

## Conference Report

### Health Data Quality: a Dynamic Complexity Health Data Forum 2022



This report is one part of a two-fold report on the conference. The second part includes the Porto declaration. This publication was developed with the help of the Programme Committee, chairs and minute takers:

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- Jens Declerck, i~HD
- Fernando Araújo, Portuguese National Healthcare Service (SNS)
- Vanessa Candeias, Global Healthcare Specialist
- Maria Christofidou, i~HD
- Pascal Coorevits, Ghent University
- Ricardo Correia, Porto University
- Altamiro da Costa Pereira, Porto University
- João Fonseca, MEDCIDS
- Nathan Gatpandan, i~HD
- Nathan Lea, i~HD
- Christophe Maes, i~HD
- Maria Marques, UNINOVA
- Paul Nunesdea, Health Data Forum
- Sofia Palmieri, Metamedica – Ghent University
- Francisco Rocha Gonçalves, Sanofi
- Delfim Rodrigues, Portuguese National Healthcare Service Hospitals
- Mats Sundgren, i~HD
- Geert Thienpont, i~HD
- Francesco Vigna, i~HD - Ghent University

### Conference keynote speakers:

- Carlos Agostinho, UNINOVA
- Paolo Alcini, European Medicines Agency
- Paula Blancarte Jaber, ICHOM
- Joseline Carías Galeano, Central American Health Informatics Network
- Sara Cerdas, Member of the European Parliament
- Este Geraghty, Esri
- Tom Goffin, Ghent University
- Alexandre Guedes da Silva, Society of Multiple Sclerosis (SPEM)
- Nigel Hughes, EHDEN
- Ricardo Jardim Gonçalves, UNINOVA
- Rhidian Hurle, Digital Health and Care Wales
- Markus Kalliola, Sitra
- Pedro Miguel Camara Ramos, Madeira Regional Secretary of Healthcare and Civil Protection
- Sofia Nogueira da Silva, Portuguese Health Regulatory Authority
- Patrick Pavlick, Sanofi
- Rajendra Pratap Gupta, UN Dynamic Coalition on Digital Health, Internet & Jobs
- Peter Rijnbeek, Erasmus MC
- Rui Santos Ivo, Portuguese National Authority of Medicines and Health Products
- Philip Taillieu, Cascador Health
- Tiago Taveira Gomes, MTG and Sigil Scientific Enterprises
- Yiannos Toliás, DG Health and Food Safety (EC)
- Pascal Verdonck, Belgian Association of Hospital Managers

### Organisers:



**NOTE: Don't miss the comprehensive conclusions of each session presented in the blue boxes.**

## 1. Foreword – Health Data Quality: a Dynamic Complexity

The European Institute for Innovation through Health Data (i~HD), working in collaboration with the University of Porto and the Health Data Forum and its partners is proud to present the outcome and results of the Health Data Forum conference, held in Porto on 17 and 18 November 2022. This event attracted over 400 experts and participants from multiple public and industry organisations and stakeholders, including representatives from key policy-making bodies such as the European Commission, WHO and national governments.

The conference's objective was to emphasise the importance of collecting, maintaining, and curating high-quality data. One of the most important challenges in our healthcare ecosystem. The quality of health data is a critical success factor for all the ways in which it can deliver value to patients, healthcare and research organisations, and to society. This is highlighted by many stakeholders, formalized through data quality assessment methodologies and improvement strategies, and embedded within the forthcoming European Health Data Space (EHDS) Regulation. However, it is still a Holy Grail that is more often discussed than acted upon. It is now vitally important that the quality of health data is taken forward by all health data ecosystem stakeholders, each contributing to the enhancement of data quality right across Europe, for all permitted purposes and stakeholders.

Data quality is an ever-changing requirement that needs to be redefined over time and over different projects. That is the reason we refer to data quality as a dynamic complexity. Obtaining, maintaining, and improving data quality is not a one-man job. It is important to note that all stakeholders within the healthcare ecosystem should actively participate in the data quality effort. We need all stakeholders, but to get them on board we need to answer some important questions:

- Who should invest in data quality?
- Why should I invest in data quality?
- What is my return on investment (patient safety, better health pathway, financial aspects...)?



## 2. Summary & highlights – 17<sup>th</sup> November 2022

### Plenary session 1:

#### Welcome

Moderator: Paul Nunesdea, Health Data Forum Firestarter

All participants were welcomed by:

- Altamiro da Costa Pereira, dean of the faculty of Medicine at the University of Porto.
- Ricardo Jardim Gonçalves, full professor and director of UNINOVA.
- Geert Thienpont, Managing Director at i~HD.



