# **EHTEL Symposium - Monday 4 December 2018 and Tuesday 5 December 2018**

## **Welcome**

**The first day began with a warm welcome.**

Various welcomes to the Symposium were offered on the part of the various hosting and sponsoring organisations. Thanks were offered in advance to the **three sponsoring organisations**, **IBM, SITRA**, and **UPMC** for their support in organising the event. The event’s profile had especially drawn attendees from all over the European Union, including the **Czech Republic**, and as far afield as **Russia, Tunisia, and Turkey**.

The European Economic and Social Committee (EESC) especially acknowledged its interest in digital matters. As a result, it has produced reports on “**digital transformation**”[[1]](#footnote-1); **artificial intelligence**[[2]](#footnote-2); and the bringing together of information and communication technologies (ICT) with **social security**.[[3]](#footnote-3)

EHTEL General Secretary, **Marc LANGE** introduced the event on behalf of **EHTEL President, Simona ABBRO**. Users could especially gain benefit from the event, with its focus on “digital health” and “digitisation”. It is crucial that, whatever its infrastructure, digital health should be built on user needs. As a **multi-stakeholder organisation** of users, managers, health authorities, therefore, it was EHTEL’s hope that all Symposium attendees would find content to meet their own needs – from **policy to implementation**, and **state-of-the-art to future technology orientations**. Mr LANGE’s main message was that,

“*Today, tomorrow and on the third day of the Symposium, we hope that you will build initiatives and co-create them with your colleagues, so that you share and learn about digital health-related ideas. As a result, you’ll be able to find new organisational partners and concrete solutions that will help you to do your own work*.”

## **Setting the Scene**

**Three invited speakers, speaking on behalf of different sets of stakeholders – patients, health and care providers, and civic society – introduced the event. Each offered a stakeholder voice with regard to “user-driven digitisation”. A strong message from each speaker related to the need to listen to people (i.e., end-users) and to pay careful attention to their needs and desires in relation to digitisation.**

**Setting the Scene: “User-driven Digitisation” – Viewpoint of Patients/Citizens**
Christoph Thalheim, European Multiple Sclerosis Platform and European Patients’ Forum, Brussels

**Christoph THALHEIM** spoke “with a double hat”: he talked on behalf of the **European Patients’ Forum (EPF)**[[4]](#footnote-4) (which represents 74 different European patient groups) and **European Multiple Sclerosis Platform** (which focuses on the 700,000 people with multiple sclerosis (MS), and which is “*fighting for a world without MS*”). Both believe that ”*it is crucially important to have* *a strong patients’ voice to drive better health in Europe*”.

For example, the EPF has produced several patient-related position papers[[5]](#footnote-5): recent work responds to the launch of the (May 2018) General Data Protection Regulation[[6]](#footnote-6). The Forum set up on an internal **“digital health” working group** in April 2018[[7]](#footnote-7).

Following the 25 April 2018 publication by the European Commission of a Communication on the “digital transformation of health and care”[[8]](#footnote-8), Mr THALHEIM stated that:

*“There is still room for very important improvements in digital health. Ultimately, a more realistic picture of what works in digital health is needed.”*

To illustrate his point about the need for further improvements, Mr THALHEIM used examples from the field of **various medical conditions**. He offered three examples: **minimum data sets for data pooling** in real-world situations; projects supported by the Innovative Medicines Initiative 2 (IMI2) joint undertaking e.g., **Big Data for Better Outcomes** (BD4BO)[[9]](#footnote-9); and efforts to be made to **structure the professional education of nurses**.

Mr. THALHEIM particularly encouraged Symposium attendees to comment on the **European Medicines Agency’s discussion paper** (circulated in November 2018) on **patient registries**[[10]](#footnote-10) and their use in monitoring rare conditions.

As an overview, Mr THALHEIM is of the opinion that:

“[Patients are] *open for anything* *digital that helps society to function in an accessible, affordable, and sustainable manner*. [However, whatever is done] *needs to be paid more than just lip service. It needs to bring in patients in terms of real participation*.”

**Setting the Scene: “User-driven Digitisation” – Health Care Planners and Authorities**
Don McIntyre, Digital Health and Care Institute (DHI), Scotland, United Kingdom

**Don McINTYRE, a member of Scotland’s Digital Health and Care Institute (DHI) drew on the important theme of the transformative power of design innovation.**

**User-driven digitisation is a major topic in Scotland**. **Don McINTYRE** wanted to show how people in Scotland go about doing user-driven digitisation, especially since “*Scotland has now got more of a voice in digital health, and wants to make that voice heard*”. These opinions are heard through the work of the DHI, which was established in 2014 as a bridge between “*research, civic responsibility, and business*”. The Institute works together with Scotland’s eight innovation centres.

Scotland’s digital strategy is all about the **effective use of data**, standards, broadband; incorporating **digital participation**; and being a world leader in **cyber resilience**. The focus on innovation takes three forms in relation to **services, business**, and **technology**.

Scotland’s **National Health Service (NHS24)** is a devolved service. The service believes that, if an innovation can be rolled out, advantage can be taken of it. The DHI, which works closely with NHS24, “*provides a safe space for innovation*”, and so it uses a co-design process.

The DHI believes in **treating the people** with which it works as **individuals.** Describing the co-design process, Mr. McIntyre stated:

“*We started from scratch! We built on other research. We start to prototype really early. The earlier you actualise, the better. Iterate, and then rule things* out.”

As a result, the Institute has developed a **simulation and demonstration environment**[[11]](#footnote-11), which has now been up-and-running for a couple of months in 2018. In it, NHS data can be combined with non-statutory data in the environment. The environment needs people’s input to fine-tune the results, and the resulting output can be explored.

Concentrating on the future of health, the Institute is working on **a number of key projects** that focus on topics as wide as atrial fibrillation, diabetes, “modern outpatients”, and fifth generation (5G) mobile network systems (for people who have asthma).

Mr. McINTYRE cited a recent **co-design initiative**, done with the **Scottish ambulance service**. The experimentation was about changing people’s attitudes and behaviours about the reasons why one would go to / use a hospital accident and emerging unit. In this, the end-users and employees showed impressive creativity – they walked through the outpatient service step-by-step, and **proposed a new triage system**. As Mr. McIntyre announced:

“*We all have an innate capability to be creative. … In the Institute, we have developed a playful basis to co-design, using various artefacts. If you do co-design in a playful way, people are far more creative*.”

