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# Session 5. Health Information: a Lot of Data but Little Use?

Moderated by Ms. Annika Veimer, Director of the Estonian National Institute for Health Development (TAI), the 2023 IANPHI Europe Meeting's session 5 focused on *health information, and more specifically on the availability, quality and use of existing health data.*

## The European Health Data Space: opportunities and challenges for NPHIs

By Prof. Sofie de Broe, Scientific coordinator, Sciensano, Belgium

The European Health Data Space organizes the collection, access, storage and re-use of healthcare data that require a regulatory framework best serving individual interests and rights in the use of digitalized health data for both primary healthcare and research innovation purposes. Towards European Health Data Space (TEHDAS)'s joint action looked at the various aspects of the European health data space preparedness for each of the twelve countries involved and identified National Public Health Institute (NPHI)'s needs at organizational, technical and legal levels. These involved incentives and guidance to achieve full digitalization, standards for collection, storing and structuring data, as well as a clear framework around secondary use in accordance with the EU General Data Protection Regulation (GDPR). Therefore, a NPHI-level data strategy would set up the necessary standards to help NPHIs choose what data, how to manage and analyze it, and identify sharable content. It would increase NPHI's impact by providing policy relevant information and undertaking surveillance, monitoring, research and innovation. Moreover, NPHIs would benefit from aligning data strategies. The United Nations measurement tool for data maturity enabled Sciensano to identify its level of maturity for each of the several indicators connected to human, technical, data and organization, which are the four identified dimensions of interoperability. As a result, the Belgium NPHI created a short-term implementation plan to achieve pre-determined level of maturity goals. Among these steps, *Prof. S. De Broe* mentioned compliance with FAIR data principles (which stands for findable through common metadata catalogs, transparent access procedures, interoperability and reusability), legal access to virtualized data, data ethic committee and data science community.

## Health data for public health monitoring

By Dr. Hanna Tolonen, Programme Director, Research Development and Innovation, the Finnish Institute for Health and Welfare (THL)

Data itself is only a sequel of zeros and ones, and there are over a thousand WHO-identified indicators. NPHIs must use data to generate indicators, which once analyzed will generate information that can be turned into knowledge, and only then into actions of public health by dissemination and communication. *Dr. H. Tolonen* focused on three specific data sources, its advantages, information that can be generated from it and its uses. First, real world data is based on daily observational healthcare data from multiple sources. Volumes of data are large, often incomplete and unstructured. Vital statistics, mortality data and electronic health records are mentioned as relevant data sources that can be used by NPHIs. Second, population based health surveys can be interview or biological examination-based to get information on health status, social determinants and biological risk factors. Nevertheless, this method suffers from awareness, recall, non-response and social desirability biases. Third, linking different data

sources is an opportunity to enrich and complement limitations of individual data sources. Connections do not always require to be between health-related sources, NPHIs can use demographic, societal, policy changes for instance. Big data play an important role in health monitoring and research. No data linkage or statistical method can replace true responses and observations from individuals. If none of the presented data sets are perfect, NPHIs must be aware of each data source's pros and cons and choose relevant data sources for each indicator of interest in accordance to the purpose it is meant to meet.

Written by Jessica Borges, IANPHI Secretariat