



This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Grant Agreement No. 826353.



HORIZON 2020
The Framework Programme for Research and Innovation



Project acronym: DigitalHealthEurope
Grant Agreement Number: 826353
Project full title: Support to a Digital Health and Care Innovation initiative
in the context of Digital Single Market strategy
Call identifier: SC1-HCC-05-2018

Digital Health Europe Summit 2021

Report on the 2021 Digital Health Europe Summit

(28-30 September 2021)

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Scope of the Digital Health Europe Summit 2021

The Digital Health Europe Summit 2021 brought together a large number and wide variety of stakeholders for inspiring and forward-looking debates.

Topics covered in the Summit’s scope ranged from real-life transformation through digital health (Day 1), via empowering citizens (Day 2), to scaling up innovation through health data (Day 3). During the three days of the Summit, 50 speakers made presentations in 12 sessions.



Figure 1 Showcasing the speakers of the Summit: A promotional display

Scope is also taken to cover numbers and types of registrants and attendees.

A total of 535 people registered for the Summit. Registrations were spread over many geographies. The five main European Member States represented were Belgium, Germany, Italy, Spain, and Portugal. Around 10 other countries, including Brazil, had about 10 registrants each. A quarter of registrants came from an even more international range of countries.

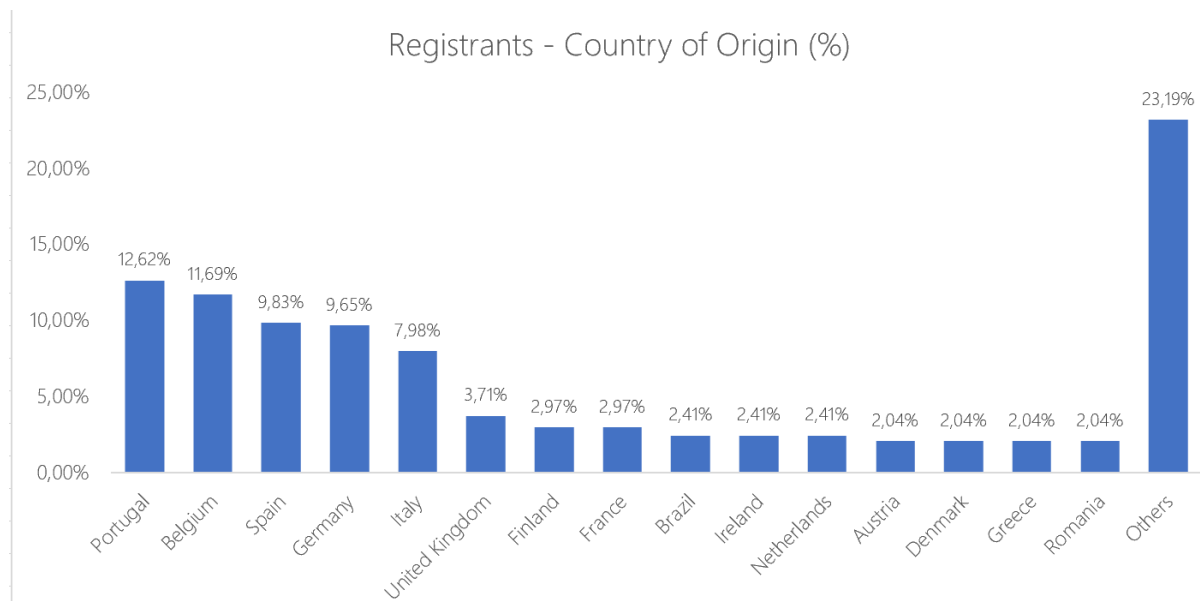


Figure 2 Geographic distribution of registrants

The range of stakeholder types of people who registered was also very wide, covering nine main categories. More than three-quarters of the registrants came from six types of organisation (consulting, industry, health authorities or policy makers, health professionals, researchers or academia, and 'other'), three further types of stakeholders registered.