In terms of the process, “*Let’s understand what people want*. *Just because you’ve got the technology, however, there’s no need to use it.”*

Scotland is now well on its way in **prototyping user-driven digitisation**. As Mr. McINTYRE concluded:

*“People really don’t mind sharing data, especially if they have played a role in capturing it*.”

**EESC Opinion INT/852 Digital transformation/health and care on COM(2018)233**
Diego Dutto INT Section, Rapporteur on Opinion INT/852, EESC, Brussels

**On behalf of the European Economic and Social Committee (EESC), Diego DUTTO declared that, over the past 20 years, the field of digital health has seen a real revolution in the way in which people experiment with handling their health and care**.

Given the social/societal orientation of the EESC, however, **Diego DUTTO** remarked that technology does not always enable people to understand what is fundamentally a **problem of justice**. Overall, Europe needs to **re-align the rights of people** with the new possibilities offered by technologies.

Mr. DUTTO was the rapporteur for the EESC’s October 2018 Opinion on the European Commission’s Communication on the **digital transformation of health and care**. To respond to the Communication, the EESC formed a multi-stakeholder team of colleagues who bore in mind **the needs of real people**. The team members examined two sets of opportunities: those made possible by various technologies (e.g., robotics and wearables) in offering **higher quality health-related services** to people; and the need for **new forms of digital and health knowledge** on the part of people themselves as well as health and care operators/providers.

Mr. DUTTO’s personal focus was on **data and its use**. To end, he had this to say:

“*Everybody is producing data that somebody else uses, often making economic profit out of it. Very often, the people who themselves are the subject of the data do not know that it is produced, bought, sold on with an economic value. The EESC believes, ultimately, that it is crucial that people (i.e., citizens, patients) have a copy of their own data, and could potentially use that data for scientific but also for commercial purposes*.”

**A short discussion**

A short discussion followed the three presentations. On the one side, an audience member pointed to the usefulness of the **American Blue Button 2**[[12]](#footnote-12) initiative and **MyHealthEData** (again, in the United States of America)[[13]](#footnote-13), through which patients allow the **secondary use of their data**. On the other side, there was a discussion about the way in which – if properly applied – technologies could enable **a more efficient and quality use of health and care professionals’ time with patients**. This was contrasted with situations in which health and care professionals may still have less time available to themselves to devote time to their patients.

## **From Lightweight Wellness Apps to Managing Serious Conditions**

**This second session permitted attendees to learn about health-related apps. The apps covered the state-of the-art in wellness and patient-centric apps; health games for prevention; and support for people with chronic health conditions with – as an example – children with the specific (most common rare) disease of cystic fibrosis. The session featured the results of a regularly organised patient survey; outcomes of the Games for Health Europe conference series; the use of apps by a specific, Israeli-based, health provider; and the outcomes of a four-year European project. Each presentation benefitted from a short question-and-answer period. The session ended with a brief discussion that originated from commentary provided by a representative of the European Consumer Organisation. Current dangers are seen as being the insufficient quality of apps brought onto the market, and the fragmented evaluation methods e.g., on the accuracy of measurements or medical dosages.** **Here the focus was on certification for apps and useful certification schemes.**

**State of the Art *for Wellness and Patient Centric Apps***Dee O’Sullivan, Director, myhealthapps.net at PatientView, United Kingdom

**Patient View is a UK-based research and publishing company[[14]](#footnote-14); it has been conducting regular patient-related surveys and collating patient-reviewed apps for the past 6-7 years. Patients, it says, are looking for data quality and security, when they use a health-related app.**

Patients have been **researching their own conditions** and collecting data for some 20 years.

**Mobile apps** have now come on the scene. There are lots of challenges, however, about app sustainability. The reality is that lots of apps do not last for very long: patients may easily lose access to the app and any data it provided.

Designed to be a neutral platform, Patient View launched its **website service** five years ago. Working with larger and larger patient groups, the site aims to answer questions about whether people can trust apps and if the apps are good. On the site, there is information about **500 apps** that includes background on who the developers are, and how they were funded.

As a snapshot, **two-thirds of the apps** available are still **health and wellness-related**; 17% are about some kind of disability, and 24% are classified as medical.

One example is the **“MySugr” app**, which originated in Austria and is still reimbursed through the Austrian Health System. It gained huge support from the patient perspective and today has more than **one million users** around the globe. In 2017, it was bought by the pharma company, **Roche**, and is offered as part of its diabetic care service[[15]](#footnote-15).

Overall, surveys have shown that “*patients aspire to getting more than information. They want to understand their medical condition(s), and do their care planning*.” What has prevented them? “*Too many apps*.”

In 2016, Patient View undertook **a survey with the consultancy company, Deloitte**. The survey results showed that only 30 per cent of patients would have been willing to share their data with the pharmaceutical industry. In contrast, patients trust was high in view of **sharing data with health care professionals**.

Ending the presentation, and reflecting on the combined use of health data and artificial intelligence, **Dee O’SULLIVAN** quoted the UK’s Information Commissioner, Elizabeth DENHAM (reflecting the words of Professor Joseph WEIZENBAUM): “*It’s not just because we can do it, that we should*.”

**Question-and-answer session**

Attendees were curious about how the PatientView **website** is supported and funded – this occurs as an offshoot from the research PatientView conducts. They were interested in what the association has done on **certification** – it has explored the notion of kitemarks and has also noted the work of the App Quality Alliance[[16]](#footnote-16). A future interest of PatientView is in **mHealth apps to support mental health**.

**State of the Art *for Health Games and their Impact for Health, Prevention and Rehabilitation***
René Luigies, Games for Health Europe, The Netherlands

**“S*erious games are at the start of a new era.*” According to this speaker, serious games in the health field, can help save costs, make people happier, and make the work of physicians more pleasant.**

Games for Health Europe is a not-for-profit association, founded in 2010, that focuses on **the development of impactful, serious games**. **René LUIGIES** introduced the association’s work by saying:

“*We see the world as a poor designed game. We see health as a poor designed game. It is only in a well-designed game that you can be really creative: learning by doing or playing*.”

