data on fetal and neonatal deaths, which does not allow reliable international comparisons on mortality-related perinatal health indicators.

The main problems with the current statistical data on perinatal health at Eurostat are the following:

(1) Data on stillbirths are collected voluntarily only. There are no recommendations about whether induced abortions due to fetal anomalies at 22+0 weeks or after should be included as stillbirths. The solution for this has to be found within the technical group of causes of death at Eurostat, where all member states have their representation. (2) Information on neonatal and infant mortality is available, but not by gestational age and birth weight, as recommended by Euro-Peristat. The solution for this has to be found within the experts on demographic statistics at Eurostat. The proposal to introduce a satellite list for infant deaths by age at death (under 24 hours, 1-6 days, 7-27, and 4 weeks-1 year), by sex and cause of death is welcomed. (3) Information on maternal age and parity is available for live births, not by deliveries (mothers), as recommended by Euro-Peristat. The solution for this has to be found within the experts on demographic statistics at Eurostat. (4) Information on maternal mortality is available at Eurostat for all cases and maternal age, but not published. Data on maternal deaths by mode of delivery remain unavailable. The proposal to reconsider a separate satellite list for maternal deaths with additional data from other sources is welcomed. (5) Of the core indicators, data on distributions of birth weight and gestational age, multiple births, and mode of delivery (excluding Caesarean sections) are not available at Eurostat. A solution for getting these data could be a regular ad hoc data collection within

the future health information activities at DG Health and Consumers. (6) Of the recommended indicators, data on congenital anomalies, Apgar scores at 5 minutes, maternal smoking, maternal education, births after fertility treatments, timing of 1st antenatal visit, mode of onset of labour, place of birth, breastfeeding at birth and very-preterm births by the level of care are not available at Eurostat. A solution for getting these data could be an ad hoc data collection within the future health information activities at DG Health and Consumers. The feasibility of using EUROCAT data on congenital anomalies, and ESHRE data on fertility treatments, should be evaluated.

V. Discussion

The InfAct project outputs would support developing a more sustainable distributed health information infrastructure for population health research. This upcoming infrastructure is called DIPoH. The DIPoH (Distributed Infrastructure for Population Health) aims to facilitates the identification, access, assessment, and reuse of population health data across Europe and ensures research is interoperable and in line with ethical and legal requirements [8]. Another European initiative TEHDaS (Joint Action Towards a European Health Data Space [TEHDaS]), was initiated in September 2019 [9]. One of the priorities of TEHDaS is to enhance the secondary use of health data for population health research. One of its tasks is to define the specific legal, technical and economic requirements for setting up a pan-European structure to support the secondary use of health data, including a cost-benefit analysis.

On January 30th 2020 – after the spread of the coronavirus outbreak beyond the Chinese borders and the notification of the first cases of coronavirus disease 2019 (COVID-19) in Europe, the COVID-19 epidemic was declared as a Public Health Emergency of International Concern by the WHO [10]. A joint action of European countries called PHIRI (Population Health Information Research Infrastructure) focused on Covid-19 was initiated to facilitate the public health response more efficiently. It was launched on November 1st, 2020. This joint action would focus on the European mechanism for COVID-19 exchange to organise and share information between countries urgently needed, especially in population health, to facilitate multidisciplinary European research and underpin decision-making. One of the tasks of PHIRI is to provide an overview of existing practices and guidelines on ethical and legal aspects of performing and exchanging health information on COVID-19. PHIRI is the pilot project for DIPoH.

When the InfAct project was launched, few European initiatives for sustainable health information structure were in place. There are some commonalities between TEHDaS and DIPoH, such as both initiatives will facilitate and support open, interconnected, and data-driven research through the use and reuse of data following ELSI (Ethical, Legal and Societal Implications) and FAIR (Findability, Accessibility, Interoperability, and Reusability) principles. These initiatives would support the further development of comparable and harmonised approaches for secondary use of data across European countries. The outputs of these initiatives would add more evidence to the current opportunities and obstacles for integrating health indicators.

VI. Implications and limitations

This study reports that compliance with Eurostat regulations may improve the collection and production of comparable health indicators across European countries.
The information on obstacles and opportunities for the uptake of health indicators was not collected from each European country due to lack of time. The findings of this study may not reflect the current status in all Member States.

VII. Conclusions

The uptake of health indicators into the regular EU data collection system requires comparable data sources, data collection methods, statistical methods, the definition of indicators, ICD-coding, reference population and reference period. The compliance with Eurostat regulations may improve the quality of data, update certain existing indicators or sub-groups, and ensure the comparability of methodological aspects. The variability in data sources, data gaps, methodological aspects, limited resources at organisational and structural levels and limitations of Eurostat data collection protocols may hinder to ensure the comparability and consequently the uptake of health indicators into the regular EU data collection system. The outputs of upcoming European initiatives for a sustainable health information system (i.e., TEHDaS, DIPoH, PHIRI) would support the development of a harmonised and comparable health information system across European countries. Moreover, the uptake of health indicators into the regular EU data collection system, using and reusing data and a harmonised and a comparable health information system for improved population health research across European countries, would be strengthened.

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Sciensano | Rue Juliette Wytsmanstraat 14 |
1050 Brussels | Belgium| e-mail: infact.coordination@sciensano.be|
Website: www.inf-act.eu |Twitter: @JA_InfAct