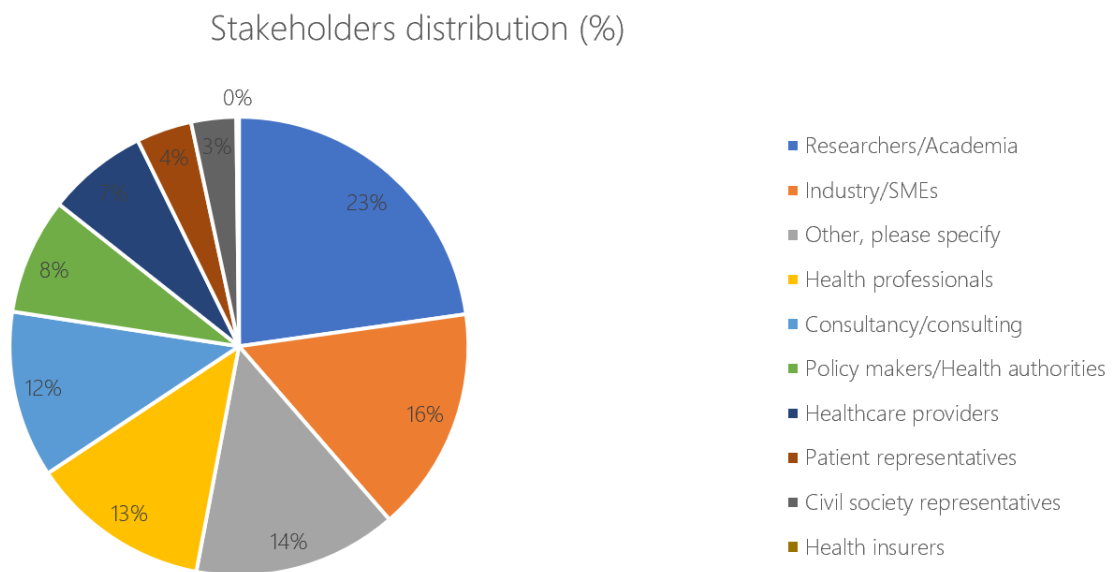


Figure 3 Stakeholder distribution of registrants

The conference overall attracted over 400 (406) unique participants (including staff), which represents an impressive 75% of all registrants. On each single Summit Day there was an average of more than 225 unique attendees (Day 1: 255; Day 2: 231, Day 3: 191). The average view time of the Summit event and activities per participant was 1:34 hours for the overall event.

1 Day 1: Real-life transformation through digital health

1.1 Introduction to the topic

Day 1¹ of the Digital Health Europe Summit was kicked off with an introductory session on the topic of real-life transformation of digital health. Marco Marsella (DG CNECT), Head of Unit for eHealth, Well-Being and Ageing, reflected on the history of the work on the digital transformation of health and care for a healthier society. He emphasised that this digital transformation should be forward-looking. For Mr. Marsella, it is crucial that the focus of the digital transformation is on new data and how citizens and the healthcare sector can use it. Reflecting on what DigitalHealthEurope has had to offer, he said that the project has been valuable and has leveraged the sense of urgency.

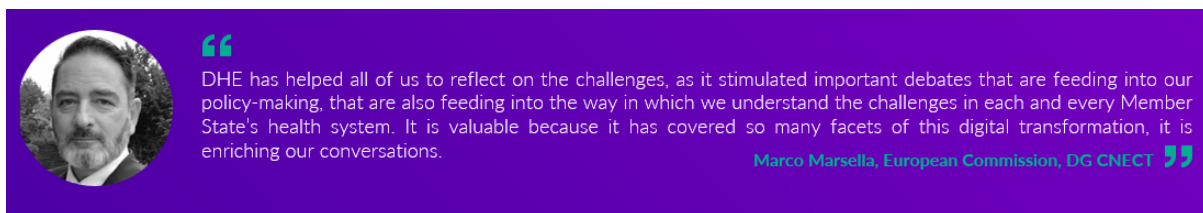


Figure 4 Marco Marsella (DG CNECT): Quote on the impact of DigitalHealthEurope

Concluding and leading into the core of the Summit programme, he focused on the recent past and remarked: “Let’s hope these reflections and lessons learned from COVID [in] Europe” come together in an event (the Digital Health Europe Summit) “that helps us better tailor our actions in the future.”

During the second speech of the introductory session, Dr. Birgit Morlion (DG CNECT), DigitalHealthEurope Project Officer elaborated on *Transformative Digitalisation - empowering citizens and building a healthier society*. She covered many different technologies – including high-performance computing and 5G – which can offer a tremendous amount of computing power for health. Due to the threats posed by the COVID-19 experience, the first benefits arising from the availability of these technologies are now being harvested, helping citizens, and building a healthier society. One of the most prominent examples in this regard is the COVID-19 vaccination certificate (see slide below).

¹ The full recording of Day 1 of the Digital Health Europe Summit can be found here: <https://youtu.be/hjsTxmXIX38>



Figure 5 Dr. Birgit Morlion (DG CNECT): Overview of the Digital COVID-19 vaccination certificate

Dr. Morlion remarked that, as a coordination and support action, the DigitalHealthEurope project has very much been working to help the European Commission to implement this strategy.

1.2 Keynote speech by Esko Aho

Next, keynote speaker Esko Aho (former Prime Minister of Finland) took the floor. Mr. Aho highlighted the tendency to underestimate digital technologies and overestimate what has been achieved. He reflected that in the past months of 2019-2020, achievements made in telehealth and telemedicine have been seen that had previously typically taken ten years to accomplish. He expects no return to 'normal', but instead a continuation in the increased interest in moving forward faster. In terms of targets, Esko Aho explained that the focus should be on four points²: predictive care, preventive care, personalised care, and participatory care. In summary, he stated that COVID-19 has changed people's mindsets on telemedicine. In this context, the topic of telehealth has moved from being simply relevant to being absolutely urgent.

Following Esko Aho's keynote speech, Dr. Veli Stroetmann (empirica) concluded the introductory session of the Digital Health Europe Summit by giving the audience a short glimpse into the DigitalHealthEurope project itself as well as its results and publications³.

1.3 Digital Transformation through replication of European best practices in health and care

The third session of Day 1 focused on digital transformation through replication of European best practices in health and care. Five Twinning partners shared with the audience their first-hand experiences in the DigitalHealthEurope Twinning scheme⁴ and their thoughts on scaling

² Adapted from so-called 'P4 medicine', originally named by Dr Leroy Hood and colleagues: https://en.wikipedia.org/wiki/Leroy_Hood

³ See <https://digitalhealtheurope.eu/results-and-publications/>

⁴ See <https://digitalhealtheurope.eu/twinnings/dhe-twinning-results/>

up best practices through collaboration. Strahil Birov (empirica) defined Twinning as mini-projects focused on replication and scaling up that enable European healthcare systems to adopt solutions and practices. In total, DigitalHealthEurope funded 21 Twinning projects that have represented 72 organisations from 19 countries.

