FAIR Health Data Scan Sharing data for the public good? FAIR enough!



Guided survey about the FAIR principles for non-technical and technical stakeholders applied on a specific data source

- 1. Current FAIRness
- 2. Recommendations to improve FAIRness
- 3. FAIR literacy

To fully harness the potential of health data, it is important data collected for one purpose can later be used for other research questions too. Making data sources more FAIR (Findable, Accessible, Interoperable, Reusable) is an important step to lower the threshold for that

To help the different stakeholders in healthcare do this, imec has developed the FAIR Health Data Scan in 2022. This was done in conjunction with Filip Pattyn, guest professor FAIR data and public data integration at the University of Ghent. By means of the scan, healthcare

1. Background

Modern healthcare is data-intensive: it both generates and requires large volumes of (qualitative) data. To enrich health-related insights, we need to be able to combine data from different sources (data diversity). But the healthcare ecosystem struggles to use health data secondarily.

Data are traditionally being collected for a certain purpose. When we want to use them for a different application or research project, things go wrong: we have difficulties finding them (findability), accessing them (accessibility), connecting them with other data (interoperability) and/or reusing them across settings (reusability).

That's why high-level data analysts are now spending huge amounts of time to find databases, find out how to access them, clean and standardize data, etc. And why the potential to improve our healthcare remains largely untapped, both on a personal and a population level (individual care & population management).

To facilitate the secondary use of health data, we need to improve their FAIRness. However, not all data sources can (nor should) suddenly become FAIR. Therefore, we also need to prioritise, focusing on those sources for which an increase in FAIRness will have the highest impact.

2. FAIR Health Data Scan

What is it?

We developed a web application for organisations to assess the FAIRness of a data source. Both technical and non-technical profiles can use the scan. The scan:

- helps to evaluate the FAIRness of an existing data source, as a first step to gradually improve its FAIRness and make the data ready for secondary use;
- helps to collect and store new data more FAIRly to facilitate secondary use later on.

How does it work?

The scan is a tool to objectify how findable, accessible, interoperable, and re-usable a certain data set really is. The assessment is done in the context of a specific use case. The output of the scan is threefold. Users:

- receive an assessment of the current findability, accessibility, interoperability, and re-usability, of the data set which can serve as a baseline measurement and a measurement of progress;
- receive concrete recommendations to help improve the findability, accessibility, interoperability, and re-usability of the data set and the estimated efforts to do so;
- gain a better understanding of the FAIR principles and improve their FAIR literacy

3. Target stakeholders

Any stakeholder in healthcare providing and/or using data, can make use of the FAIR Health Data Scan: governments, healthcare organisations, pharmaceutical companies, healthtech companies, research institutes, etc. Initially, imec developed the scan for Belgian stakeholders, but the scan can be used in other countries too.

4. Who are we?

Imec

Imec is an internationally renowned technological research institution with an important Belgian base. We have a vast experience in health technology, both in hardware and in software, and are a valuable partner for governments, healthcare institutions and industry.

- Hardware: imec is perhaps best known for its expertise and knowledge in chip and nanotechnology. The technologies we (help) develop are deployed across the entire spectrum of health management: from prevention and diagnostics to monitoring and treatment.
- Software: additionally, imec develops software and systems to enable data sources to be easily accessed and connected, as well as artificial intelligence applications for obtaining new insights from data sources.

In 2021 and 2022, imec and Zorgnet-Icuro conducted a survey with C-levels of different Flemish hospitals on their knowledge of FAIR health data and their current practices and encountered barriers regarding the secondary use of healthcare data.. Additionally, in 2022, imec and several other stakeholders in Belgian healthcare organized a series of panels on how to accelerate access to health data in Belgium.

Filip Pattyn

Filip Pattyn is a health data enthusiast and guest professor in FAIR data and public data integration at the University of Ghent. In his role at the university, he is conducting research on technological solutions to improve the reusability of health data for secondary use.



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