DigitalHealthEurope Workshop on improving availability and re-use of health data at the 2019 EHTEL Symposium in Barcelona, Spain

Background: Digital technologies are transforming healthcare, from the way big pharma does business and citizens self-manage their own health through to the way that medical care is delivered. This **transformation is driven by data**. These data hold **great potential** for research and personalised medicine, if only they could be re-used more widely. Unfortunately, the European health data landscape is characterised by fragmentation, intersected by many institutions and jurisdictions. Instead, better **integration of health data could deliver impactful results** for research and medicine, with **benefits** for citizens, patients, doctors, researchers, healthcare decision-makers, and others, in Europe and beyond.

Workshop and its composition: On **December 4th 2019**, together with representatives from DigitalHealthEurope, DHE partners, empirica, EHTEL and the project management Jülich, the workshop participants brainstormed on how to get more and better health data available for re-use in Europe.

Some **25 participants** gathered together in this parallel session workshop. They covered a large geographical spectrum, ranging from **Finland to Croatia, Spain and the UK**. They also represented a wide range of stakeholders, including **educators, legislators, managers and researchers** from the healthcare domain.

In the first part of the workshop, the participants were introduced to the work of **DigitalHealthEurope** and the importance of developing a European focus on the **secondary use of health data**. In the second part of the workshop, participants' **experiences and concerns** were investigated. In a third part of the workshop, the focus was on the **European Health Data Space**.

Past use of secondary data: About **a third** of the participants had already made **secondary use of health data** originally collected for another purpose. It was not surprising, given the strong emphasis of this year's EHTEL Symposium on AI applications, that most respondents had used **health data for testing and training of algorithms**, for instance, **for diagnosis or decision support systems**. Other uses were also reported, such as **evidence-based** clinical and business **intelligence** and health policymaking; the **discovery of new disease risk factors or biomarkers**, and **improved disease management**, e.g. of chronic diseases.

Challenges faced: Irrespective of the use made of the data, participants were confronted with largely the same challenges. The main, common challenge was **legal**: **obtaining consent** from the citizen or patient that her/his health data can be re-used for another purpose. Further complicating this challenge was **a general lack of trust on the part of citizens**. **Feeding information on the impact of re-used health data** back to citizens (the data subjects) could effectively promote trust. In the end, this would generate **a better, general consciousness about the benefits of sharing health data**. Other challenges reported by the participants were more **technical**, for instance, data collected from different sources can be very **heterogeneous in structure and quality**.

European Health Data Space – by whom and for what: In a third part of the workshop, the participants brainstormed on how the new concept of **a European Health Data Space**, proposed by the new European Commission in its launch on 1 December 2019, could **facilitate the re-use of health data**.

When asked which stakeholders have the greatest need to access this space, **academic researchers were regarded by far as the main users**, much more so than commercial health researchers, patients or clinicians. **Routine clinical data from electronic health records (EHRs)** were thought to be the kinds of data these researchers would be most keen to find there. Great potential was also seen in **historical cohort data**, **medical images** or **public health data**, for instance, on the incidence of **rare disease**s or the **comparative effectiveness of therapies**. Finally, the participants suggested a few applications best suited for **piloting the European Health Data Space** and **demonstrating** the benefits of re-use of health data. These included: **AI training** with larger datasets including images; and **pattern detection** of high morbidity or premature mortality and population-based outcome measurements in patients with complex health and social problems.

<u>**Overall**</u>: The workshop also succeeded in:
- Enlarging the DigitalHealthEurope "Better Data"-stakeholder community
- Providing valuable input for European policymakers on how to support their vision for the Digital Transformation of Health and Care in Europe.