Dr. Oscar Zanutto introduced “SoCaTel”, a co-creation platform. Its five-step method allows for the digital co-creation of long-term care (LTC) services. SoCaTel’s particularity lies in its holistic approach – involving many different types of stakeholders in a joint effort to find the best solutions to existing gaps in LTC service design and delivery. The stakeholders in SoCaTel have included formal carers (healthcare personnel) and informal carers, such as family members, as well as elderly citizens and academic researchers.

The second Twinning, “REHABLAB4ALL”, was presented by Mathieu Thébaud. REHABLAB4ALL is a person-centred care innovation lab that uses digital tools. It aims to transfer the concept of an innovative 3D-printing laboratory, born in France, to six other European locations. Ultimately, it will launch a collaborative IT platform that will enable long-term collaboration and feedback.

Benjamin Cid-Bourié introduced a third Twinning, “CISMED”, which is a medicine shortage detection system that aims to identify where medicine shortages occur and how to prevent them. The system provides an overview of the medication availability in three countries (Portugal, France, and Italy).

The “CCEResearchInfrastructure” Twinning was presented by Lasse Kaalby Møller. This fourth Twinning solution uses algorithms to review the videos of colonoscopies that help to examine patients’ conditions and ensure high-quality investigations. After a rigorous data collection process through clinical trials, the Twinning partners created a common database, thereby ensuring comparability between the data collections.

The fifth and last Twinning presented, “AI4Multimorbidity”, was introduced by Júlia Altarriba and Dr. Rosana Magalhães. In this solution, a digital health company from Spain and a state-owned hospital from Portugal have come together to put an AI system into use. The system can monitor and predict future relapses of patients who are experiencing multimorbid conditions. It consists of a remote monitoring platform and an integrated AI prediction algorithm.

In the discussion that followed, Dr. Birgit Morlion explained in more depth how the Twinning instrument fits European Commission (DG CNECT and DG SANTE) policy. Esko Aho emphasised why one should organise Twinning projects, relating this viewpoint to the need to encourage more start-ups to be involved in the digital health sector. He also underscored the need to focus on (digital) solutions for senior citizens, which might be an up-and-coming sector that is of market interest to small and medium-sized enterprises.

Strahil Birov asked about the Twinning originators’ motivations for participating in the DigitalHealthEurope Twinning scheme. Benjamin Cid-Bourié, Mathieu Thébaud, and Lasse Kaalby Møller highlighted the opportunity the scheme had offered them to share knowledge, learn from the adopters, and enlarge their European networks. Strahil Birov then asked the Twinning adopters how they had located their Twinning partners. Dr. Zanutto, Campbell MacLeod, and Dr. Magalhães – who were involved in three different Twinning projects – remarked that they had all already established a previous contact with their originator, and then took advantage together of the Twinning call opportunity.

To conclude the session, the panellists were asked what the next big Twinning topics were likely to be. Esko Aho stressed that the next big winner in digitalisation is health care – which should be a guiding principle for further policy actions. Dr. Morlion called for focussing more on sharing lessons learnt and less on technologies. Jon Switters emphasised the role of the Twinning projects in identifying new ‘pain points’ where digital health can help. Dr. Zanutto stated that the focus should be on improving digital skills and interoperability among platforms. Mathieu

Thébaud added that care needs to be more affordable and more accessible. Lastly, Lasse Kaalby Møller highlighted the need to move results into everyday life.

1.4 Going digital: Sustainable approaches to scaling up, knowledge sharing, and capacity building

Donna Henderson (European Health Telematics Association) kicked off this fourth session of Day 1 by asking the panellists what the most burning issues are to ensure sustainable approaches.

Dr. Gian Matteo Apuzzo (Central European Initiative) responded that there are several challenges, especially from the perspective of Central and Southern European countries. These challenges cover the need for a shared governance model, digital literacy, knowledge sharing, and the balance between access and privacy. Additionally, pre-accession countries and South-Eastern European countries must be included in Horizon Europe funding. Partnerships are vital, and how they are organised ranges from the cross-country to sub-regional level.

Dr. Maddalena Illario (European Reference Sites Collaborative Networks) added that another challenge is that health systems need to be aligned, since silos still exist between sectors and services. Thus, efforts to connect sectors are critical. According to Dr. Illario, the main challenge lies in implementing stakeholder engagement in scaling-up. The goal is to build a dynamic system that is always open to innovation and adaptation.

During the panel discussion, Dr. Niamh Lennox-Chhugani (International Foundation for Integrated Care) highlighted the importance of evaluating the lessons learnt from COVID-19. Born out of necessity due to the pandemic, many solutions had to be established quickly. She added that there is a particular need to aim for high-quality person-centred care involving both patients and carers.

As a closing remark, Dr. Apuzzo stated that technology is neither a solution nor a medicine. Instead, it is there to support the medical aspect of healthcare. Overall, the digital transformation of the health and care sector is inevitable, and cannot be ignored.

