

How can we strengthen the impact of national health information systems in policy and practice?

Authors: Marie Delnord¹, Alicia Padron-Monedero², Angela Fehr³, Martin Thissen³, Mariken Tijhuis⁴, Brigid Unim⁵, Isabel Noguer-Zambrano², Rodrigo Sarmiento-Suarez², Petronille Bogaert¹, Thomas Ziese³, Herman Van Oyen¹

Affiliations:

1. Sciensano, National Institute for Public Health, Belgium
2. Carlos III Health Institute, Spain
3. Robert Koch Institute, Germany
4. National Institute for Public Health and the Environment, the Netherlands
5. National Institute of Health, Italy

Contact information:

Marie Delnord, MA, MSc, PhD
Dpt. Epidemiology and public health, Sciensano, Belgian Public Health Institute
14 rue Juliette Wytsman, 1050 Brussels, Belgium
Email : marie.delnord@sciensano.be

Recommended citation:

Delnord M, Padron-Monedero A et al. How can we strengthen the impact of national health information systems in policy and practice? In: Robert Koch Institute, Bundeswehr Medical Service Headquarters (eds.). Public Health Intelligence Wochenbericht (Public Health Intelligence Weekly Report) [internal document]. Issue 28.10.2020; p. 11-14. Berlin: Robert Koch Institute; 2020.
(Published with permission from Robert Koch Institute, public-health-intelligence@rki.de.)

Summary: At the World Congress on Public Health 2020, public health experts and representatives of the EU Joint Action on Health Information (InfAct) addressed this important question: “How can we strengthen the impact of national health information systems in policy and practice?”. At country-level, it begins with the adequate prioritization of health information (HI), and investing in broad dissemination and communication efforts to facilitate the (re) use of evidence for decision-making. This is also a governance issue, and there is a general agreement on the need of an integrated EU health information system infrastructure to monitor risk factors, non-communicable diseases, and health system performance. The Distributed Research Infrastructure on Population Health (DIPoH) may host this work, as well as provide expert fora across European countries to further develop shared issues in HI prioritization, reporting, and translation to policy.

For the first time, this year the World Congress on Public Health (WCPH2020) took place virtually, gathering over 3000 delegates from all around the world. The online event focused on how to build public health for the future of humanity through analysis, advocacy and action. This theme strongly echoes the specific priorities of the German EU Council Presidency^{1,2} to: 1) establish a high-performance European digital infrastructure, and provide relevant indicators for policy-making; 2) promote access to data, responsible data use, technological innovation and security standards in European data policy; and 3) ensure the ability to make evidence-based decisions and take political actions in the EU.

At WCPH2020, during a one-hour workshop, public health experts and representatives of the EU Joint Action on Health Information (InfAct)³ addressed this important question: “How can we strengthen the impact of national health information systems in policy and practice?”. The online session⁴, attended by close to 60 participants, provided valuable insights on the determinants of evidence uptake for decision-making and intervention.

Getting evidence into the hands of key stakeholders is still a challenge in many European countries. Indeed, a majority of attendees recognized that scientific evidence is not the main driver in health policy development (See Poll results in Table 1). This reflects more a reality than a desir-

¹ https://www.destatis.de/EN/eu2020/downloads/german-presidency-programme.pdf?__blob=publicationFile

² Programme for Germany's Presidency of the Council of the European Union. Available at:

<https://www.eu2020.de/blob/2360248/e0312c50f910931819ab67f630d15b2f/06-30-pdf-programm-en-data.pdf>

³ <https://www.inf-act.eu/>

⁴ Session 14.1: Strengthening the impact of national health information systems in policy and practice on Wednesday Oct. 14th 2020 from 15h45-16h45

able objective with major implications for health information systems (HIS), and health system performance (HSP). As illustrated within the context of the current COVID-19 outbreak, having access to accurate and timely surveillance data has been critical to track the progression of the disease including short term consequences and risk factors, gather evidence on health care systems' capacities, and develop therapeutic approaches and containment measures.

Therefore, ensuring decision-makers in policy and care, researchers and the general public can leverage high quality evidence is paramount. It begins with the adequate prioritization of health information (HI), and a reflection on which public health indicators and estimates are the most relevant for intervention. As part of the work within InfAct, Dr. Angela Fehr from RKI presented the results of an online European Policy Delphi. Her study showed that very different approaches to prioritizing HI are currently implemented in Europe. Having a national HI strategy was identified as a desirable option to guide HI prioritization. Several challenges exist however, these relate to the selection and involvement of stakeholders, the application of defined criteria for prioritization, and the actual consensus process across relevant actors and decision-makers.