Among the **health-related games** that Mr LUIGIES described were: **Medi&Seintje** developed by Games for Health Europe in conjunction with AbbVie and Sint Maartens Kliniek, which is intended to facilitate medical and therapeutic compliance via game-playing and puzzle-solving; also, mentioned were games about how easily **virus infections** spread in public settings, how to help patients combat **anxiety** ahead of medical appointments, and how to assist **women with endometriosis** obtain useful information about the condition.

Non-medically related games mentioned were: **FoldIt**, a protein-folding scientific game aimed at involving gamers in helping science.

More recently, the association has developed **a Game Solutions Lab** that is an in-house games and solutions laboratory. Here, the association’s founders have dropped the word ‘health’ and instead concentrate on **games for government** and **games for large companies**.

The next conference to be organised by the association is **“Playful Intelligence”**, which will take place on 7 and 8 October 2019, in Eindhoven in the Netherlands[[17]](#footnote-17).

**Question-and-answer session**

Attendees were especially interested in older people’s willingness to play digital games whether on digital television or online, especially if they have played non-digital games (e.g., quizzes, Sudoko, cards) during long periods of their lives.

**The Case for Patient Apps to Improve Prevention and Management of Chronic Conditions ... *in Integrated, Hospital-based, Health Networks in Israel***Rachelle Kaye, ConneCare, Assuta Medical Centers[[18]](#footnote-18) and Maccabi Healthcare, Israel

**This presentation involved an introduction to apps that can support integration and empowerment of people with complex needs, including work developed by Israel-based Assuta Medical Centers and the European project, Connecare[[19]](#footnote-19). The work is being undertaken with a hospital in Ashdod, Israel’s sixth largest city with a large immigrant population.**

**Rachelle KAYE** started her presentation by focusing on **two use cases**, one of a man who speaks only Russian and who takes 12 forms of medication; the other of a patient who had a stroke three years ago. The app developed is described as a “pre-habilitation” programme for complex patients aged 55+.

With regard to **lessons learned about the use of apps**, Ms KAYE is of the following opinions. On preparation:

“*The work needed is not trivial; it is a big job; it requires a lot of time and effort; it can take up to 20 minutes’ explanation; people can overlook jobs as simple as forgetting to charge their Fitbit.”*

On the skills needed to work with, or use, apps:

*“We are, of course, a sort of the transition generation. The older generation today is not where our children or grandchildren will be in the future*.”

Using such apps contributes to the inclusion of integrated care in health and care. **Participation, collaboration, and co-design** are very much needed:

“*It is basically the getting the people to work together.* *The patients and their families are very much part of the team*,” said Ms KAYE. “[The game] *is a useful tool and can be part of the treatment’s success. This too can be an enabler and can add value to the whole process. But, true integration is really about how people work together and cooperate.”*

**Question-and-answer session**

Attendees were particularly interested in the **differences to be expected** among diverse users of the app; the kinds of **health and care professionals** involved in a team approach to developing the app; the **liability** issues arising; and the extent to which clinicians/doctors are willing to be in close contact with their patients using apps[[20]](#footnote-20); the extent to which **medical or health “case managers”** are involved in the whole process, and whether patients are aware of **back-up** provided by the case manager.

Ms KAYE commented that **clinicians are keen users of some apps**:

“*Clinicians are enthusiastically using What’s App. In Israel, doctors and their patients are communicating using What’s App, e.g., sending photos of particular conditions. However, the app is not connected at all or integrated into to any medical record, especially not the electronic health record. This is a real challenge*.”

**The Case for Patient-Apps to Improve Prevention and Management of Chronic Conditions *... for Cystic Fibrosis Patients in Europe through App-based Diet Advice***
Hilde De Keyser, MyCyFAPP & Cystic Fibrosis Europe Association, Belgium

**The final presentation in this session concentrated on an app designed in a recent research project to serve patients with a specific health condition – cystic fibrosis.**

Cystic fibrosis is described, said **Hilde DE KEYSER**, as the **most common ‘rare’ disease in Europe**: it is a genetically inherited disease with an impact on the lungs, pancreas, and guts. People with cystic fibrosis often take medicines to reduce the levels of mucus in the body.

MyCyFAPP[[21]](#footnote-21)[[22]](#footnote-22) is an H2020 research project that focuses on cystic fibrosis. It comes to a close at the end of December 2018[[23]](#footnote-23). The initiative has been cited as a ‘star’ European project. The project brought together different elements – basic science, clinical research, patients, and mHealth – with the intention “*to develop an app for, by, and with the patient*” specific to cystic fibrosis. It coordinated a number of issues, such as the self-management of the condition, useful documentation, professional advice, educational resources, and a game oriented at children aged under 12 who have cystic fibrosis., and ended with a successful six-month clinical evaluation (trial) of the app.

**Commentary: Consumers’ and Patients’ Voices on the Impact of Health and Fitness Apps**
Jelena Malinina, Digital Health Policy Officer, BEUC, Brussels

**BEUC is an independent umbrella association, based in Brussels, that represents national consumer organisations throughout the European Union and wider. Among the consumers represented are those who use mHealth apps on a daily basis – purely as an example, that includes the association’s own digital health policy officer**.

In October 2018, BEUC published **a position paper on digital health**[[24]](#footnote-24). It cites a number of **principles** and nine r**ecommendations**, including in relation to the European General Data Protection Regulation[[25]](#footnote-25). It expresses opinions on safety and security. For BEUC, health data deserves the strongest privacy and security protection and should be at the basis of **some form of mandated statement**.

In terms of **safety**, for example, **Jelina MALININA** expressed the view:

“*We would like the apps to be safe. Some of these apps are created with a lot of heart and soul put into them … and are really useful. But control of what goes on the market must be checked. For example, there should be tools for consumers to check out an app!*”

Besides data protection, other forms of European (international and national) legal protection are also important. **Liability and consumers’ right to redress** deserve particular attention.

Ms MALININA describes how **complex** are the **terms and conditions** in the (organisational / commercial) policies that govern many apps as well as the privacy-related policies. She used a personal example of a health-related app that she had herself selected to use. Having downloaded the app, it took her more than an hour to understand the policy, and then she could not simply delete the app after a month of usage: “*I struggled for several days in order to delete it*.”