Dr. Veli Stroetmann then closed Day 1 of the Summit and offered the audience some insights into the agenda for Day 2.

2 Day 2: Empowering citizens through health data

2.1 Patient-centred health and care

The first session of Day 2⁵ focussed on patients. After Diane Whitehouse (European Health Telematics Association) introduced the panel, Lyudmil Ninov (European Patients' Forum) took the floor. He presented three recommendations to enhance the relationship between healthcare providers and patients. The recommendations ranged from co-design of digital health, to education and empowerment, and to new policies focussed on person-centricity.

Nicola Bedlington (European Patients' Forum) addressed the effects of the COVID-19 crisis from the perspective of patients who had been disproportionately affected by the pandemic. She emphasised the importance of electronic health records, and the need for patients to have access to their data. To achieve patient access to data, and take advantage of the COVID-19 momentum for change, European cooperation is crucial.

Next, Ivett Jakab (European Patients' Forum Youth League) presented the youth perspective on patient-centred health and care. She shared her personal experience by noting that young people are underrepresented in patient engagement. The central question to answer for any health appliance needs to be its direct value for patients. "*Early, often, meaningful and diverse*" should be the four words to be used to describe how to involve young patients in digital health. Ms Jakab further highlighted the imperative of including all people's perspectives in any debate.

Finally, David Magboulé (LabToMarket) presented the market view, emphasising that patients are coming more and more to the centre of innovations – this was not the usual case at all until recently. One good example of this development is the Patient Innovation Platform⁶. Another example is an online dementia platform founded by the Lithuanian start-up Dementia Lithuania⁷. To be able to apply these different forms of co-creation, patients need to understand the tools used: hence, digital health literacy is essential.

Entering into a discussion with the panellists, Diane Whitehouse emphasised that sharing people's stories is as important as the technology itself. She asked the panellists what the main opportunities and pitfalls could be in the future. Three of the four panellists mentioned pitfalls and drawbacks. Lyudmil Ninov highlighted the pitfall of having a fragmented digital health approach across countries, as has become evident through COVID-19 tracing apps. Ivett Jakab stated that the traditional medical system, which is separated into children's care and adult care, is a hindrance to the use of digital health for young people. David Magboulé mentioned up to three challenges: policy regulations are a main challenge to the rapid development of digital therapeutics; the lack of interoperability between hospitals and other institutions causes inefficiencies; and a lack of digital literacy means that people are still be left behind. Indeed, on a more positive front, Nicola Bedlington underscored that a digital health literacy system needs to be in place for everyone.

Diane Whitehouse asked how the relationship between healthcare providers and patients/caregivers might change with digital health. Lyudmil Ninov mentioned that both sides are still somewhat reluctant to engage in digital health, although the situation is improving. Nicola Bedlington stressed the importance of education and empowerment of patients in this regard.

Ms Whitehouse then invited the panellists to pronounce a key 'take-away' message. Developer, David Magboulé called for patients to be involved in digital health literacy and innovation. In a

⁵ The full recording of Day 2 of the Digital Health Europe Summit can be found here: <https://youtu.be/yJeTbcj6mg>

⁶ See <https://patient-innovation.com/>

⁷ See <https://demencijalietuvoje.org/en/>

complementary way, Ivett Jakab urged developers to reach out to patients. Nicola Bedlington emphasised the need to measure which outcomes matter to patients. Lyudmil Ninov closed the session by stressing the importance of building trust between all the parties involved.

2.2 Citizens' health data sharing

The second session of Day 2 explored citizen-centred data sharing. It started with an overview of a large-scale survey on citizens' attitudes towards health data sharing presented by Carina Dantas (European Connected Health Alliance), and continued with the analysis of the COVID-19 use case.

Nilsy Desaint (MSD) highlighted the importance of collaboration at all levels, and the development of digitalisation, monitoring and surveillance: she mentioned the EU joint action in vaccination⁸ as an example. She also emphasised that the focus needs to be on citizens, especially in the context of e-vaccination cards.

Danny Van Roijen (European Coordination Committee of the Radiological, Electromedical and Healthcare IT Industry) continued the discussion by talking about the challenges in digital healthcare that appeared during COVID-19, namely the lack of data governance structure, difficulties in accessing data, and ensuring long-term trust from patients and citizens.

Prof. Mark Lawler (European Cancer Organisation /Queen's University Belfast) underlined the importance of co-creation in the process of citizens' health data sharing. He added that it is essential to reach out to communities that have not been involved before.

After these four interventions, the discussion focused on health data management. Gözde Susuzlu Briggs (Data Saves Lives/ European Patients' Forum) emphasised the need to educate communities before engaging with them, in order to be able to hold valuable conversations. Two panellists expanded this idea. Prof. Lawler added that, at the same time, access to information should also be easy and convenient, while Danny Van Roijen argued that the focus should be on those patients who need, and want, to collaborate. Last but certainly not least, Nilsy Desaint pointed out the many financial opportunities that countries can use to improve data systems, and she urged them to use these opportunities.⁹

2.3 Accelerating health data connectivity

Dr. Henrique Martins (independent expert) opened the third session of Day 2 by defining the challenge of how citizens and patients can exert demand-side pressure to achieve more health data interoperability.