All speakers expressed their gratitude towards all participants, live and hybrid for participating in this unique conference on health data quality. Jens Declerck (Data Quality Manager i~HD) presented an overview of the structure of the two-day event and explained why we refer to data quality as a dynamic complexity.

#### Keynotes from Thought Leaders

Moderator: Vanessa Candeias, Global Health, and Healthcare Specialist

Rui Santos Ivo, President of the Portuguese National Authority of Medicines, and Health Products at INFRAMED, started off by presenting a national overview of the Portuguese health data ecosystem. Showing us the importance of health data and the areas of action of INFRAMED within this ecosystem. He concluded by it is fundamental that there is a need for collaboration between all stakeholders within our healthcare ecosystem.



Sofia Nogueira da Silva, President at the Portuguese Health Regulatory Authority, gave a presentation on risk-based supervision and how this can foster data-driven regulation of the healthcare system. From her perspective, it is important to find the right balance between enough data and too much data. She concluded that it is key to determine the amount of data that we really need, making sure it is real, verifiable, reliable, and

available on time.

At last, Paolo Alcini, head of Healthcare Data, European Medicines Agency, gave a presentation on data standardization and data quality in the EU medicines regulatory setting. Mr. Alcini's presentation provided us with an overview of the data quality framework developed by EMA. The goal of this framework is to establish an EU framework for data quality and representatives.

## Parallel session: i~HD holistic view on Health Data Quality

### How do health and ICT systems impact health data quality?

Should EHR systems embed better data quality measures and dashboards to improve quality at the source?

Chair: Pascal Coorevits, Professor at Ghent University



Carlos Sáez, Assistant Professor Biomedical Data Science Lab at the Universitat Politècnica de València, gave a presentation on the experiences of 10 years of developing data quality metrics and dashboards. Mr. Sáez concluded that data distribution dashboards over time and across sources can provide precious information about changing data patterns at the source. Which in return can improve the quality of the data at the source.

Anže Droljc, business development director at Better, presented what kind of IT systems are needed in healthcare to improve data quality and support the “data for life” concept. Vendors should have an independent view on the matter and use an open data strategy.

Tom Devree, system quality program manager at i~HD, gave his holistic view related to quality assurance in ICT systems.

Robert Vander Stichele, senior research coordinator i~HD. He presented the quality of prescribing and quality of medical documentation in nursing homes. This proved to be an important tool to increase the resilience of institutions dealing with acute challenges.



## Conclusion session

### How do health and ICT systems impact health data quality?

- Trustworthy systems and trustworthy use are a critical success factors for high quality data
- To have an innovative marketplace of trustworthy ICT products supporting care, supporting research and connecting the two, processing reliable data, we need both a market pull and a market push
  - Market pull: policymakers, regulators, DPAs, DPOs and procurers must be precise and aligned with each other, and across Europe, on what GDPR compliance means in our context and on what safeguards are expected of ICT products, services, and their users, translated into formal certification criteria.
  - Market push: ICT companies must value trustworthiness as one of their key unique selling points (USPs), take pride in their governance and security quality and be positive about certifying their products against these criteria.

## How does information governance impact health data quality? Should the quality of assurance of EHR systems be a market pull or a market push?

Chair: Mats Sundgren, Senior industry Scientific Director at i~HD

Daniel Otzoy, digital health technical advisor at John Snow Inc., promoted global collaboration during his presentation. He promoted the transfer of knowledge on digital health.

Christophe Maes, business developer at the European Institute for Innovation through Health Data (i~HD), emphasized why data quality is critical for GDPR compliance. Acquiring GDPR compliance requires high data quality processes.



Darren Lloyd, associate director of information governance and patient safety, digital health, and care Wales, explained why having information governance is important in the design and assurance of the EHR. Without this framework, the challenge of making information available to services providing healthcare becomes a far more difficult construct.

Richard Yeatman, CTO at IgniteData, explained how information governance impacted health data quality in relation to EHR-to-EDC. Mr. Yeatman concluded that information governance is at the heart of everything we do. We need to build software systems with an 'information governance and hospital first' mindset.



Ruben Roex, Professor at Ghent University, gave a legal perspective on information governance and data quality. The GDPR leaves a lot of room for interpretation by the member states, this creates difficulties for the public and private market stakeholders to use health data across member state borders.

### Conclusion session

#### How does information governance impact health data quality?

- The health data ecosystem is a complex mix of actors, purposes, data flows and processing
- We must enable these data flows to ensure complete (high-quality) data is used for the care of a person and for unbiased learning
- Data quality is the sine qua non to have an efficient and GDPR-compliant Information Governance System

## How do interoperability standards impact health data quality? What incentives would definitively scale up the interoperable sharing of health data?