In terms of **mHealth for all**, the speaker offered **two conclusions** at two very different levels: first, in terms of **infrastructure**, people need access to affordable, high-quality, high-speed Internet; second, in terms of **applications** themselves:

“*Different users should have different apps! You shouldn’t need to have a degree or be a doctor in order simply to use a mobile (health) app!*”

**A short discussion**

The final discussion of the session focused on **certification for apps**. There are indeed some examples of useful **certification schemes**: for example, **Belgium** has launched a platform on which manufacturers can register apps. Clearly, apps are available a wide range of subject matter, ranging from ones that are wellness-focused to medically-oriented. Overall, **committees** working on this issue have experienced **huge difficulties in** **finding common ground** among the various stakeholders involved. Current dangers perceived by panellists include the **lack of quality of apps** brought onto the market, and the **fragmentation of evaluation methods** i.e., how to evaluate the **accuracy of either measurements or medical dosages**.

## **Creating Value from Well-Being Data: Enabling Care Innovations**

**This session explored the huge potential for secondary use of well-being data and health care data for research, development, innovations and management, with the aim of creating better health perspectives for patients and societies. Mining such data provides new opportunities on the health policy level as well as care options for individual patients. The session was chaired by Dr** **Hannu HÄMÄLÄINEN, Senior Adviser at Sitra, Finland, who introduced the topic of data as an enabler for care innovations. Sitra was the sponsor of the entire session.**

An overview was offered of **eleven forerunner countries** in Europe by **Saara MALKAMÄKI** of Sitra. This group of countries has been working together for more than two years in order to survey how they are each handling **secondary data use**. Starting with **Finland**’s activities in this field, there is a new act on secondary use of data which is presently going through the legislative process in Finland. The country’s innovation legislation is defined as being “*General Data Protection Regulation-proof*”.

Here are some snapshots of the approaches used in various countries, including some in Europe – mostly in the Nordic or Scandinavian countries – and some further afield. **Estonia** is very keen on eHealth. **Ireland** was judged as being in first place in the European Union Open Data Assessment scheme[[26]](#footnote-26). **The Netherlands** concentrates on what it calls FAIR[[27]](#footnote-27) data principles, and provides ethical and legal advice including “FAIRification” training[[28]](#footnote-28). **Norway** is involved in what it calls “FAIR mapping”. **Sweden** has created a “register utiliser tool”[[29]](#footnote-29). **Switzerland** has an ethical framework for responsible data processing. In the **United Kingdom**, the work of the Farr Institute was highlighted on encouraging researchers to handle patient data safely and securely[[30]](#footnote-30). Last but not least, **Australia** permits secondary use of the data in the Australian My Health Record[[31]](#footnote-31).

Ms MALKAMÄKI was extremely enthusiastic about the possibilities to be offered by secondary use of data e.g., in the health and care field. She encourages the sharing of data across national borders, based on the principle of **interoperability**. The researchers involved can learn a great deal from each other. Currently, Sitra has identified **over 20 collaboration opportunities**! There are two active subgroups focusing on **“synthetic data”**[[32]](#footnote-32) and **metadata[[33]](#footnote-33)**. Of course, in many countries the challenge remains of how to **build public trust** about this use of data, and having got the trust, maintaining it.

What are the **lessons learned from Finland**? Sitra is Finland’s innovation fund[[34]](#footnote-34), which is independent from any government in power in the country. Sitra has been working on **research data** for some 50 years. Yet where will data come from in the future? Finland has access to lots of **health registers**. As researchers, this data can be used and re-used. Real-world data is relevant for developments in the world of **pharmaceuticals (‘pharma’)** and for **health care**. **Future opportunities** lie in such diverse fields as: health and data analytics; artificial intelligence; and personalised care, decision support, targeted care, eServices, eEvaluations. All of these areas can be connected to factors such as a person’s genomics, life history, nutrition, activity, living conditions, and environment.

Finland is extremely positive and optimistic about the secondary use of such data. As **Hannu HÄMÄLÄINEN** said about his country:

“*People want to have the results of this data in their lives. Finland possesses a ‘national treasure’ of people’s data: this health and social data is tomorrow’s raw material*.”

Another example was offered of a **Partnership operating in Denmark**. **Anne-Katrine NIELSEN** of the **Copenhagen Healthtech Cluster**, described “*the Nordics*” as possessing world-class data, and “*yet each country has specific ‘uniquenesses’*”.

In Denmark, there is a lot of willingness to store data and use data. Yet “*the organisation around our health data was outdated*.” Debate about health care data over the years has been based on emotions and very polarised. General practitioners have been very offended by some of the observations made. Health data leaks have taken place, e.g., in 2016, data was sent to the Chinese embassy by mistake[[35]](#footnote-35).

In response, in order to be more positive, the Copenhagen Healthtech Cluster, a public-private partnership, has worked since 2017 to promote the idea that health “***data saves lives***”[[36]](#footnote-36).

“*We felt no-one was doing anything. We always talked about the fear, BUT we should also talk about the opportunities. We work with private partners e.g., in the pharma industry. We have suggested developing: a national data map; a data entry-point; and data ‘sandboxes’.”*

Work of interest also being undertaken in Denmark includes the **National Experimental Therapy Partnership**[[37]](#footnote-37) and the **Danish National Life Science Supercomputing Center** – its Computerome[[38]](#footnote-38). Worth reading also is the Danish government’s health data strategy (2018-2022), which dates from January 2018[[39]](#footnote-39). All of this is extremely supportive of the field of **data analytics**.

Many of these topics can also be associated with work being undertaken in the second of the European Commission three priorities from its Communication on the digital transformation of health and care, relating especially to **better data to promote research, disease prevention, and personalised health and care**[[40]](#footnote-40).

As a third example, **Koos PECHT** and **Wietse RYPKEMA** of Intelligence to Integrity (I2I)[[41]](#footnote-41) described the work of “*an ecosystem in the Netherlands*”. Their firm works with health care providers and insurers in order to **eradicate inefficiencies in the health care system** and indicates where improvements can be made. The firm founded itself as a **trusted third party**, with a desire to offer a **win-win scenario**, benefitting both the public sector and the private sector. The partnership offers providers **a certificate** if they achieve certain healthcare outcomes and cost outcomes. Gradually, there has been a shift to **value-based outcomes** and away from pay for performance. Conflicting incentives have also been removed. Doctors can now get together and share (medical) learnings with each other. A specific example is, for example, how **hip replacements** are handled in the country.