Dr. Rainer Thiel (empirica) presented the *Monitoring the Interoperability of Electronic Health Records in the EU (2019)* study¹⁰, which demonstrated the state of health data interoperability in the EU. The study revealed a very heterogeneous picture throughout Europe which identified significant obstacles to data exchange even on a national level, due to the fact that large portions of electronic health records still contain unstructured data. For instance, in almost half of the surveyed countries, today less than 25% of general practitioners are able to exchange data with hospitals or specialists.

Dr. Dipak Kalra (European Institute for Innovation through Health Data / European Institute for Health Records) took the floor. He stated that the current status quo of substantial non-interoperability is not acceptable, since the need to connect patient data points has become

⁸ See <https://eu-jav.com/>

⁹ DigitalHealthEurope offers a funding catalogue, as well as a dedicated webinar on "Challenges and Best Practices in Securing European Funding and Exchanging Knowledge" on its website: <https://digitalhealtheurope.eu/resources/funding-opportunities/>

¹⁰ See <https://digital-strategy.ec.europa.eu/en/library/interoperability-electronic-health-records-eu>

especially urgent in times of multimorbidity. However, the ‘standards landscape’ that could link these data points is still not well adopted. This situation compromises patients’ situations since, as a result, they receive less than optimal care. Knowing about standards is important. Dr. Kalra therefore briefly presented the Digital Health Standard Portal on the i~HD website¹¹, which answers enquirers first questions about data-related standards.

Sara Riggare (Uppsala University) then intervened, offering her perspective as a patient researcher living with Parkinson’s Disease. She emphasised the point that many opportunities have been missed. In addition, people in the healthcare system often have unrealistic perceptions of the priorities and needs of patients. At the same time, however, patients frequently do not perceive the value of interoperability. Thus, there is a need for a new surge in health data activism.

In the panel discussion that followed, Dr. Kalra acknowledged that there is a possibility to create a market for health data solutions (as long as it is not presented as a vendors’ market but, rather, a market populated by informed players and patients who are in control of their own data). Health systems should monitor the quality of health apps, and regulate their licensing. Dr. Thiel emphasised that, in his opinion, strong legislation and political will are more successful in advancing digitalisation than is education. Sara Riggare stressed that the development and use of health data are currently driven by industry and research interests – this creates a gap that needs to be filled with health data activism, education, and agency for both patients and healthcare professionals. Moreover, Ms Riggare stipulated that, before discussing data donation, patients’ access to their own data needs to be ensured.

Dr. Martins closed the session by stating that the Summit and the underpinning DigitalHealthEurope project can act as solid starting points for accelerating efforts towards health data activism.

2.4 Data-driven health and care: Is the future federated?

Dr. Oliver Zobell (Jülich Research Centre) opened the fourth session of Day 2 by describing the challenge of ‘breaking up’ data silos by introducing various practical approaches. The federated approach could be a good solution in this regard, by making algorithms ‘travel’ to the data rather than transferring the data to a hub for analysis.

Prof. Dr. Jan Baumbach (Hamburg University), the first panellist, took the floor to present the federated analysis approach of the FeatureCloud project. In this project, instead of bringing the data to the cloud, the model learner algorithm is brought to the individual sites. The learning results are aggregated in the central model without the model learner having to know the individual data. He presented some federated learning apps for specific use cases from the FeatureCloud app store¹².

The second panellist, Prof. Oya Beyan (University of Cologne), presented the FAIR platform federated analytics that her team is building. The project is part of the Medical Informatics Initiative Germany¹³ and NFDI4Health¹⁴, and works with different use cases, like rare diseases and radiomics – a sophisticated form of medical imaging. In a project that is building synergy between GAIA-X¹⁵ and NFDI, the aim is to enable data reuse between industry and research data through federated analytics.

¹¹ See <https://www.i-hd.eu/health-standards/>

¹² See <https://featurecloud.ai/>

¹³ See <https://www.medizininformatik-initiative.de/en/start>

¹⁴ See <https://www.nfdi4health.de/en/>

¹⁵ See <https://www.gaia-x.eu>

Prof. André Dekker (Maastricht University) presented the “Personal Health Train” project¹⁶, which illustrates a metaphor in which train stations are data, trains are research questions, and the track is the governance model. One example on which the project team works is an AI model that predicts which brain cancer patients would benefit from proton therapy – a new form of radiotherapy – rather than classical radiation. The Personal Health Train addresses each proton therapy unit (i.e., the data), and uses the data acquired to improve the AI used.

The following panel discussion focussed first on the limitations and advantages of the federated approach. Professor Dekker and Beyan highlighted diverse levels of data types and qualities (e.g., due to different types of medical equipment), which might be an advantage and make federated learning outperform centralised learning. Prof. Baumbach emphasised that federated analysis does not always mean privacy by design: however, it is nevertheless the most promising way forward in making AI use possible in medicine without jeopardising people’s privacy.

Going beyond hospitals, other sources of data can also benefit from the federated approach. Prof. Dekker pointed to various other forms of socioeconomic data, whereas Prof. Beyan mentioned the use case of water resources.

Other factors that still limit the expansion of the federated approach include, as mentioned by Prof. Beyan, the lack of legal requirements and lack of clarity regarding the sharing of algorithms, not data. Prof Dekker specified that the 2016 GDPR and other legal regulations are (still) not prepared for the federated approach. Another threshold to be crossed is the interoperability challenge’, which is, however, not unique to federated approaches. A FAIR data economy is currently missing, since hospitals bear the risks while the patients benefit. Prof. Baumbach called for more monetary incentives to remove the legal burdens on clinicians to companies that certify apps.