Chair: Ricardo Correia, Auxiliary Professor University of Porto at the Faculty of Medicine



Carlos Luis Parra-Calderon, member of the SEIS board of directors in Portuguese National Healthcare Service Hospitals, presented how interoperability standards impact health data quality for precision medicine research. He concluded that data quality is critical in the ecosystem and that it serves as feedback for continuous improvement.

Catherine Chronaki, Secretary General at HL7 Europe and President European Federation for Medical Informatics, gave an HL7 FHIR perspective on how interoperability standards impact health data quality. She emphasized the fact that data quality costs money and it is still not clear who is financially responsible for this. It will be important to develop incentives to tackle this challenge.

Robert Jakob, team leader of Classifications and Terminologies at the World Health Organization (WHO), gave a presentation on ICD and WHO-FIC.

Steve MacFeely, director of Data and Analytics at the World Health Organization (WHO), gave a presentation on how to achieve data interoperability. Mr. MacFeely concluded that there should be a trade-off between efficiency and privacy. If we want to achieve high-quality data, we should work with data owners and understand how and why the data was created.



### Conclusion session

#### How do interoperability standards impact data quality?

- We need to educate healthcare professionals on data quality. And therefore data quality standards are paramount
- To create a common language, a common playing field for experimentation, management change is important.

## Plenary session 2:

**Moderator: Mats Sundgren, Senior Industry Scientific Director at i~HD**

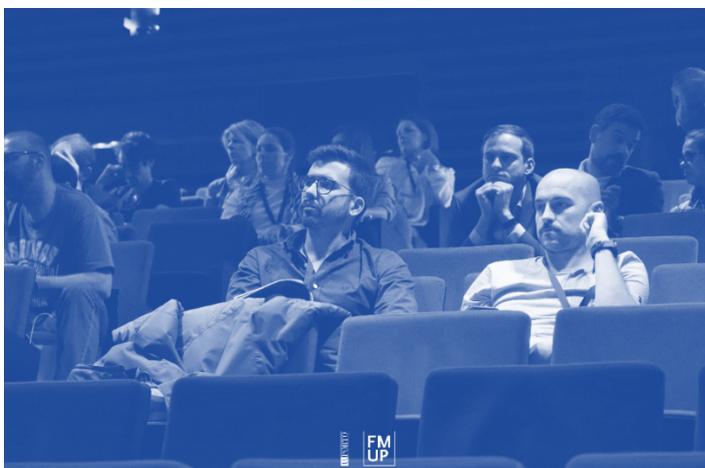


**Markus Kalliola, Project Director at Sitra, presented all health data quality requirements defined in the European Health Data Space (EHDS). Mr. Kalliola explained why the EHDS is a game changer in our healthcare setting, pushing all stakeholders to reuse health data. Due to the EHDS, a virtuous cycle of data quality improvement could be established, coming from the data re-user. He ended by presenting some personal takes on health data quality.**

**These takes have been taken into consideration for the conclusion that you can read at the bottom of the page.**

**Yiannos Toliás, Legal Lead on AI and AI Liability in Healthcare and Director General for Health and Safety at the E.C. Mr. Toliás gave a keynote on AI and data in medicine. He presented the most important challenges related to this topic and how the European Commission is responding to these challenges. He also made the link between the AI act and the EHDS, showing how these two could prevent biases in training AI algorithms.**

**Ricardo Jardim Gonçalves, full professor and head of international development at UNINOVA, presented all the important projects UNINOVA is doing during his keynote. All these projects emphasized the importance of health data to foster innovation in digital health and wellbeing. Mr. Gonçalves concluded that all this technology should be citizen-centred.**



## Parallel session: What are the new topics regarding data quality?

### Artificial Intelligence and its impact on data quality and data governance

Can the AI community self-determine minimum data quality standards for AI training, below which the data is unsafe to use?

Chair: Sofia Palmieri, Researcher at Metamedica (Ghent University)

Karolina Mackiewicz, Innovation Director at the European Connected Health Alliance (ECHAAlliance), highlighted the opportunities and risks of AI in healthcare. The presentation emphasized on the importance to engage the community in the co-creation of AI and apply end-users' perspective.



Gordon Johnston, Leader at Johnson & Johnson Technology Quality & Compliance, presented his view on what data quality can mean in the practice of AI development. Working with data means working with potential false positives and false negatives, some levels of errors are inevitable. Mr. Johnston concluded that we should come to an ethical compromise when it comes to biases in AI algorithms.