**Question-and-answer session**

Symposium attendees were interested in various aspects of this session, in particular **precisely what and how data is shared with various (commercial) partners**, such as health insurance schemes and pharma companies. In response, speakers emphasised the **safety and security** of the data environments, the fact that they do not give data away but, at the same time, they stressed the fact that there will be certain **(budgetary) restrictions** on the kinds of work that the **purely public sector can do in the future**. Focusing on secondary data use, speakers offered the case of **hospital-related data and risk group handling** in relation to medical innovation and service innovation. To conclude, as Ms MALKAMÄKI identified, there are several aspects to the questions raised: these include how the **individuals** themselves view the use of their data in both **primary and secondary health care** use; **transparency** on the part of the **health and care providers**; and the fact that – ultimately – this can be a **big business area** in Europe as a whole.

**Closing Symposium Day 1 – Messages on Digital Health by EESC**Dimitris Dimitriadis, Vice-President INT Section, Rapporteur on HTA, EESC, Brussels

The first day of the Symposium was closed by one of the Vice-Presidents of the Single Market, Production and Consumption (INT) section of the EESC, **Dimitris DIMITRIADIS**, who thanked the speakers for their reminders of work in “**the real world**”. He alerted Symposium attendees to the current European legislative work being done on **health technology assessment**[[42]](#footnote-42). Mr Dimitriadis showed particular concern about how to assess and evaluate **artificial intelligence**, and emphasised the need to explain what it is about and what its consequences and effects can be especially for ordinary people. This provided a useful linkage to the content of the Symposium that was to take place on the following day.

## **Creating Value from Well-Being Data: Enabling Care Innovations**

**The European Policy Agenda for Digital Health and Care is about to move into the next decade, 2020-2030. This work will be supported by funding and mechanisms embedded in the 2021-2027 Multiannual Financial Framework. Four specific questions addressed during this plenary session that opened the second day of the Symposium included: What are the visions and envisaged benefits of the proposed new policy framework? How will it materialise for all Europeans? What lessons are being learned in Member States? How can state-of-the-art service-oriented Health-IT-Infrastructures be implemented? Policy-oriented officials from a Member State, the Czech Republic, and the European Commission offered lots of insights during the session. They reflected on what a Member State can do to move its digital health agenda forward, and what directions Europe may move in the future. They were posed lots of questions by audience members on their work.**

**Dr Alena STEFLAVA**, Deputy Minister of Health in the Czech Republic, offered the audience insights into the Czech experience of implementing digital health.

There is currently considerable commitment to furthering eHealth into the country, thanks to a relatively new, young Minister of Health. As Ms STEFLAVA said:

“*While we are starting with the top management in the Ministry of Health, we are also involving lots of other institutions e.g., the Institute for Health Informatics, the National Medical Library, and the Czech Medical Association*.”

Over the years, the country’s priorities have included a focus on **ePrescription** and **eHealth literacy** (and have worked and are working with other countries on these initiatives). The health ministry wants to “*bring the evidence and form a movement. We are focused on using an internationally adopted and accepted approach*”.

Having a National eHealth Portal will help with health literacy. “*The Czech Republic will guarantee that the portal is this trusted source*.”

A National eHealth Centre is now being established in the Republic. It will be part of the ministry, not independent. To succeed with its setup, the centre is being supported by the Ministry of Health, and by funding/consultancy support offered by the **European Commission’s Structural Reform Support Service**. **Austria**, in particular, is offering assistance. **EHTEL** too is part of the assignment, and is providing the centre with expertise drawn from its expert network[[43]](#footnote-43).

Initial preparation explored the advantages and disadvantages to **eHealth** **implementation approaches** used in other countries in Europe. A first stage of cooperation between the Centre and the ministry has now been reached.

**Question-and-answer session**

Audience members congratulated the Deputy Minister on the country’s passion for its work, and remarked on EHTEL’s pride on being involved in this assignment[[44]](#footnote-44). While one attendee sagely forewarned that – for the years that lie ahead – there are “*a lot of nice initiatives that just die, because there is no follow-up*”. Two others were curious as to how the Ministry had managed to get clinicians so intensively involved in the initiative – e.g., through promotion of the ideas at conferences and via training sessions – and at what stage actual end-users are engaged – e.g., through the portal[[45]](#footnote-45).

**Ioana-Maria GLIGOR** from the European Commission’s DG SANTE and **Ceri THOMPSON** from DG CNECT collaborated to make a single presentation on European policy on **digital health** and ideas for **a data-sharing European Community**.

The European Commission Communication on the **digital transformation of health and care** was launched on 25 April 2018[[46]](#footnote-46). Responding to the pressures placed on health systems currently, the European Commission is hopeful that (new) digital technologies will provide some solutions. The institution has outlined **three major goals (“three priorities”)** that it wishes to achieve[[47]](#footnote-47).

Europe is trying to combine opportunities for development in domains where the Member States have their own competence (e.g., health) with the strengths of the Digital Single Market. It recognises that the **2011 Directive on the Application of Patients’ Rights in Cross-Border Healthcare**[[48]](#footnote-48) enshrines the current mandate/legal framework for Member States on health. The **eHealth Network**, which is the voluntary network of Member States laid down by the Directive, has put forward several areas of cooperation. In May 2017, a mid-term review of the **Digital Single Market** showed that there are still major areas of fragmentation in health in Europe[[49]](#footnote-49).

The implementation initiative that results is a way of putting into effect the both European Commission and Member State’ initiatives. As a result, a European movement of **health data** has begun. Work is being concentrated in the **eHealth Digital Services Infrastructure (**eHDSI). The Member States have now started to engage together on working on data related to e.g., **patient summaries**. The first countries to “go live” with the initiative will do so in 2019. This is regarded as a widening and deepening of **interoperability**.

**Patient summaries** and **ePrescriptions** continue to be viewed, over the past decade and onwards into the future, as two key areas of work on which there needs to be a focus. The two applications will be implemented in waves up until 2021. Twenty-two Member States will start with ePrescriptions and patient summaries. For example, in **Estonia** and **Finland**, it is intended that the system will be put in place before Christmas 2018[[50]](#footnote-50). The **Czech Republic** and **Luxembourg** have received the green light to concentrate on ePrescriptions for citizens. There are relevant national contact points in each Member State and around each there are expert groups uniting. All relevant regulations are to be respected.