Reconciling different HI prioritization approaches under a single integrated EU framework constitutes a demanding, but relevant task. There are inevitable differences in priorities across European countries which reflect differences in health system characteristics and country-specific issues. Yet international indicator sets are also available, and these constitute powerful tools to compare experiences across countries, and identify desirable benchmarks for intervention.

Starting in 1998, the list of European Core Health Indicators (ECHI) was developed as a joint endeavour of the European Commission (EC) and EU-Member States (MS), providing a 'snapshot' of the state of European public health and care. The list contains 88 indicators, of which about 60 have been implemented with relatively good comparability across Europe. As pointed out by Dr. Mariken Tjhuis from RIVM, the ECHI list is an essential instrument for EU and national population health monitoring and policy development. One significant concern however, is ensuring the list remains relevant and will be, in the future, sufficiently agile to address emerging policy needs. During the session, the majority of attendees agreed that this should be the responsibility of the EC and EU-MS (Table 1). This warrants the establishment of a formal structure to sustain the highest value of the ECHI in policy and practice.

Dissemination and communication efforts are integral to the development of a shared understanding between data-users and data-providers. Therefore, national public health institutes (NPHIs) have a central role to play in

enabling the greatest number of stakeholders to (re)use evidence for decision-making: whether state or local policy planners, health care providers, patients, parents, or members of civil society at-large.

Across Europe, public health reports are the most frequently used health reporting format. Based on the work of Martin Thissen from RKI, pragmatic approaches should be taken to disseminating good health reporting practices and facilitating their use. An extensive web-based desk research was conducted, and a guidance document on feasible quality criteria for preparing standardized and comparable public health reports has been developed. It includes general good practice recommendations for national health reporting for EU-MS⁵, such as carefully identifying in the planning phase the target stakeholders of health reports, and presenting the evidence in a way that meets their needs and competencies. The workshop attendees noted that besides health reports, other solutions such as indicator dashboards and policy briefs can be considered suitable formats for policy decision-makers (Table1).

More efforts should be devolved to monitoring this process of evidence uptake in policy and practice, also known as "Knowledge Translation"⁶. Traditionally, the focus has been on the production of evidence, and less on evaluating the impact of this evidence in the health system. Yet, it is crucial that we understand better who is using the data, the dashboards, the reports, and to what ends.

During the workshop, a new tool, The HI-Impact Index was introduced by Dr. Marie Delnord from Sciensano. The HI-Impact Index consists in 30 evaluation criteria that EU public health agencies could use to identify barriers to knowledge translation within countries. It was developed with a participatory approach and input from over 130 public health professionals in 38 countries, with the aim to capture the determinants of evidence uptake at systems-level. As such, the HI-Impact Index promotes transparency and better accountability in evidence-informed mechanisms.

Now more than ever, as public health professionals, we are challenged two-fold. On one hand, and for a greater societal impact, actionable evidence is needed. This entails producing timely evidence with a sufficient level of granularity for intervention at the national, regional or local level. Second, our recommendations cannot be construed without acknowledging the broader context in which they would be implemented. Thus, addressing grand societal issues extends the mandate of NPHIs and research institutes beyond "just" producing data and information. This challenges us to reflect on the limits of the scientist's mandate, and to provide strong evidence-based recommendations that might not always align with political considerations alone. Bearing this in mind, renewed partnerships with civil society and opening the dialogue across sectors of evi-

⁵ The guidance document will be available from the Infact project website (www.inf-act.eu): Deliverable Task 8.3.2

⁶ Marie Delnord, F Tille, LA Abboud, D Ivankovic, H Van Oyen, How can we monitor the impact of national health information systems? Results from a scoping review, *European Journal of Public Health*, Volume 30, Issue 4, August 2020, Pages 648–659, <https://doi.org/10.1093/eurpub/ckz164>



dence could ensure we address complex health issues responsibly.

Bringing evidence forth in decisions is certainly a governance issue. As indicated by the RKI Policy Delphi, structured „horizontal“ cooperation is considered a good approach to determining and implementing HI priorities. There is also a general agreement among public health policy makers and researchers on the need of an integrated EU-HIS infrastructure to monitor risk factors, non-communicable diseases, and HSP.

The InfAct consortium provides solid grounds for EU-MS and countries from the European Economic Area (EEA) to generate consensus on a future Distributed Research Infrastructure on Population Health (DIPoH). As explained during the session by Dr. Alicia Padron-Monedero from the Carlos III Health Institute, this requires integrating both technical and political views and interests⁷ (Table 1). This is achieved through two main boards; each of them provides strategic feedback, guidance and support:

A) Technical Dialogues (TD) in which national HI experts participate are focused on feasibility aspects, added-value and new adaptation requirements for DIPoH.