Nathan Lea, DPO and Information Governance Lead at i~HD, emphasised on how we can set a safety bar for AI. He concluded that the AI community can't self-determine minimum data quality standards. The AI community is just one stakeholder in this ecosystem, we need to consider multiple other aspects and stakeholders.



Pedro Duarte, Corporate Manager for External and Legal Affairs at Microsoft, gave his view on what the role of the AI community should be. As mentioned in previous presentations, the more powerful the AI, the greater the damage it can create. Considering this, it will be very important to include different stakeholders when building AI solutions.

### Conclusion session

#### Artificial Intelligence and its impact on data quality and data governance

- Decision makers and data scientists must work together – urgently – on a European standard for data quality labelling, so that AI can then be accurate in the transparency provided to users
- Decision makers, regulators and educators must work together to help the AI community working in health (especially SMEs with limited access to expertise) to understand the AI regulation and instruct them on what they have to do to comply for the health context.

# The European Health Data Space

## Can we rapidly scale up the quality labelling of healthcare data sets?

**Chair: Maria Christofidou, Data Protection Researcher at the European Institute for Innovation through Health Data**



**Licinio Kustra Mano, EHDS Strategic Advisor for the European Commission, gave an overview on the European Health Data Space and how this will accelerate health data quality. The presentation showed us how the EHDS is driven by all stakeholders, and which benefits we could expect. Better diagnoses and treatment, improved patient safety, better health policy are just some few benefits rising from the implementation of the EHDS.**

**Enrique Bernal-Delgado, Senior Scientist at the Institute for Health Sciences in Aragon, addressed our main question of the session. He concluded that we cannot rapidly scale up the quality (and utility) labelling of datasets. But that it is possible if we use a consensual approach, Mr. Bernal-Delgado presented takeaway messages to prove his statement. These takeaway messages are summarised in the conclusion section at the bottom of the page.**

**Emmanuel Bacry, Chief Scientific Officer at the Health Data Hub France, presented the health data hub. This hub is a unique gateway for easy, unified, transparent, and secure access to health data. The health data hub aims to facilitate access to health data in France.**



### Conclusion session

#### The European Health Data Space

- **The EHDS regulation must better align primary and secondary use data quality expectations and labelling**
- **Implementing legislation must formalize (standardize) data set labelling to include data quality, FAIR metadata and clinical content characterization. The EC must consult with ecosystem stakeholders on these standards, who have a lot of expertise to offer**
- **All actors along the data flow pathways must have the capacity and competence to add their part of the context to the data set labels – they will need incentives for this**

## New Frontiers in Data Quality

What are the new opportunities that arise from real-world case studies and are we maximizing their potential?

Chair: Maria Marques, Researcher at UNINOVA

Rachel Powell, Associate Director of Information, Intelligence and Research at Digital Health and Care Wales, gave a presentation on delivering information and technology for better care.



Sergio Roll, President of the Brazilian Society of Minimally Invasive Surgery and Robotics (SOBRACIL) highlighted the importance of big data and robotic surgery. Mr. Roll emphasized how better data and surgical robotics will improve healthcare and patient outcomes.

Ravi Shankar Santhana Gopala Krishnan, Head of Geographic Information Systems (GIS) at the World Health Organization (WHO). Mr. Shankar presented the importance of geo-enablement microplanning, an application of geospatial data and technologies to foster the microplanning process. It is a data-driven process to ensure that health services reach every member of every community.



Dries Hens, Chief Business and Medical Officer at Lynxcare, presented case studies on real-world evidence in clinical medicine. Ensuring data validity in electronic health record-based research requires access to unstructured data. Unlocking this unstructured EHR data is needed to provide accurate real-world evidence.

### Conclusion session New frontiers in data quality

- Member States, working through the European Commission and the eHealth Network, must align their evidence requirements for the approval of digital health innovations within their health systems, including the criteria to qualify for reimbursement (but not necessarily the reimbursement level)
- National health systems must support digital innovators to access health systems data, including disease, outcomes and economic data, that assists them with generating the required evidence portfolio

## Plenary session 3: Across the world plenary on Health Data Quality

**Moderator: Vanessa Candeias, Global Health, and Healthcare Specialist**

**Format: Structured dialogue format. With the moderator directing specific pre-defined questions to each speaker.**



This across the world discussion aimed to demonstrate the importance of quality of healthcare data. If healthcare is to truly leverage the power of data, it is vital that standards, safeguards, and safe ways of using and sharing quality data are developed to break down silos, thus improving the accessibility, utility, and scalability of healthcare data. Doing so will have a profoundly positive impact on medical research, drug pricing, clinical decision making, patient empowerment, and ultimately, improvement

in care outcomes and population's health.