As a result of the Communication[[51]](#footnote-51), **a stronger legal basis** is being given to the eHDSI and the eHealth Network (e.g., in terms of the use of data and data protection, on which the Member States’ roles will need to be clarified further).

Of particular interest to Symposium attendees is surely the 12 September 2018 letter of intent written by President Juncker[[52]](#footnote-52), which places pressure on the Commission completing its many responsibilities before the May 2019 parliamentary elections. The intention is to encourage the Member States to start moving towards common tasks and activities that are at the heart of the **interoperability of systems** and what **systems’ developers can do to work together**.

Currently, **health information systems have developed in very different ways**, and measure very varied items or figures in diverse parts of the Union. Some countries are very centralised in how they look at procurements, and in others – like the Netherlands – “*the centre has no say*”. What should be the priorities? How to give it initiative impetus and momentum?

The presenters therefore focused their attention to two issues: **pooling or linking data for research purposes,** and **mHealth apps and wearables** and a third related to **artificial intelligence**.

In terms of the use of data for research purposes, the Communication bases its ideas around the view that “*there are truly vast data sets – such as real-world (health) data and genomic data – that can bring benefits to Europe” through wider European collaborations, both within and across countries*.”

Taking **genomic data** as an illustration, 18 European Member States are currently signed up to linking up **one million sequenced genomes** by 2022[[53]](#footnote-53). The Commission is of the view that, reaching the figure of one million will not be the challenge, the real question is about getting the infrastructure ready and linking up the technologies. It is critical to develop **a suitable use case** to explain how the data should be collected in the first place: rare conditions or diseases can provide such an example. (According to EURORDIS, rare implies that fewer than one in 2,000 people have such a disease or condition[[54]](#footnote-54).)

If knowledge about **rare conditions** can be pooled, this could improve treatments for many individuals resident throughout the European continent. Of crucial importance is therefore the work of the **European Reference Networks**[[55]](#footnote-55). Currently, 24 different networks of reference centres exist e.g., working on endocrinology, and conditions affecting the liver and the lungs. Some 900 healthcare units in 300 hospitals in 26 countries in the European Union. Yet, not all the countries in Europe are covered. The administrative capacities of the European Reference Networks are currently being strengthened. Stronger financing (which could come e.g., from either DG SANTE or the Connecting Europe Facility) also needs to be assured.An expanded set of members of the European Reference Network(s) should be endorsed by their own Member States whenever they apply to join.

The Commission sees **mHealth apps and wearables** as a way for people to be involved in their own health and care outside of the institutions e.g., to prevent certain health conditions or monitor them. It is keen to find **good (mHealth) solutions** and to promote them; create partnerships that bring together the supply and demand sides; and find ways in which different health authorities throughout Europe can communicate on these issues. While, at pilot level, there have been good projects, the challenge remains how to scale them up.

Europe’s network of **pan-European Digital Innovation Hubs** is also a mechanism for getting small- and medium-sized enterprises, in particular, in “going digital”[[56]](#footnote-56): it is relevant for industrial and commercial entities working in many different fields, not just digital health.

There is a strong sense that the use of **artificial intelligence** (AI)[[57]](#footnote-57) needs to be enhanced in the health and care sectors. The intention of the Commission’s 2018 Communication on this technology is to help Member States to identify the challenges posed by AI and to mitigate them, thereby ensuring a solid ethical and legal framework. A high-level group of 52 men and women are looking at this issue[[58]](#footnote-58), and have written a December 2018 report that is open for commentary until 18 January 2019[[59]](#footnote-59).

There are a variety of ways in which health and care-related initiatives can be financed in the future in European terms. Among those are: the **2021-2027 Multi-Annual Financial Framework**. The **Digital Europe** programme is likely to back the creation and strengthening of the Digital Single Market. Some 9.2 billion euros will be spent on super-computing, AI, cyber-security and trust, and advancing digital skills across both economies and societies. Meanwhile, the **Connecting Europe Facility** will target funds at a more fundamental level e.g., on connectivity, gigabits, and remote servers. **Research and** innovation in the area of health, will be funded through e.g., cluster I and cluster III – digital and industry. An example could be for a rare disease registry. The ESF+, ERDF, and InvestEU programmes are also worth some attention, with their focus on “*a new and improved European Social Fund; regional development with five specific objectives, and more social Europe*” e.g., for community centres or for regional hospitals. The **European Globalisation Adjustment Fund [[60]](#footnote-60)**can help people in different fields – presumably including in the health sector – who have lost their jobs. Last but not least, the **European Structural Reform Support Service[[61]](#footnote-61)** can offer technical assistance to Member States. So far only a few Member States have used this service to support their health care sectors. The Czech Republic and EHTEL, however, have had a great experience of using this service to ensure that a new eHealth Center can be set up in the Republic[[62]](#footnote-62).

**Question-and-answer session**

Symposium attendees recognised the degree to which this shift towards digital transformation in health and care is a “*big project*”. It is challenging to consider how to move forward authentically on **what citizens genuinely need**, how this can be delivered technically, and the extent to which citizens can get access to their own health data.

Attendees were interested in **which ‘use case’ should be the first**. They raised possibilities like: data-sharing among diverse European health centres; language translation of health and care data; structuring/coding of health and care data; and/or working together with other relevant fields e.g., social security/social services. A view was expressed that “*some information is at least better than nothing*”.

There is, furthermore, **a shift towards a widening of the potential use cases**, and which ones would be good cases to explore further. The European Commission recognises that different countries want to move at **various speeds**. Hence, Europe is likely to aim for a series of **“set principles”**, with countries sharing with each other their **learnings** about what they are doing in health and care – creating **interoperability** with other systems as well as undertaking **horizon scanning**.

The European Commission believes that, in terms of movement towards these **future initiatives**, “*there’s a fair wind behind this now, at all levels*”.

Many audience members remarked on how pleased they were to see and hear the **two European Commission officials co-present**.

