Briefing note on the strategic application of big data and their use for policy-making

Purpose of the technical briefing

The purpose of this technical briefing is five-fold:

- To discuss the strategic role of big data as a data-driven approach for supporting health decision-making and evidence-informed policy development;
- To discuss some examples of big data use for health in European Member States;
- To highlight information-specific barriers to big data use;
- To explore whether Member States would favour the development of a European regional strategy on big data in health; and
- To solicit input and guidance from Member States in determining concrete next steps under the European Health Information Initiative (EHII) to assess the usefulness of big data in public health.

Questions for discussion

1. What are the information-specific opportunities for and barriers to the use of big data for health in the European Member States?
2. Do we have good examples from the country level that elucidate these?
3. Would Member States favour the development of a European regional strategy on big data in health?
4. What would be concrete next steps under the European Health Information Initiative (EHII) to assess the usefulness of big data in public health?
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### 1) Strategic generation and use of information, evidence and research are more important than ever before

a) **Health information is at the core of evidence-informed policy-making**

Evidence-informed policy-making aims to ensure that the best available data, information and research evidence are used to formulate policies to improve the health of individuals and populations. At the core of this policy-making cycle is health information – measuring and understanding the health status of the population and the impact of policies that are aimed at improving the population’s health and well-being.

The WHO European Region’s cultural, economic and social diversity is a strength that requires concerted regional policy action and specifically adapted approaches to public health strategies, initiatives and programmes in the Member States. This was outlined in the Health 2020 European health policy framework [1]. Health 2020 was ahead of its time in: calling for equitable development in health and well-being; its commitment to working across and engaging a diversity of government sectors and levels, communities and societal groups; and proposing novel targets and indicators to measure multisectoral action. In addition to public health research systems, national health information systems are the foundation for generating evidence to inform health policy development.

Health information systems (HIS) and research systems are at the core of the European Region’s and Member States’ ability to inform policies and measure their impact over time.
Health information systems provide knowledge of the health status of the population, surveillance for health hazards and disease, as well as the performance of the health system. They are therefore essential for national policy-makers to gain a reliable picture of the health situation in their country and to understand the determinants that influence the health and well-being of their populations. This will also allow linking the determinants of health across the dimensions of the United Nations Sustainable Development Goals (SDGs).

b) **Health information systems are challenged to respond to the needs of multisectoral and increasingly complex policy action for health**

Well-functioning health information systems provide information for any relevant monitoring framework that is measuring policy action. They further feed into the information needs of policy-makers.

The HIS must be flexible enough to systematically respond to policy needs and, at the same time, to enable the consistent assessment of longer-term measures to analyse trends in population health and the impact of policies. To fulfil its role, HIS requires strategic and coordinated management with an emphasis, first and foremost, on collecting and analysing information that is useful for decision-making at all levels of government, and for operational management practised by data contributors.

Despite efforts to increase the availability and accessibility of information, health information systems in the European Region face difficulties with standardization, interoperability and integration.

- With the increased use of technology in the provision of government and health services, health information systems are generating larger amounts of administrative and routinely collected information. However, the availability of increased amounts of data does not directly translate to better data for better decision-making.
- Even routine data sources used in population health analysis are known to provide only partial information and must be cross-checked with others and have their data carefully interpreted. Therefore, methodologies such as the Global Burden of Disease are increasingly important to effectively use diverse data sources and understand the burden of disease in the population.
- In addition, health information systems have been challenged to innovate and add to the selection of tools and approaches that can be used to understand and measure the subjective concept of “well-being” and new concepts such as “community resilience”, “cultural contexts of health”, and others.

Bearing in mind the vision to integrate and harmonize health information systems and to make them flexible enough to respond to the needs of policy-makers and provide relevant information, big data approaches may pose opportunities that must still be defined.
2) Use of big data and the emerging field of data science for public health policy-making

Big data and the associated emerging field of data science have been receiving much attention as potential new sources of information for sustainable development efforts — outside routine information systems [2, 3], in official statistics [4, 5], and to inform policy-making [6]. Consequently, some reviews have been done to take stock of the current barriers to and opportunities for the use of big data in government, including case studies in using big data sets for public health and the provision of health care [7, 8, 9].

However, despite many promises of the potential that big data can offer — to policy-making for health and well-being to support Health 2020 policy objectives or to the achievement of the 2030 Agenda for Sustainable Development — these are yet to be fully explored. For example, there is still no clear and unanimously agreed definition for the use of big data for health, nor is there a vision of how health information systems can use the innovation and advances coming from big data and associated developments, such as for data governance, ethics, technology, interoperability-, and analytics.

For the purposes of the discussion in the technical briefing, big data for health and well-being is understood to include data sources and approaches that:

i) enable better and/or new uses of existing data sources either through innovations in methods of analysis or integration, such as within and across organizations, or between different data sources;

ii) contribute to the collection of information and enable data sharing for the synthesis of data sources in health, and feed into advanced analysis methodologies, such as the Global Burden of Disease; and

iii) allow for the identification of new data sources and analysis methods that can provide new information, evidence and contexts to existing knowledge.