B) The Assembly of Members (AoM) in which political representatives from Ministries of Health and Ministries of Research participate, provides the framework of political acceptance, implementation, and future developments. In the AoM, the focus is rather on resources, and the expected return of investment of an integrated EU-HIS infrastructure.

Since 2019, two TD meetings have been held with the participation of 15 countries. The interpretation of the General Data Protection Regulation (GDPR) is considered a major concern, and adopting consensual guidelines on the anonymization of data was encouraged. Issues of interoperability across data systems within and between countries were addressed. Additional governance options were discussed, including the set-up of 19 National Nodes responsible for the coordination of HI activities within countries.

In addition, three AoM meetings have been held with the participation of 21 countries, and a final meeting took place on October 27th, 2020. Country representatives find the DIPoH proposal well-articulated at national and European level, and they have underlined the importance of building National Nodes. They also welcomed setting up as a practical use case of DIPoH: a Population Health Research Infrastructure (PHIRI) for COVID-19, because it fills a gap on the needed rapid data exchange between countries. Representatives also encouraged linking with other initiatives on HI at national and European level. Nonetheless, there are also barriers for political support: (1) some countries need to secure financial support beforehand; (2) in others, the funding responsibility is incumbent upon the Ministries of Science; (3) while remaining countries support an enlargement of the scope of the European Centre for Disease Prevention and Control (ECDC) instead.

In conclusion, this WCPH2020 Session 14.I provided delegates with an overview of the latest developments in public health reporting and monitoring across European countries, and solutions for better knowledge management across European HIS. As the COVID-19 crisis has shown there is a need for increased solidarity in health data sharing, to support the ambitions of a European Health Union⁸. With enough support from EU-MS and in liaison with the EC, DIPoH may host the shaping and governing of an agile and up-to-date ECHI list, as well as provide expert fora to further develop shared issues in HI prioritization, reporting, and translation to policy. This work may prove essential to inform future EU health policy processes, and contribute to international capacity building in health information and exchange.

When a joint understanding between data-providers and data-users is achieved, we will have the basis for a more successful bridging of science and policy, bearing the promise of better health outcomes.

Table 1. Workshop 14I. Online Poll results at the World Congress of Public Health 2020

Questions (N respondents)	Yes	No
1. There are different approaches which countries take to develop and prioritize health information for national health reports. Do you think that countries need a defined strategy for the development and prioritization of health information? (N=19)	79%	21%
2. Do you think that health reports are a suitable format to address policy decision-makers? (N=22)	63%	37%
3. Keeping the ECHI (meta-data and policy relevance) up-to-date should be the joint responsibility of the European Commission and Member States? (N=19)	89%	11%
4. Do you think scientific evidence is the main driver in health policy development? (N=20)	25%	75%
5. To obtain political commitment for a European Health Information System infrastructure, do you need two meeting grounds for Member States to discuss and generate consensus: one board at the technical level that provides feedback for the other board at the political level? (N=18)	56%	44%

⁷ Summary will be available by the end of the Joint Action InfAct from www.inf-act.eu. Deliverable 4.2. Reports on AoM Assessments. Deliverable 4.4. Reports on key holders and relevant EU- international partners meeting (TD). Deliverable 4.5 Sustainability Plan.

⁸ <https://www.europarl.europa.eu/news/en/press-room/20200710IPR83101/parliament-wants-a-european-health-union>



Acknowledgements: WCPH2020 Session 14. I invited speakers were: Dr. Angela Fehr (AF) and Mr. Martin Thissen (MT) from RKI, the Robert Koch Institute in Germany; Dr. Mariken J. Tjhuis (MJT) from RIVM, the National Institute for Public Health and the Environment in the Netherlands; Dr. Marie Delnord (MD) from Sciensano, the National Institute for Public Health in Belgium; and Dr. Alicia Padron-Monedero (APM) from Carlos III Health Institute in Spain. The session was held virtually and moderated by Dr. Thomas Ziese (TZ) from RKI, and Pr. Herman Van Oyen (HVO) from Sciensano. MD is funded by the Marie Skłodowska-Curie Actions [Individual fellowship GA No 795051]; MT, MJT, APM, INZ, RSS, PB and BU are funded within InfAct by EC grant No 801553

Author contributions: MD drafted the commentary with APM and AF. All invited speakers (AF, MT, MJT, MD, APM) and moderators (TZ, HVO) provided comments, suggestions, and approved the final version, as well as INZ, RSS, PB, and BU.