## **Data and Well-Being in Practice: Co-Creating for Patients’ Benefit**

**This session involved co-creating a set of six scenarios related to how patients will benefit from the sharing of data in the health and care fields in the future. It provided an interesting bridge to the presentations later in the day and also the match-making session which took place on the following day.**

This highly interactive set of break-outs involved all the Symposium attendees working together to **co-create a set of scenarios** of how data might in future be used to support patients. Among the key topics were: **risk assessment and prevention** (in patient-centred care); **chronic disease management** (applied, for example, to rehabilitation, mobility, coaching and management solutions for people with type 2 diabetes); and **public health/population health solutions** (which will help to guide the allocation of resources to health and care.

More detail will be included in a Day 2 report.

## **Innovation Initiative Spotlight: “Living Labs for Digitisation in Healthcare”**

**This session focused on learning about how living labs support digitisation for health and care. Four examples of co-design were offered from Belgium, Finland, Scotland, and Spain. The speakers showed how both the demand and supply sides of digital transformation can be brought together in co-creative ways.**

**The Role of Design Innovation in the DHI**Don McIntyre, Digital Health and Care Institute (DHI), Scotland, United Kingdom

**Don MCINTYRE** emphasised the importance of creating the setting/context in which **design-driven innovation** can take place in the field of the digital transformation of health and care. Scottish citizens are becoming far more demanding about their healthcare than they were a decade ago. It is now critically important to engage with them to bring together their ideas about **what healthcare should look like in the future**.

He described the kinds of agile design processes that the Scottish DHI uses, while being keenly aware of the non-linear character of innovation. Excited by the processes that can be used with stakeholders, he suggested, “The minute you put pen on paper and draw, the more the neurons fire!”

He outlined a number of recent design experiences e.g., with the Scottish Ambulance Service; as well as with people who have multiple sclerosis and with people with different forms of diabetes.

He also placed an emphasis on machine learning and data-sharing: “There is no-one else doing this, but we are doing it in Scotland, in Glasgow. The more we can open up the APIs, the richer the data will be.

Other speakers followed.

## **Looking Ahead: Leveraging Synergies of Machine Learning and Digitisation**

**Three insights were offered from industry, large-scale hospital, and a medical cluster. They focused on what AI is promising, and what options arise for meaningful new services.**

The speakers gave further details.

## **AI as a Game Changer: Patients’, Professionals’ and Provider Views**

**This interactive debate covered the existing achievements of Artificial Intelligence (AI), and how they can be integrated into and change daily medical practice. What will we see in the next years? Is it realistic that young doctors should stop investing into becoming specialists in fields like radiology? Or will be just see a gradual change in tasks that Health IT can deliver? The discussion was chaired by Lester Russell of IBM’s offices in the United Kingdom.**

Discussion was varied and wide-ranging.

Nu THAM, from AGE Platform Europe, started the reflection by reflecting on how prone healthcare is in general to **ageism**. Often people are counted as “old” from aged 65+ onwards, but in reality there is a huge diversity in the health and conditions of people after that age. She queried whether – as a result of systems like AI – ageism will be transferred electronically into the way health systems work. How will a person, e.g., a young designer, who does not have scientific and technical expertise in multi-mobilities, assess a suggestion for a technology to be used by older adults in 20-25 years’ time?

Attendees enquired about whether the panellists thought that the caution (**ethics**) of **Joe WEIZENBAUM** – one of the founding fathers of artificial intelligence (AI) – with regard to this technology is still valid. With technologies, there are always certain things one should do and others one should not[[63]](#footnote-63). Other attendees considered the implications of **AI in health and care** more generally: they saw AI “*not as an add-on, but complementary*”. Yet others wanted to know in **what specific medical fields** AI should be used: for example, can AI be used for **diagnosis**, especially if it is more effective and efficient than human beings. Finally, others wanted to know what advice could be given to **decision-makers at the global level**. Can **knowledge exchange** be better organised so that faster progress can be made on AI, by using the **FAIR principles** of findability, accessibility, interoperability, and re-usability?

As concluding remarks, **Lester RUSSELL** emphasised how **excited and challenged** he is by AI. He believes that the way forward is to **lead and inform public opinion** and spread the debate more widely. He especially valued that over 30 people had stayed to the very end of the Symposium to debate these key issues. He welcomed the attendance at the session of two medical students, they would also be keen to welcome **more young professionals** into these kinds of discussion forums.

