

Innovation Round-Table, EHFG 2017

Executive Summary

The Innovation round-table was a side event of the EHFG 2017, intended to test the mutual benefit of extending the Gastein vision specifically to innovators and their contribution to society, beyond the fields of pharma and health tech. The hypothesis was upheld, both in the workshop and throughout this year's sessions: health needs to embrace an all-SDG approach to achieve its goals, and all aspects of sustainability somehow depend on innovation. We cannot solve the problems we face with the approaches that have created them. Also, as decision-makers we have to deal with both perception and reality, as both of them can be equally challenging.

Specifically, during the round table, new voices from the art-technology space, from the EIT health communities, from best practice applications of AI, to health management all pointed to one conclusion: health is innovative and deserves to be more widely recognised as such. Health is one of the spaces where the dictionary of problems around data use can be reframed in a language of solutions.

The keynote speech introduced the notion of both the inter- and intrasectoral collaboration, the need for interoperability and standardisation, as well as the need for the EU-based patient registries, pointing out that the technology should always be user-friendly.

The panel of speakers, together with the participants, drew up a framework that would include new health market regulations which strengthen and support innovation, a broader, holistic societal approach to producing and implementing innovation, and the greater political will for the integration of interoperability on all levels. Moreover, it was accentuated that there needed to be a distinction between product innovation and innovation in services. Product innovation alone would not suffice - it still needs to be integrated in innovative processes to be successfully implemented and scaled up in the end. Finally, in line with the main topic of this year's Forum, it was suggested that we would need to work on bringing health to all politics, aligning political agendas, and helping decision-makers understand the potential of big data. For big data to be implemented and used not only correctly, but also fairly and responsibly, some basic requirements need to be met. New methodologies need to be put in use, allowing for a more critical and relevant data collection, interpretation and contextualisation. They should aim for a future in which data cannot be in private company possession, but should rather be a public good, serving the public and civic sector in constructing better living conditions for the entire society.

The discussion on this topic in the framework of the EHFG should proceed in two streams: data and artificial intelligence on the one hand, and health technology and systems modernisation on the other. It was concluded that there was already a clear emergence of a digital health society, and the EHFG should help to co-create that new reality. The newer participants in the IRT all saw this potential and seem open to join in making it happen. Some suggestions included a stronger collaboration with the EITHealth community, both in terms of sponsorships, and in terms of bringing in new players, as well as the inclusion of the digital art and media culture. Furthermore, the future EHFG conferences should open the discussion for all the conference participants, and provide a slot for the Young Forum Gastein to take part in the discussion (for example, include them in a plenary with the topic of innovation, and hear their input on the futures of the digital advocacy).

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Full report

Main challenges

- As decision-makers, we have to deal with both perception and reality, as both can be equally challenging.
- We should not only be focused on technology – we should assure that patients and health professionals are on board with the innovation that is being introduced.
- Digitalisation is happening across all sectors, and healthcare will not be exempted - without standardisation and interoperability the advancement of the EU in this sector is not possible.

When talking about innovation in health, all stakeholders need to insist on working together, to tackle the challenges that the entire EU is facing. The public is concerned about the new technologies, and the concerns vary from the quality and reliability, to privacy and security. For us as decision-makers it is important to bear in mind that we have to deal with both perceptions and reality, as both can be equally challenging.

We should not make the mistake of being too focused on technology itself – we get excited about technology just for the sake of it, not taking into account that the users need to be on board with the innovation that is being introduced. Namely, if any kind of technology requires extra time - of either the health professional or the patient - it is very likely that it will not be accepted, no matter how cutting edge or cost saving it is. The products need to be designed from the perspective of the user (professional, patient, everyone else involved).

One of the issues we are facing within the EU is fragmentation, especially in terms of unequal implementation of initiatives across the EU. We should invest more in cross-border hospital networks, outsourcing and exchanging of data. This is a very complex task, as it requires technical, semantic and legal standardisation. In order to advance both on the state and the EU level, all of the stakeholders must join forces to facilitate digitalisation, in order to achieve standardization and interoperability at the EU level. One specific example for where a lot could be won by using data in the right way are interoperable European patient registries. Good governance systems and a clear strategy on the usage of data, as well as the setting of clear priorities are the prerequisites for this initiative to be successful.

Stakeholder viewpoints

The problems of a health app developer

- The EU market is extremely fragmented, even within countries.
- The health market is neither free nor liberal, and there are no market mechanisms like in other sectors.
- Health apps and their content are not clearly defined or regulated.
- Finding the right business model is tricky: different stakeholders have different, often competing interests.

In the case of diagnostics of rare diseases, it normally takes ten years from the first symptom to the final diagnosis, and this mostly happens by luck and chance. If it were not for a lack of information or misinformation, each year, 1,5 million lives could be saved with the right diagnosis. Physicians are expected to have in mind more than 20.000 diseases at once, which is, understandably, more than they can handle.