3) WHO European Health Information Initiative – the coordinating mechanism to advance integration, harmonization and innovation in health information systems

Information, evidence and research are key to successfully implement the Health 2020 values and the 2030 Agenda. Recognizing this, the WHO Regional Office for Europe and the Member States have commenced with the implementation of the Action Plan to Strengthen the Use of Evidence, Information and Research for Policy-making in the WHO European Region [10]. Its action areas reflect the European Region’s commitment to systematically inform policy decisions in order to contribute to reducing inequalities in health within and between countries, and to improve the health status and well-being in the Region.

The Action Plan outlines concrete actions, within four key action areas, that the Regional Office and the Member States will take to strengthen the systematic use of evidence, information and research in informing policies.
One task of the Action Plan is to strengthen the HIS through the assessment and promotion of new innovations in the area of health information. The European Health Information Initiative (EHII) [11] is the platform where those actions can be taken forward. The EHII is a WHO network committed to improving the health of the people of the European Region by improving the information systems and information that underpin policy. Its 34 participants mostly include Member States, as well as international organizations.

The EHII works in six strategic areas that are required to strengthen the use of innovation in health. Its umbrella of activities enables focused effort in several areas, from the development and mainstreaming of new methods in analysis and policy-making, to institutionalizing these methods in the HIS, building capacity and communicating their benefits, and streamlining their eventual application to health policy-making.

The EHII’s concerted effort to integrate health information systems and harmonize health information aims at making it a responsive provider of relevant information and analyses that inform policy-makers about the health of populations and the impacts of policies. The EHII is therefore uniquely positioned to drive the discussion of opportunities that big data may pose for health information systems.

4) Highlights of global, regional and subregional discussions

The current discussions around data innovation reflect the diversity of opportunities in using big data as a source of information, and the challenges this poses to the systematic use of information for policy-making.

- Statistical offices are exploring the possible use of new data sources for official statistics. Monitoring progress towards meeting the SDGs will require the collection of data for a large number of indicators that, in many countries, are currently not routinely available or not available at the expected level of disaggregation. The Global Action Plan for SDG Data [5] commits to developing principles for incorporating, into official statistics, new and innovative data which are generated outside the official statistical system – of which innovations associated with big data are one.

- UN Global Pulse discusses how big data can be used for sustainable development efforts [2] as a complement to official statistics by enabling faster access to insight gleaned from large amounts of rapidly produced and diverse digital data. In addition to having access to such data, this also requires new analytic skill-sets and technologies. However, applications of these cases to public health have not yet been fully demonstrated.

- Data privacy, security and ethical concerns need addressing.
  - A UNDG guidance note, on the use of big data for the achievement of the 2030 Agenda [3], points out ethical, privacy and security aspects of data sourcing and their use/reuse. A major challenge is the absence of a common set of principles on data privacy, ethics and protection, and diversity in legal frameworks and their applications across countries.
  - Data privacy challenges apply more broadly to the use of data, and affect the whole of the health information system. The 2016 WHO European Report on
eHealth [12] identified the top three most important barriers to big data in health, rated as very or extremely important, as: a lack of data privacy and security laws, limited integration between different health services and other systems collecting data, and a lack of support for new analytical methods.

- In addition, other challenges for big data use in public health, eHealth (as related to telemedicine and health care provision), and research highlight the need for: raising awareness of the benefits of new approaches, and investing in education and training; developing standards for interoperability; and sustained funding and resources [7, 8].

**European Advisory Committee on Health Research recommendations on big data**

In May of 2017, the topic of big data was addressed in a meeting of the European Advisory Committee on Health Research (EACHR) which considered potential actions by the Regional Office for Europe to accelerate the adoption of big data in Member States and the research community. The key inputs from the EACHR, together with selected recommendations from the research community, are summarized below.

- More examples are required to demonstrate the benefits of big data and how it can be used to provide answers to questions arising during the policy-making process.
- Big data application in other sectors could also be applied in the health context, thus fostering intersectoral collaboration.
- The Regional Office can play a role by: explaining what constitutes big data and how to use it through sharing best practices from around the world; leading in regulating and seeking solutions to safeguard the appropriate use of big data; and monitoring advances in the field.

**5) Next steps for the European Health Information Initiative**

With this input and advice from the EACHR, the Regional Office seeks further input from Member States during the technical briefing on big data at the 67th session of the Regional Committee for Europe in September 2017. With this combined feedback, the Regional Office will define, under the coordination of the EHII, the next concrete steps to assess the usefulness of big data in public health.
References


[10] Action plan to strengthen the use of evidence, information and research for policy-making in the WHO European Region [website]. Copenhagen: WHO Regional Office for Europe;