**This panel includes the following participants:**

- Rhidian Hurle, Chief Clinical Information Office Wales, Digital Health and Care Wales
- Joseline Carias Galeano, General Manager, Central American Health Informatics Network (RECAINSA)
- Paula Blancarte Jaber, Project Manager, International Consortium for Health Outcomes Measurement (ICHOM)
- Rajendra Pratap Gupta, Chairman, Co-Chair Digital Health Summit Expo & Awards
- Este Geraghty, Chief Medical Officer, and Health Solutions Director at Esri

**This plenary session was placed under the following guiding questions by the moderator for each speaker:**

**Rhidian Hurle, Chief Clinical Information Office Wales, Digital Health and Care Wales**

**Moderator: Part of the NHS Wales Family and a trusted partner, Digital Health and Care Wales is taking forward the next generation of services needed to transform health and care delivery. Technology and quality data are the backbone of this transformation.**

- What are some of the key elements of this transformation and how do you see the use of technology delivering better outcomes for the patients in Wales?
- What are some of the challenges that you see in gathering and using technology as an enabler of high-quality health care?
- Where do you see the biggest opportunities for change in the care system? And what do you think would make patients' lives easier?

**Joseline Carias Galeano, General Manager, Central American Health Informatics Network (RECAINSA)**

**Moderator: The Central American Health Informatics Network – RECAINSA – is a network of volunteers that was created in 2013, with the aim of supporting national digital health strategies and creating a platform for sharing knowledge and good practice in both the public and the private sectors.**

- Can you share some breakthrough examples from central America of how health quality data has been used to improve population health?

- How do you see countries and companies addressing some of the challenges of maintaining data quality in healthcare? Are there some examples of good practices you can share with us?
- Where do you expect the most progress to happen in the coming years when it comes to health informatics in Central America? What are some of the key enablers for that progress to happen?

**Rajendra Pratap Gupta, Chairman, Co-Chair Digital Health Summit Expo & Awards**

**Moderator: Having quality healthcare data is complex and countries are at various levels in their ability to generate and use quality data. You have seen a lot of this variability and readiness to leverage digital health in your work.**

- What are the trends you are seeing in the quality of healthcare data worldwide, particularly post-Covid?
- What were some of the changes/innovations that you have seen countries or companies implement that have allowed them to move towards the goal of digital health for all?
- Where do you see the biggest digital health opportunities for a country like India? And what do you think will need to be in place for these opportunities to materialize?

**Paula Blancarte Jaber, Project Manager, International Consortium for Health Outcomes Measurement (ICHOM)**

**Moderator: At ICHOM, you're developing a new paradigm focused on health outcomes – the results that matter most to patients. With the aim of having patients ask their doctors about meaningful outcomes, and doctors being able to respond with data-driven answers. You can only get there through standardization, measurement, feedback loops and an in-depth understanding of what the data is showing.**

- What are the ICHOM set of Patient-Centred Outcome Measures and how do they help with data quality and ultimately with better health outcomes? Can you share with us what are some of the main challenges in building a high-quality standardized data set and how ICHOM has overcome those?
- How does ICHOM involve patients in the development of the sets and in improving health outcomes?
- Can you share about the work ICHOM did in the Netherlands with the Santeon Hospitals which is focused on patient care and quality improvement?

**Este Geraghty, Chief Medical Officer and Health Solutions Director at Esri**

**Moderator: Spatial data and geographic information system (GIS) technology can underscore coverage gaps in the populations, the opportunities to improve workflows, and the ability to plan for and mitigate against unforeseen events.**

- Can you share an example of how applied geographic information systems have led to improved health outcomes/increased accessibility to health care/ or healthier communities?
- How do you think high-quality data can enable health equity?
- Where do you see the biggest opportunities for using geospatial data to change the care system?

**Final question addressed to all speakers**

**Moderator: If you could change one element that would improve data quality leading to benefits for patients what would that be and why?**

### 3. Summary & highlights – 18<sup>th</sup> November 2022

#### Plenary session 4

**Moderator: Christophe Maes, Business Developer at i~HD**

**Tom Goffin, Health Law Professor at Ghent University, gave a keynote on the quality of data and quality of care, and how to close the gap. Is the quality of data a precondition of quality of care or is it the opposite around? Mr. Goffin raised some very important questions regarding the trustworthiness of digital health and on how we can achieve this. If we want to ensure patients trust digital health systems, all stakeholders need to combine all their strengths and skills. Because the quality of data within the quality of care means quality and trust for the patients in our healthcare system.**