There is an innovative app which aims to tackle these issues by allowing physicians to select symptoms, age and sex, and to access all the possible diseases sorted by the probability of their occurrence. This app has gathered the biggest disease database in the world over the last 10 years. Although operating at a profit, it has experienced the following issues: the EU market is extremely fragmented, even within countries; the market is not free or liberal, but is subject to several market failures; health apps and their content are not clearly regulated (e.g., it is not clear whether or not they are medical devices); finding the right business model is tricky: different stakeholders have different interests, and most of the interests are competing.

Therefore, although it is not simple, innovation issues have to be addressed in healthcare management across Europe, and this example should be a reminder that there are threshold problems with market access, and with scaling up once the market is entered, that are stopping innovation from gaining its full impetus.

Innovation as a new part of society

- The data challenges we are facing are now bigger than the expertise we can have as humans – meaning that many developments are beyond our control.
- There needs to be a paradigm shift: we should stop seeing innovation as disconnected tools, but really see it as integral part of life
- Innovations are not a product of individual sectors, but rather a product of society.

All sectors are facing the same problems: Industry 4.0, Medicine 4.0, no matter which term is used, is a cultural phenomenon. The most significant point in every field is that our own expertise is no longer enough to cope with the challenges; due to the fast pace of technological innovation, many developments are stepping out of our control.

Healthcare problems are manifold, and the medical industry is becoming too expensive and unsustainable. It is no longer enough to look at your own field of expertise: there needs to be a paradigm shift towards really integrating technology in our lives rather than seeing it as an assortment of disconnected tools. Innovations are not limited to a sector, but are rather a product of our society. In the same way, they are

becoming a whole new part of the entire society, and the society is interacting with them on all levels. Nowadays, we live together with the machines, and we even adapt our bodies to be in tune with them. However, we are all limited to our education and our mindset, which is why we need technical innovation and new means of communication to match it. Part of the problem is the notion of 'just trust us, tech is great!' – we need better research to prove to the public sector that it should invest in innovation. Considering the innovation as a movement of the entire society, we should include the new stakeholders: artists, cultural experts, communication experts – we all have to work together to deliver the final product. Only when we realise our limits, we can actually start to make the right moves.

Big Tech players

- Healthcare has left the walls of the hospital, which brought about new challenges related to remote care, such as ensuring continuity.
- Rather than thinking about Patient Health Records, we should be thinking about Holistic Health Records to better diagnose and cure patients.
- We need to design a right policy framework to allow for secondary use of data for research, especially in the context of the GDPR

We need to be aware that healthcare has left the walls of the hospital, which means we need to ensure continuity of remote care. Nowadays, we are witnesses of telemedicine with advanced tech use, for example motion sensors supervising physiotherapy, or remote vital functions monitoring, using AI algorithms to spot abnormalities and send immediate alerts to doctors. With this development, doctors have partially lost their role as gatekeepers: the patients want to have more control of their care management. Within the context of this “consumerisation”, the border between lifestyle and medical devices is getting blurred, and it certainly needs policy reflection. Rather than thinking about Patient Health Records, we should be thinking about Holistic Health Records, encompassing i.e. lifestyle data, to better diagnose and cure patients. In any case, telemedicine needs to be captured and incentivised in regulations as the modern way of delivering both preventive care and treatments.

In order to make these policies work, we need to permit secondary use of data, especially in the context of the GDPR and new EU regulations on the data usage. We should also work on the scientific research definition, specifically occurring in the public-private partnership, or in private sector alone. There should be a definition of adequate safeguards (i.e. based on international standards such as NEN-7510, or ISO 27xxx), and tech capabilities (i.e. AI-driven automated data classification). Furthermore, we need to bring about scenarios where the collected data is being repurposed to combat not only the diseases it was collected for, but also the other ones. We should see data as the new blood, as there should be a framework for data donation that unites both individuals and data systems in a common cause - to preserve data integrity, and to use data to help others.

Health professionals

It is important to keep in mind that, although GPs are generally not against the data flow, they also face a significant level of uncertainty regarding the patients' consent and its validity along the data transmission pathway. This is primarily because there is no certainty about the possible secondary uses of the shared data. Is the data being used for monitoring of appropriateness of care, research and epidemiological inferences, or is it instead being used for a commercial profiling of patients, or worse?

Furthermore, GPs are facing the problems of data reliability, especially given the individual, national and regional differences in diagnostic approaches and coding. It is still very difficult to use and store data appropriately, because there is close to no standardisation on the regional, state and EU level.

Inputs from the participants

Redefining scientific research

Although innovation sounds exciting and is widely seen as positive, there is always a risk of inaccuracy, and there is a need to assess whether the possible benefit justifies that risk. Big data does have a huge potential, and many say it is our future, but is big data actually big knowledge? That is where we need to find our place – not every research result brings about the truth, and many of them have external validity limits – they should be taken with a grain of salt. Apart from that, as we know correlation does not necessarily imply causation. Big data will introduce new and aggravate old problems that we need to prepare ourselves for, creating new methodologies and adapting our perspectives to the new reality. In the end, when using big data in medical practice we always have to ask ourselves what are the outcomes we want to be measuring: is it the savings, is it the quality of service, is it the number of highly educated staff, or is it something else – what is the best way to measure health?

