ENRF Briefing Note

Co-creation & Co-design with the end-users!
Real time data for the European Health Data Space

The ENRF participated in a EU research meeting on real world, real time data for the anticipated European Health Data Space, a revitalised European Research Area, as well as other key digital policies such as the European approach to AI and data strategy.

Lara Bloom, President & CEO, Ehlers-Danlos Society, said that it Is really important for health and mental health to plan the future provision of health. Particularly with those vulnerable, people who have lost their jobs, people living with chronic diseases. There is still a long way to improve for those living with rare diseases. She spoke on the importance of patient co-creation and co-design, two concepts EFN has been pushing for 3 years and now gets picked up by many EU stakeholders. It is therefore key the EFN and the ENRF prepare themselves for co-creation.

Andrzej Rys, Director for Health Systems, Medical Products and Innovation, DG SANTE, European Commission, said that the COVID-19 outbreak has taught us that we need to focus a lot more on healthcare at the EU level. Preparedness is key (see EFN Report). The data ecosystem plays a key role as data is in so many health-related places. Health data should be usable and interoperable, but the reality shows this is far from the reality. The European Commission is just starting negotiations with the Member States on the new EU4Health Programme as COVID19 has pushed this forward. It is key ENRF reference points get in contact with their national negotiators to push for nursing research in the EU4Health Programme, now! as the Commission wants to conclude with these negotiations by the end of this year. The EU's Health budget has been increased – particularly in research. The European Commission has lessons learned from the 2009 pandemic, as EFN pushed for in its Report: nurses learned from Ebola and Covid19. There is a need for healthcare digitalisation among healthcare professionals and the European Parliament EFN-ENRF-NURSING NOW event brought together 250 participants to exchange views on co-creation and co-design.

Didier Jourdan, Chairholder, Global Health & Education, UNESCO, reminded the audience that the EU needs to be a driving force to support the care paradigm in many EU Member States to move from care giving to healthcare prevention. The COVID-19 outbreak may change the EU competences in healthcare for the better. Moreover, in the EU health ecosystem data collection and sharing is of utmost relevance. Health literacy is an area in which the EU should do a lot more. We need to foster the health literacy of European citizens, which at the moment he considers to be very little. Rightly so!

Tomislav Sokol, Member European Parliament, said that the social competencies of the EU cannot be changed, and hence it is not realistic giving the EU more healthcare competences, because then all EU Member States would have to approve that move. Instead, EU action is needed in those areas where Member States cannot solve problems by themselves. One of these areas is pandemics. He agrees that the EU needs more healthcare competencies, but we also need to better use the competencies that we already have.

Minna Hendolin, Senior Director, Health and Wellbeing, Ecosystems, Business Finland, stressed the importance of health outcomes. Instead of measuring the cost of healthcare, we should look at how much money goes into prevention and how much into curing. We should change our mindset on how to measure things. The societal impact of healthcare is huge. Moreover, digital health is going to play a key role in the future: we need to foster digital consultations, etc. We need to move to outcomes-based healthcare.

Mark Pearson, Deputy-Director for Employment, Labour and Social Affairs, OECD, said that one of the key take-aways of the COVID-19 pandemic will be the importance on health outcomes for patients. Many of the countries who managed better the pandemic are those with stronger real time health data collecting systems. This is what has been missing in Europe. The word we will hear most in the future is "resilience" – we need to apply it to out healthcare systems and foster it.

Janneke van der Kamp, Head, Region Europe, Novartis, said that we need to find solutions to bring patient fasters to the therapy that they need. Health data could place a role in this. We need to advance healthcare innovations for patients, to deliver to their needs. Industry plays a role in how their health products should be perceived. For her, in healthcare, we should compete "as Europe" (against the US, China, etc.) and not "within Europe". Patient outcomes are key, and we should agree on certain standards on how to measure these (PREMS & PROMS – a topic ENRF worked on in 2019). We need a "Digital Health Marshall Plan for Europe".