**Peter Rijnbeek, Head at Erasmus MC Department of Medical Informatics, presented a keynote on enabling large-scale analysis of observational health data. The main question within the quote is, “how can we generate reliable evidence from observational data at a large scale, i.e., on many data sources in Europe for many research questions?”. Mr. Rijnbeek presented different challenges our healthcare ecosystem is facing regarding real-world data and research. And what it will require to face these challenges.**



## Parallel session: Return of investment from different stakeholders' perspectives (1)

### What is in it for citizens as data providers?

#### What would motivate patients to care about the quality of their health data?

Chair: Nathan Lea, DPO and Information Governance Lead at i~HD

Gözde Susuzlu Briggs, Project Coordinator at the European Patients' Forum (EPF), presented the Data Saves Lives initiative. Data Saves Lives is a multi-stakeholder initiative led by the European Patients' Forum. Communications towards patients as stakeholder is most important aspect. She concluded that good communications start with a KISS, Keep It Simple, Stupid.

Birgit Bauer, Digital Health and Social Media Entrepreneur/Healthcare and Patient Expert gave her view on how to motivate patients to share their data into health apps. Birgit concluded that we don't need to convince patients, but that we should give them correct tools, involvement as a stakeholder and to provide them with understandable information. Patients are open to share their data, but they want to know how, where, and why.

Anke Verheyen, International Project/Quality and Compliance Manager at Novellas healthcare, talked on the use of patients' data obtained from patient support programs. Patient support programs are an easy and comprehensive manner to generate accurate insights and real-world evidence. But to obtain the full potential of these programs, health data needs to be of a high quality.

### Conclusion session

#### What is in it for citizens as data providers?

- Health ministries, health insurers and the data reuse industry sectors must join forces and co-invest in educating and empowering patients to:
  - Capture their own data to a high quality
  - Lobby for, and help ensure, high quality of their professionally captured health data
  - Have channels to enable their health data to be reused for purposes they support
  - Learn how health data has been used and generated societal benefits
- Initiatives like Data Saves Lives must be scaled up within countries as well as at EU level, and need infrastructural funding for this

## **What is in it for data facilitators?**

### **Does data mapping always lead to diminished data quality?**

**Chair: Delfim Rodrigues, Coordinator of Home Hospitalization Units at the Portuguese National Healthcare Service Hospitals.**

**Christel Daniel, Director at AP-HP Data, IS Research and Innovation, gave her view on the general question within the session. The conclusion of the presentation was that data mapping not always led to diminished data quality. It is important to note to select a common data model that is relevant for the use case. And to obtain high-quality mappings you will need to find resources with the correct quantitative and qualitative expertise.**

**Andreas Kremer, Managing Director at Information Technology for Translational Medicine (ITTM), concluded during his presentation that data mapping does not lead to diminished data quality. Mr. Kremer presented how the mapping process is done at ITTM.**

**Myriam Sturkenboom, Data Science and Biostatistics Professor at UMC Utrecht, presented a view from medicines' real-world evidence generation. There is a proven value to working together on RWD and re-use data for learning purposes. But that there are multiple common data models. Myriam emphasised the most important difference between OMOP and Conception.**

**Maxim Moinat, Scientific Researcher at Erasmus MC, highlighted the data quality framework implementation in OHDSI and EH DEN. The focus was on data quality assessment of the harmonized data, even though there are multiple moments within the data flow to perform an assessment.**

#### **Conclusion session**

#### **What is in it for data facilitators?**

- **It is hard to deliver high-quality data mappings, from multiple data sources of variable quality**
- **We should agree on and focus attention on high-value data sets:**
  - **To concentrate education, skills and efforts on the capture of high-quality high-value data**
  - **To promote standardized mappings including semantics to the common data model(s) for these data sets**
  - **To develop standardized analytics and tools that can process these data for multiple purposes**

## What is in it for data research users?

Should research users passively depend upon the quality of the data they can get?

**Chair: Francisco Rocha Gonçalves, Head of Market Access, Public Affairs and Trade at Sanofi.**

**Jana Makedonska, Program Manager in Health Research at the European Health, and Digital Executive Agency (HaDEA) presented all relevant health data projects at HaDEA. Mrs Makedonska highlighted all data quality topics ongoing in Horizon Europe Projects. For example, new methods for the effective use of real-world data and/or synthetic data in regulatory decision-making and/or in health technology assessment.**



**Mark Little, Nephrology Professor at the Trinity College Dublin and Consultant Nephrologist concluded that data providers should participate as active partners in the health data quality effort.**

**Nadir Ammour, Global Lead of Clinical Innovation and External Partnership at Sanofi concluded that collecting data in a structural manner at the source would lead to better clinical study outcomes. We need to go beyond the scientists, we need all stakeholders to achieve high-quality data and we will define incentives for achieving this goal.**