1. <https://www.eesc.europa.eu/en/our-work/opinions-information-reports/opinions/digital-transformation-health-and-care-communication> [↑](#footnote-ref-1)
2. <https://www.eesc.europa.eu/en/our-work/opinions-information-reports/opinions/artificial-intelligence> [↑](#footnote-ref-2)
3. <https://www.eesc.europa.eu/en/our-work/opinions-information-reports/opinions/sustainable-social-security-and-social-protection-systems-digital-era> [↑](#footnote-ref-3)
4. <http://www.eu-patient.eu> [↑](#footnote-ref-4)
5. <http://www.eu-patient.eu/library/position-papers--briefings/> [↑](#footnote-ref-5)
6. <http://www.eu-patient.eu/whatwedo/Policy/Data-Protection/> [↑](#footnote-ref-6)
7. <http://www.eu-patient.eu/News/News/call-for-interest-to-take-part-in-new-epf-working-group-on-digital-health/> [↑](#footnote-ref-7)
8. <https://ec.europa.eu/digital-single-market/en/news/communication-enabling-digital-transformation-health-and-care-digital-single-market-empowering> [↑](#footnote-ref-8)
9. [www.bd4bo.eu](http://www.bd4bo.eu) [↑](#footnote-ref-9)
10. <https://www.ema.europa.eu/en/human-regulatory/post-authorisation/patient-registries> [↑](#footnote-ref-10)
11. <http://dhi-scotland.com/demonstration-simulation-environment/> [↑](#footnote-ref-11)
12. <https://bluebutton.cms.gov> [↑](#footnote-ref-12)
13. <https://www.cms.gov/newsroom/press-releases/trump-administration-announces-myhealthedata-initiative-put-patients-center-us-healthcare-system> [↑](#footnote-ref-13)
14. <https://patient-view.com> [↑](#footnote-ref-14)
15. <https://www.roche.com/media/releases/med-cor-2017-06-30.htm> [↑](#footnote-ref-15)
16. <https://www.appqualityalliance.org> [↑](#footnote-ref-16)
17. <https://www.gamesforhealtheurope.org/submissions-for-2019/> [↑](#footnote-ref-17)
18. <https://www.assuta.co.il/en/> [↑](#footnote-ref-18)
19. <http://www.connecare.eu> [↑](#footnote-ref-19)
20. An EHTEL task force has worked on producing a short report on how smart messaging can be used in health and care systems and services. It is anticipated that the report will be published in 2019. [↑](#footnote-ref-20)
21. <https://ec.europa.eu/digital-single-market/en/news/app-cystic-fibrosis-patients-and-nutrition-game-children> [↑](#footnote-ref-21)
22. <http://www.mycyfapp.eu/index.php/en/> [↑](#footnote-ref-22)
23. <https://ec.europa.eu/digital-single-market/en/news/cystic-fibrosis-app-reduces-childs-symptoms-and-takes-some-worries-away?fbclid=IwAR0Q0AqYsvP1efkHgGgqi_CVltXNoLOnx9GNKIob_EpaKyg_gfME9eRVB60> [↑](#footnote-ref-23)
24. <https://www.beuc.eu/health> [↑](#footnote-ref-24)
25. <https://ec.europa.eu/commission/priorities/justice-and-fundamental-rights/data-protection/2018-reform-eu-data-protection-rules_en> [↑](#footnote-ref-25)
26. <https://www.per.gov.ie/en/ireland-achieves-first-place-in-eu-open-data-maturity-assessment/> [↑](#footnote-ref-26)
27. FAIR stands for Findable, Accessible, Interoperable, and Reusable. [↑](#footnote-ref-27)
28. <https://www.dtls.nl/fair-data/fair-principles-explained/> [↑](#footnote-ref-28)
29. <https://www.registerforskning.se/en/register-i-sverige/verktyget-rut/> [↑](#footnote-ref-29)
30. <http://farrinstitute.org/news/how-uk-universities-are-using-patient-data-in-research-new-datasaveslives-animation-launched> [↑](#footnote-ref-30)
31. <https://www.myhealthrecord.gov.au/for-you-your-family/howtos/secondary-uses-data> [↑](#footnote-ref-31)
32. <https://en.wikipedia.org/wiki/Synthetic_data> [↑](#footnote-ref-32)
33. <https://en.wikipedia.org/wiki/Metadata> [↑](#footnote-ref-33)
34. <https://www.sitra.fi/en/> [↑](#footnote-ref-34)
35. <https://www.reuters.com/article/us-denmark-data-idUSKCN10025I> [↑](#footnote-ref-35)
36. <http://www.cphhealthtech.com/data-saves-lives/about-data-saves-lives> [↑](#footnote-ref-36)
37. <https://nextpartnership.dk/en/> [↑](#footnote-ref-37)
38. <http://www.computerome.dtu.dk> [↑](#footnote-ref-38)
39. <https://www.healthcaredenmark.dk/news/listnews/danish-digital-health-strategy-2018-2022-now-available-in-english/> [↑](#footnote-ref-39)
40. <https://ec.europa.eu/digital-single-market/en/european-policy-ehealth> [↑](#footnote-ref-40)
41. <https://www.i2i.eu/i2i/> [↑](#footnote-ref-41)
42. <https://ec.europa.eu/health/technology_assessment/overview_en> [↑](#footnote-ref-42)
43. <https://www.ehtel.eu/news-press/the-upcoming-national-ehealth-centre-of-czech-republic-explores-good-practices> [↑](#footnote-ref-43)
44. <https://www.ehtel.eu/news-press/the-upcoming-national-ehealth-centre-of-czech-republic-explores-good-practices> [↑](#footnote-ref-44)
45. OECD, Health at a Glance – Europe 2018: <http://www.oecd.org/health/health-at-a-glance-europe-23056088.htm> [↑](#footnote-ref-45)
46. <https://ec.europa.eu/digital-single-market/en/european-policy-ehealth> [↑](#footnote-ref-46)
47. EHTEL structured the whole of its Symposium according to these three priorities, by focusing on: xxx. [↑](#footnote-ref-47)
48. <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A32011L0024> [↑](#footnote-ref-48)
49. <https://ec.europa.eu/digital-single-market/en/content/mid-term-review-digital-single-market-dsm-good-moment-take-stock> [↑](#footnote-ref-49)
50. For example, <https://news.err.ee/866134/finnish-digital-prescriptions-to-become-valid-in-estonia-in-december> [↑](#footnote-ref-50)
51. <https://ec.europa.eu/digital-single-market/en/european-policy-ehealth> [↑](#footnote-ref-51)
52. <https://ec.europa.eu/commission/sites/beta-political/files/soteu2018-letter-of-intent_en.pdf> [↑](#footnote-ref-52)
53. <https://ec.europa.eu/digital-single-market/en/news/netherlands-18th-member-state-join-eu-cooperation-linking-genomic-health-data-across-borders> [↑](#footnote-ref-53)
54. <https://www.eurordis.org/about-rare-diseases> [↑](#footnote-ref-54)
55. <https://ec.europa.eu/health/ern_en> [↑](#footnote-ref-55)
56. <https://ec.europa.eu/digital-single-market/en/digital-innovation-hubs> [↑](#footnote-ref-56)
57. COM(2018) 37 final – *AI for Europe* is a useful and interesting Communication published by the European Commission. [↑](#footnote-ref-57)
58. <https://ec.europa.eu/digital-single-market/en/high-level-expert-group-artificial-intelligence> [↑](#footnote-ref-58)
59. <https://ec.europa.eu/digital-single-market/en/news/have-your-say-european-expert-group-seeks-feedback-draft-ethics-guidelines-trustworthy> [↑](#footnote-ref-59)
60. <https://ec.europa.eu/social/main.jsp?catId=326> [↑](#footnote-ref-60)
61. <https://ec.europa.eu/info/departments/structural-reform-support-service_en> [↑](#footnote-ref-61)
62. <https://www.ehtel.eu/news-press/the-upcoming-national-ehealth-centre-of-czech-republic-explores-good-practices> [↑](#footnote-ref-62)
63. <https://www.amazon.com/Computer-Power-Human-Reason-Calculation/dp/0716704633> [↑](#footnote-ref-63)