Monica Dietl, Advisor to the Director-General; Coordinator Action Plan Europe, DG R&I, French Ministry for Higher Education, believes that we do not need a new definition of healthcare outcomes after the COVID-19 pandemic. However, we do need to put greater attention to those. We need decision-makers to put money on the table to help current health initiatives grow.

Health infrastructures need money. Measuring patient's outcomes relate to patient's education – we should put more attention to that. Health starts in the school.

Douglas Gregory, Senior Director, Government Affairs Strategy & Excellence, Bristol Myers Squibb, repeated that healthcare outcomes are essential. Patients do not need high-level discussions but key changes to take place on the ground. One of the better changes brought by COVID-19 is the augmented willingness of EU institutions to put more money into healthcare. In measuring health outcomes, standardisation is key. The European Semester Country Reports are a good framework to see which areas in EU healthcare to improve. EFN has made a summary report on 5 years European Semester, and it is obvious that "healthcare" is missing from the Commission recommendations, showing the low interest in healthcare for the last 10 years. Covid-19 changed that! But know it is up to EFN and ENRF to push for European Semester modifications, so it measures what is a priority for EU citizens.

Kaisa Immonen from EPF said that for patients, health innovation does not only relate to "the new", but to improving already better things. Patients should be health research partners. Co-production with patients and citizens should be a compulsory requirement for obtaining EU support through projects. Patient participation should not only be a "tick box". The EU should be a leader in co-production of research and science.

Mariya Gabriel, Commissioner for Innovation, Research, Culture, Education and Youth, European Commission, highlighted that the EU needs to cooperate with all levels of civil society – including patients, including healthcare professions. Co-production with frontline is key. The next step is to have very targeted funding for concrete projects on the trendiest topics. For her, the key word is "co-creation". Now her team is working on how to strengthen public policies, including via Horizon 2020 and Horizon Europe. We need to have more resilient healthcare systems. They are planning to have a partnership on pandemic preparedness. We need to increase the budget for Horizon Europe as well as allocate funds to the new EU4Health Programme. We need to build partnerships and cooperation and give rapid funding to timely projects. In Europe we have the needed leadership. International cooperation is possible and is positive for the EU, but at the same time, the EU values, principles, and interest need to be always defended.

Mirit Eldor, Executive Vice President Strategy, Elsevier, information centre already has about 31.000 COVID-19 related articles. They prepared manuals and documents for retired nurses who came back to practice during the outbreak. Some of these resources were not medical-oriented. We need better and easier data-sharing infrastructures in the EU. These need to be interoperable. Often, sharing health data is difficult even across regions. Big-data capturing is difficult yet important in healthcare.

Xosé Fernandez, Chief Data Officer, Institut Curie, said that there are many improvements done in healthcare after the COVID-19 pandemic that has come to stay. There are many obstacles that we need to overcome. We need to find ways to diagnose diseases even before these become diseases in the individuals and welcomed the EU's Mission on Cancer. Artificial Intelligence is useful and important, but it is not the answer to everything.

Jan-Philipp Beck, Jan-Philipp Beck, Chief Executive Officer, EIT Health, believes that the healthcare sector is not the fastest one when it comes to the uptake of IT-produced solutions. We need to invest in data quality and infrastructure with interoperability of data being the key. We need to create a field with more security which healthcare providers can navigate and understand its security, interoperability, governance, etc. We cannot leave it up to each healthcare provider alone. He believes we need to challenge healthcare providers to look beyond their legacy systems and improve patient's experience.

Mateo Valero Cortes, Director, Barcelona Supercomputing Center, stressed that in healthcare we need to act together and act fast. Most COVID-19 related data are still not available for researchers – even though it should. Healthcare data should be converted into computational models. We need to use Artificial Intelligence to develop models of health data that we still do not have.

Finally, Casper Klynge, Vice President Government Affairs, Microsoft, said that the EU has been lagging in the share of health data. He believes that the EU should develop a stronger system for data exchange and sharing with a focus on privacy and data protection and believes that there is more policy and regulation is needed in the governance of health data.

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