### Conclusion session

#### What is in it for data research users?

- **The clinical research community (pharma, Medtech, Big Tech, AI) must work in partnership with healthcare providers**
  - Work toward a common vision and understanding of what data quality means, why it is important, how to assess it and how to achieve improvements
  - Work together on business models that co-finance the investments needed
- **ICT companies, especially EHR system developers, must build in “data quality by design” so that users find it easy to enter high-quality data**
- **Research projects and innovation initiatives must assess and take into account the quality of the data they use for design, development and evaluation**

## **Parallel session: Return of investment from different stakeholders' perspectives (2)**

### **What is in it for data providers (hospitals)?**

**What would incentivize busy junior staff to care about the data they enter into HER systems?**

**Chair: Fernando Araújo, Executive Director at the Portuguese National Healthcare Service (SNS).**

**Seval Agkün, Chief Quality Officer at the Baskent University Hospitals Network, presented different EHR incentive programs for hospitals. Conclusion of the presentation was that physicians must use certified electronic health records technology and demonstrate meaningful use through an iterative process at the end of each meaningful use reporting period.**

**Rhidian Hurle, Chief Clinical Officer Office Wales at the Digital Health and Care Wales, talked about leadership in data collection. Mr. Hurle concluded that leadership is what we need in facing the challenges in our healthcare ecosystem. And that we need to focus on the patient journey.**

**Pieter-Jan Lammertyn, Data Scientist at AZ Delta RADar Learning and Innovation Center.**

**Carlos Santos, President Coimbra Hospital and University Center Administrative Council, and Tiago Alfaro, Director of Innovation and Development Unit at Coimbra Hospital and University Center, gave a duo presentation on Coimbra's clinical academic centre. They both concluded that the health ecosystem should support researchers, both clinical and translational. They also emphasised the need to advance local, regional, and national research.**

### **Conclusion session**

#### **What is in it for data providers (hospitals)?**

- **Academic and other educational organizations must develop a wide range of flexible learning resources to enable HCO personnel (healthcare professionals, ICT, managers and decision-makers) about:**
  - **What data quality is and why it is important**
  - **How to assess data quality and its impact for primary and secondary use purposes**
  - **How to improve their data quality**
- **Secondary use stakeholders must urgently develop a co-investing framework to support HCOs with the uptake of education and the organizational changes needed to improve data quality**
- **Purchases and providers of EHR systems must prioritize the adoption of systems that facilitate and label high-quality health data**
- **Hospitals cannot be financially responsible for all the investment needed in education, expertise and EHR system upgrades**

## What is in it for data MedTech?

MedTech requires high-quality data, so what can it contribute to address the quality challenge?

Chair: Christophe Maes, Business Developer at i~HD



*"Health Data Quality is a concern, but should not stop us from working on projects where the quality is already 'fit for purpose'. The EU legal framework is there."*

-Philip Taillieu, Founder and CEO, Cascador Health

Philip Taillieu, Founder and CEO Cascador Health stated that a lot of data is out there but not accessible due to different reasons: slow hospital decision processes, a plethora and interoperability issues of the hospital systems, legal and ethical challenges, and one-off projects versus recurrent data provisions. As a MedTech you have to create value for your data partners by improving efficiency and effectiveness, helping them to innovate, create economic compensation. Data access service providers help other MedTech companies to create new technologic solutions. Philip ended his talk by saying that gaining trust can be achieved by the validation of the services and products.

Joris Wille, CEO at BeWell Innovations, showed some use cases such as the virtual hospital, how data points from different Medtech devices contributed to an improvement of value-based healthcare. Although interoperability of the different technologies can be seen as an important issue these innovative technological solutions endorse primary and secondary use of health data.

During the talk of Odile Bigaignon, Sleep and Respiratory Care Vice President at ResMed, it became crystal clear that high-quality data is most important when you want to make more than 15 million devices cloud-connected. An enormous bunch of data are captured and analysed to help healthcare providers access the kind of insight that can improve outcomes and reduce overall healthcare costs. High quality of data reduces costs, improves personalized care and efficiency, delivers superior outcomes and stimulates continuous innovation.

### Conclusion session

#### What is in it for data MedTech?

- DPOs give different interpretations related to the same regulatory requirements. This provides a difficult setting for MedTech companies
- A big challenge for a MedTech company, but very important is to prove the evidence of the device
- MedTech companies rely on high-quality data but are not always in the driver's seat
- High-quality data by design should be a priority when developing innovative solutions

## What is in it for data research users?

Do healthcare providers need to learn from their own health data, and what will turn them into data enthusiasts?