Returning to the overall title of this fourth session of the day, Dr. Zobell summarised that the future is federated, but it still needs strong support from policy makers.

DigitalHealthEurope coordinator Dr. Veli Stroetmann closed Day 2 of the Summit.

¹⁶ See <https://pht.health-ri.nl>

3 Day 3: Scaling up innovation through health data

3.1 Update on the European Health Data Space

Day 3 ¹⁷ moderator, Dr. Petra Wilson, opened the last day of the Summit, by introducing the keynote speech given by Ms Ioana-Maria Gligor, Head of Unit at DG SANTE, who provided an update on the status of the European Health Data Space (EHDS).

Ms Gligor started her presentation by explaining the objectives, the scope, and expected impact of the EHDS. She shed light on the challenges related to the provision of health data: limited control and access to patients, uneven national legislative frameworks, low reuse of health data, and limited provision of data for the training of AI. She then described what European Commission has already done to tackle these challenges, most particularly, the 2019 publication of the Commission Recommendation on the Electronic Health Record Exchange Format. Furthermore, Ms Gligor mentioned that the European Union has set up the MyHealth@EU infrastructure, which provides patients with information on vaccination(s) as well as their personal health summary.

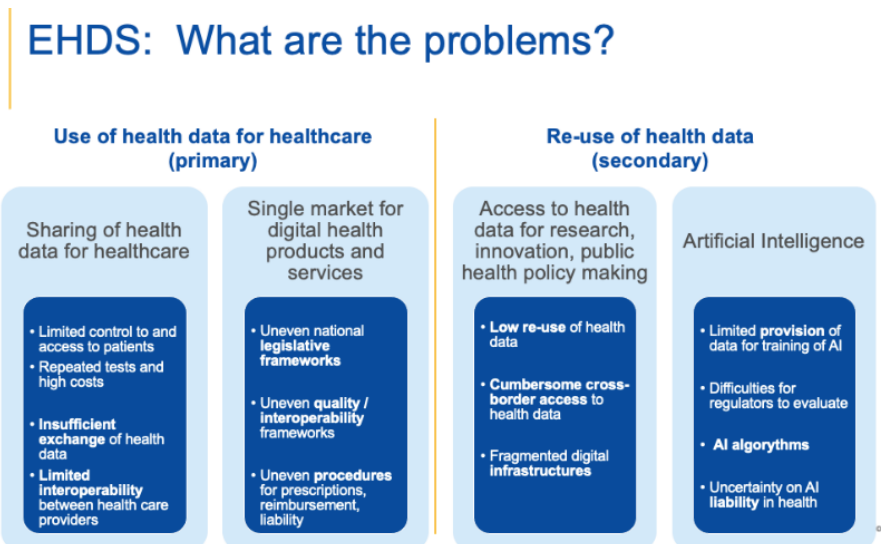


Figure 6 Ioana-Maria Gligor (DG SANTE): The four challenges posed to the European Health Data Space

One of the priorities that Ms Gligor underlined is the need to work on the actual infrastructure that could support and allow the reuse of data while still ensuring high security, preserving trust, and promoting both public interest and innovation. For this reason, in 2022, the European Commission will launch a pilot project aimed at demonstrating what this infrastructure could look like.

Ms Gligor also covered numerous funding opportunities, at both national and EU levels. Finally, she emphasised the role of national institutions and stakeholders in providing access to the EHDS and promoting data altruism among citizens. This last observation provided a logical link to the topics covered in the second session of Day 3.

¹⁷ The full recording of Day 3 of the Digital Health Europe Summit can be found here: <https://youtu.be/h9gaf9xlvTg>

3.2 Better data to promote research, disease prevention and personalised health and care

Following the introductory update on the progress being made with the EHDS, a panel discussion was launched on the improvement of data in Europe for promoting research, preventing disease, and personalising health and care.

Dr. Dipak Kalra (European Institute for Innovation through Health Data / European Institute for Health Records) welcomed five panellists – Birgit Bauer (Digital Health & Social Media Entrepreneur); Dr. Emmanuel Bacry (French Health Data Hub); Tomaz Gornik (Better); Jesper Kjær (Danish Medicines Agency); and Prof. Dr. Denis Horgan (European Alliance for Personalised Medicine).

Dr. Kalra asked several questions to the five panellists. First, he encouraged them to present their views on the most urgent challenges in enabling better data access.

First, Birgit Bauer shared her perspective as a patient living with multiple sclerosis, by emphasising the importance of cross-border health data sharing to create sufficient data to enable large-scale learning throughout Europe and beyond. Second, she stated that patients still know too little about health data and its potential.

Dr. Emmanuel Bacry underlined a second set of challenges. It is essential to provide clear rules and guidelines for governance – firstly for national governments and then at European level. He had at least three insights. His vision would be of a ‘uniformity’ of access to data that would function in all countries. There must also be more precise rules on moving data. A third ‘pressure point’ is the ‘valorisation’ of scientific and financial data.