Chair: Maria Christofidou, Data Protection Researcher at i~HD.

Koenraad Jacob, Government of Flanders Head of the Department of Information, Policy and Data. Mr. Jacob presented the Care Atlas Platform, which serves as a foundation for a data-driven policy. The presentation showed us how data is being used on a daily level and how policy is being developed depending on this data.

*"No health data, now answer, no tool. But it is not only important to share the data but also create."*

-Koenraad Jacob, Head, Department of Information, Policy and Data, Government of

Miguel Ángel Armengol de la Hoz, Head of the Regional Ministry of Health Southern Spain Big Data Department gave his view on how we can empower researchers to make better use of health data.



Emmanuel Alexandrakis, Health Economy Global Strategist at WiFOR, explained the paradigm shift in health as which should serve as an investment. Mr. Alexandrakis concluded that we should use health economy reporting as a policy tool that connects health data to macroeconomic performance, resilience, and wealth. The goal of health economy reporting is all about measuring how health-related activity affects the macroeconomy. But to achieve this we need to invest in high-quality data/metrics in health-related activity.

### Conclusion session

#### What is in it for data research users?

- There is a need to measure the impacts health data have on the economy, in order to understand future economic developments and how to scale up the potential of health data in the global economy
- A general shift seems to be required, in the sense that health data costs (such as data quality) must be seen as an investment. It is essential to calculate and apportion across stakeholders the investments needed to enable good-quality data for all
- Decision makers who rely upon good data should be co-investors in data quality

## Plenary session 4: Calls-to-Action Session

**Speaker: Dipak Kalra, President of i~HD.**

The structure of each session provided us with enough time to present the content and to have interesting discussions between participants and speakers. This conference and the discussions highlighted the importance of health data quality, which gave us the opportunity to define certain challenges towards achieving high-quality data. Mr. Kalra presented these challenges and formulated several calls to action during his keynote. These statements and calls to action will be distributed in the Porto 2022 Declaration on Health Data Quality.

## Plenary session 5: Grand Debate – Data Quality: Return of Investment

**Moderator: Mats Sundgren, Senior Industry Scientific Director at i~HD.**

**Format: Structured dialogue format. With the moderator directing specific pre-defined questions to each speaker.**

**This grand debate aimed to discuss and answer the question: what is my return of investment?**

**This panel includes the following participants:**

- **Pascal Verdonck, Vice President of the Belgian Association of Hospital Managers**
- **Nigel Hughes, Project Coordinator of the European Health Data Evidence Network (EHDEN)**
- **Paolo Alcini, Head of Healthcare Data at the European Medicines Agency (EMA)**
- **Alexandre Guedes da Silva, President of the Portuguese Society of Multiple Sclerosis (SPEM)**
- **Philip Taillieu, Founder and CEO of Cascador Health**

**This plenary session was placed under the following guiding questions by the moderator for each speaker:**

- **Why do we need to invest in data quality?**
- **What investments are most needed to improve data quality and who needs to fund them?**
- **How can this investment bring a return of investment to all stakeholders?**
- **What kind of actions/collaborations will be needed to achieve this?**

## Use Cases & Roundtable Session: Citizen-centric health and wellbeing data

**Chair:** João Fonseca, Director of MEDCIDS

**Moderator:** Paul Nunesdea, Health Data Forum Firestarter

**Use cases presentations:**

- Carlos Agostinho, Senior Researcher at UNINOVA
- Este Geraghty, Chief Medical Officer and Health Solutions Director at Esri
- Patrick Pavlick, Diagnostics Information Director Rare Diseases US Scientific Affairs and Diagnostics at Sanofi
- Nuni Marujo, Founder of Ablute
- Tiago Taveira Gomes, Founder and CEO of MTG and Sigil Scientific Enterprises.

The use case presentations were followed by a final roundtable with Q&A and closing remark.

### Closing Ceremony

**Chair:** Altamiro da Costa Pereira, Dean at the University Medical School

- Ricardo Jardim Gonçalves, Full Professor and Director at UNINOVA
- Licinio Kustra Mano, representing Sandra Gallina, Director-General DG Health and Food Safety at the European Commission
- Dipak Kalra, President, The European Institute for Innovation through Health Data
- Sara Cerdas, Member of the European Parliament for the Socialist Party Portugal
- Pedro Miguel Camara Ramos, Madeira Regional Secretary of Healthcare and Civil Protection
- Fernando Araujo, Executive Director Portuguese National Healthcare Service (SNS)

### More information:

- **Porto Declaration on Health Data Quality**
- [Health Data Forum 2022 – Health Data Quality: a Dynamic Complexity on i~HD](#)
- [Conference programme](#)