Tomaz Gornik added, as challenges, that it is vital to promote a ‘data first approach’, meaning that institutions should consider their data model first before they use public procurement to choose a specific data-related application: he highlighted the Catalan health system as a good example in this regard. Procurers should state more boldly that they want to have an interoperable approach because, otherwise if the market left on its own it will instead produce siloed solutions.

Jesper Kjær emphasised the role of health data literacy and that the stakeholders need to provide a solid foundation in educating citizens about the value of their data: one powerful use case is the COVID-19 digital vaccination certificate. It is important to continue the momentum of trust in health data that has been created during the course of the 2019-2021 pandemic.

Prof. Dr. Denis Horgan also mentioned the issue of trust in relation to data: its value, use, and quality. This comment can be linked to the three issues of challenges related to government frameworks, legislative frameworks, and interoperability. A first starting point needs to be a regulation that will enable data to contribute value to society.

Tomaz Gornik mentioned the lack of IT-skilled healthcare professionals as a challenging barrier to exploring the full potential of health data. He mentioned, however, some good practice programmes in the area.

Dr. Kalra then posed the question of whether the status quo already enables the creation of high-quality data.

Jesper Kjær stressed that the European countries are moving at different speeds towards this goal: a complete acknowledgement of the importance of digital technologies in health is still not present on a large scale. Prof. Dr. Horgan spoke about the need for more public-private collaboration to drive forward good models for using data in a valuable way. Dr. Bacry stressed

that, nevertheless, the French Health Data Hub¹⁸ is already close to the status of provision of high-quality data and that other countries are getting closer. Birgit Bauer elaborated on the role of the patient as a data creator: indeed, many patients would eagerly share their data, but they should be involved in such initiatives as people as it is they who will be the beneficiaries of the solutions created with their data.

Regarding the central question posed by Dr. Kalra of how to enhance trust in data sharing from society at large, Birgit Bauer considered a key point to lie in making people understand the value of data and how it is collected: this message should be conveyed through a prominent public relations strategy. Dr. Bacry warned that the goal should be education rather than convincing people to enable citizens to make informed decisions. Tomaz Gornik corroborated this point: he argued that special attention should be paid to transparency when communicating on health data sharing. Jesper Kjær emphasised the importance of co-creating and co-piloting concepts with patients and citizens in order to facilitate trust: he highlighted precision medicine as an example of where this approach has been successfully employed. Prof. Dr. Horgan put forward a complementary approach: he proposed a top-down institutional framework that would guarantee to patients and citizens that their data will be used in an appropriate way – this could take place in addition to educational approaches that would gain the public's trust.

Dr. Kalra posed the question of how transparency can be fostered. Dr. Bacry shared with the audience the approach of the French Health Data Hub, which presents a database that can be used to check what purpose any data has served. Jesper Kjær stated that one goal of transparency efforts could be to notify patients and citizens what 'good' their data did. Prof. Dr. Horgan stated that another element – cost – should also be weighted in the greater discussion: whereas transparency is an important goal, it can also be costly. Moreover, he stated that a framework needs to be established on how to create transparency: the framework should reflect how the data is used (e.g., if there has been any data misuse) rather than the data itself. Tomaz Gornik highlighted the challenge of feeding back information on data to various audiences, once the data has been used for research purposes. Birgit Bauer further explored this idea: she stated that patients could benefit from short, understandable, informative, and patient-friendly information regarding the research results that emerge from the use of their data. Such feedback could foster a sense of appreciation on the part of patients who share their data. Ms Bauer further argued that citizens might differentiate between use of data by different actors: whereas patients might be willing to share data with public institutions, e.g., universities, they could be more hesitant about sharing data with commercial actors.

When asked, as a last question, to consider whether health data should be regarded a public good, all the five panellists agreed that this should be the case, at least to some extent. Prof. Dr. Horgan argued that a proper institutional framework is necessary in this context. Whereas Tomaz Gornik highlighted that anonymisation of data is a prerequisite for data being used as a public good, Dr. Bacry disagreed, by stating that such an approach would be unrealistic: he further argued that not all data could be considered as a public good. This attitude was echoed by Birgit Bauer, who indicated that it would make sense to differentiate between different categories of data, some of which could be considered as a public good. As elaborated by Jesper Kjær, this approach to the consideration of different types or categories of data, and their roles (or not) as public goods, is one that is currently followed in some Nordic countries.

This comprehensive and lengthy discussion session among a variety of stakeholders provided some useful insights into four topics surrounding data sharing: its challenges, the status quo, the enhancement of trust and data transparency, and the consideration of different kinds of data as a public good.

¹⁸ See <https://www.health-data-hub.fr>

3.3 Ensuring innovation through health data – Where to next?

Dr. Zoi Kolitsi (DigitalHealthEurope) opened this third session of Day 3, scoping it as providing an outlook into health data innovation in the near future. Again, five panellists offered their views. On this occasion, the focus was on what will come next.

The session started with an intervention by Prof. Dr. Paul Timmers (University of Oxford/ European University Cyprus), who presented perspectives of health data innovation. He elaborated on the importance of health data sovereignty and resilience when designing technology and laws. According to him, health innovation through data is an important role for the European Health Data Space. Furthermore, he went further by exploring the potential of AI, when combined with digital twins, to be used to simulate and anticipate the effects of treatment for better diagnosis and predictive treatment. He called for a united approach, throughout Europe, in creating innovation through health data.

Nick Schneider (German Federal Ministry of Health) continued the discussion on the importance of collaboration between European countries and the inclusion of patients and citizens. He emphasised that even big European Member States are too small to thrive in direct competition with other global regions. In this regard, public health data sovereignty is as important as the personal right to access one's own data. A transparent and lawful health data infrastructure is essential to build trust in data sharing on the part of citizens in order to encourage them to share their data. Regulation urgently needs to keep pace with innovation: this is a significant challenge for several future forms of legislation, especially for the Data Governance Act, the Artificial Intelligence Act, and the upcoming European Health Data Space legislation. As an example of such cross-border research and innovation collaboration, Mr. Schneider mentioned the European Reference Networks¹⁹.

The third panellist was Steven Vermeulen (EBRAINS), who highlighted the need for the activation of data, and approved computing resources and standardisation approaches in the context of brain data research. Research mostly makes secondary use of health data, however, there are increasing cases where research reaches over to primary use. He focussed on three main points in this regard. Firstly, for instance, brain and genomic research data cannot be fully anonymised without losing their value for research. Secondly, brain data needs big and expensive equipment to be activated and analysed, which makes its federation more urgent: research needs to "*get closer to the patient*". Thirdly, making a plea for more brain-based data, he stipulated that, outside of genomics, the standardisation of health data is still insufficient.

Dr. Ilias Iakovidis, the fourth panellist, brought up another environmental perspective. He talked about the opportunities that can arise when the health community intersects with the environment sector. Several learnings from digital health can be transferred to other fields. One such possibility for transfer is the concept of digital twins of patients, an idea which can also be applied to a digital twin of the environment. Vice versa, digital health could benefit from a possible green data space since many behavioural factors that influence well-being are related to the environment (including aspects like quality of air, food, and water). In this regard, there is a need for one single data space, not data spaces that are separated into silos. It is important to recall that the healthcare sector footprint is immense, which adds to an appeal for the greening of this sector. Interoperability, cloudification and virtualisation are, all three, measures to take towards this goal.

Dr. Tapani Piha (SITRA) stressed the need for the Member States and the EU to agree on common actions. TEHDAS²⁰, the Joint Action on the European Health Data Space, is one tool

¹⁹ See <https://webgate.ec.europa.eu/ern/>

²⁰ See <https://tehdas.eu>

for Europeans to achieve common agreed actions, apart from agendas designed and put into place by dedicated EU presidencies. Another crucial aspect of what is next is trust. It has become evident that “*citizens w]ho trust less*” are less likely to get vaccinated in times of major pandemics such as COVID-19. Digital health literacy, as an approach, needs to be tackled in order to enhance people’s trust. Similarly, Dr. Piha also argued that behavioural change is crucial in building more trust in digital health.

Following these several interventions, moderator, Dr. Kolitsi, brought into the discussion two future looking highlights of the previous day: firstly, we stand to see more patient activism for creating conditions for health data sharing; secondly, the future of data sharing may look federated, but there are outstanding barriers such as the data quality issue and the who pays for it and eventually who is liable for data quality which would require legal tools and governance for the data economy and a market approach in building trust.

As a last question, Dr. Kolitsi asked the panellists to comment briefly on what might be future ambitions for Europe. Prof. Timmers mentioned flexible approaches in legislation. Nick Schneider emphasised the further development of federated approaches. These two quick statements provided an interesting bridge into the last session of Day 3 and the Summit as a whole.

3.4 What’s next for Digital Health in Europe?

During the last session of the Summit, Dr. Petra Wilson interviewed Marco Marsella, Head of Unit at the European Commission’s DG CNECT. The discussion focussed on Europe’s ambitions for what is likely to happen next for digital health.

On the question of which tools are needed to establish the predictive, preventive, personalised, and participatory (P4) healthcare alluded to by Esko Aho on the first day of the Summit, Marco Marsella mentioned an element that is key to delivering the “4 Ps”: this is trust from the citizens, Member States, and industry. Another key element is interoperability, and more assessment of what can be done with specific technologies. Research needs to be associated with those organisations that can actually build products or services from the research. Regulation should accompany the progress made with new techniques, such as federated learning. The field needs the engagement of the Member States, stakeholders, and organisations and people keeping the data: the engagement should move in the same direction and have a common goal. Mr. Marsella also elaborated on the concept of bringing siloed data spaces closer to each other.



Figure 7 Mr. Marco Marsella (DG CNECT): Interview with Dr. Petra Wilson

Dr. Wilson asked Mr. Marsella to reflect on the lessons learnt during COVID-19. He emphasised that the pandemic has furthered the collaboration among European Commission Directorate-Generals, like CNECT, SANTE and JUST. It has shown that in times of need, intense *ad hoc* collaboration with the Member States on the part of the European Commission is possible: this collaboration became especially clear when creating the COVID-19 digital vaccination certificates. To add to his comment, Ioana-Maria Gligor mentioned that the pandemic showed that it is possible altogether to build a more standardised and unified approach. She finished by emphasising the power of the Member States in coming together while having strong standardised rules.

DigitalHealthEurope coordinator, Dr. Veli Stroetmann, closed Day 3 and the Digital Health Europe Summit as a whole, by mentioning some of the insights drawn from the three days. She thanked all 400+ participants in the Summit for their active participation and engagement.