Worlds need to meet

There are many organisations conducting different kinds of research and owning research results. We find ourselves in an era of great research possibilities, ground-breaking discoveries, and a large number of highly educated and networked scientists. However, the majority of the generated data is still unstructured and therefore not usable, and, as it is not connected to other data, it is commonly not informative enough. This lack of information and contextualisation means that targeted investment in start-ups, or in any kind of new initiatives, is challenging. The problem is twofold: on the one hand, we are reactive in dealing with the disruption that is happening, and on the other hand the tech sector lacks awareness about anything outside its reach. To change the situation the tech sector must better understand the fields for which it is developing, and vice versa. The worlds need to meet.

Bottom-up information

Within the narrative of new data, we need to focus on patient empowerment by properly including it in health literacy programmes. The question we need to address first is ‘what kind of innovation do we need, and how can we best implement it for end users?’ There needs to be a new and clever form of stewardship for patients, which might require the sharing of their data. Furthermore, the trust of the society needs to be gained and deserved. And what better way to accomplish this trust than to let the patients inform the rest of society, and with their knowledge and experience advocate for innovation and progress?

Approach to data

Data alone will not lead to any significant changes – rather, we need to make this data accessible and useable in a sensible manner. We need to develop tools to enable a new approach to data, ensuring that the information coming from this data is reliable and correct and fostering trust. Data, as well as its

meaning, needs to become a public good, and it should stop belonging to a limited group of people, and be used as a commodity. Also, as there is already too much content within our databases, an initiative to 'clean data' should be launched. Human abilities are limited, and although data exceeds our capacities, we need to find ways to tame it and use it productively. Additionally, there is a strong need to de-silo, because only then can big data efficiently be used for policy making in public health.

Knowledge in the right hands

Data in society has yet to start and function as a whole – as can be shown on so many examples in which data is used only for personal or institutional benefit, causing the inefficient use of healthcare resources, with big data being prevented from realising its full potential. We need to spread the idea of investing in the 'common good', and the only way to understand the benefit of this concept is through accessible data. We cannot assume that patients are as informed as doctors, or that financial managers have all the information that health professionals have. We are now challenged to build a firm and strong ecosystem, within which all the stakeholders are known and respectively know their place and role in innovation development.

Politics as a negative disruptor

Big Data as a term is not unified, everyone has a different notion of what it actually is: is it measuring outcomes, technology, effectiveness, guidelines, eHealth, healthcare delivery, integrated care, Google, apps...? There needs to be more nuance within the debate to avoid confusion among policy makers. If a concept ends up meaning everything, it means nothing. We should take into consideration the politics of it all, and not stay blind to the games it brings about. Rather, we should try to adjust and bring health to all politics. We should stop being naïve and stop talking about interoperability if we cannot implement it. The political agendas need to be aligned, and we need to help decision-makers understand what the potential of big data is. We need to be aware that interoperability does not function along the lines of the acronym LOST (legal-operative-semantic-technical level), but rather along the acronym P-LOST, with P standing for political will.

“Data is the new oil”

Attitudes towards data sharing are not only based on cultural differences, it is also a generational issue – privacy might not be a hot topic in ten years any more. If we want to be creating for the future, we need to talk to the young generation, to the 20-year olds and teenagers, and ask them about their perspectives about data sharing. Data is the new oil because data, just like oil, has to be drilled, refined and adjusted depending on the use – a fine process to get to the final product.

Process and change management

There needs to be a distinction between innovation in products and innovation in services. As healthcare depends on processes, this issue is very important. Product innovation alone will not suffice - it still needs to be integrated in (innovative) processes to, in the end, be successfully implemented and scaled up.

We need to put more focus on the change management and to be able to accompany technical innovation. The entire society is 'forced' to evolve, and we need to be able to accompany it, and this assistance is crucial to happen in healthcare, as it is much more essential than in some other parts of the society.

Conclusions

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- The discussion about innovation in health is essential. In particular, there is a need to reach an understanding on how innovation policy and politics are functioning. We need to take all aspects – and stakeholders – into consideration and introduce them to the discussions.
- There is a huge potential in the innovation sector, and it is clear that the next big opportunity could be Europe's – the main obstacle to taking it is not in health policy, but in the market regulations.
- The human factor is crucial, and each expert carries a heavy burden of responsibility towards the entire humanity.
- On the European policy level, health is not as aspirational as it should be. Innovation might be a good entry point for the expansion of the health movement.
- Patients need to know that they are being treated on the best available data, which can be big or small, more or less structured, epidemiological or other.
- If Europe is going to be a global player, we should think in both directions: learning from others' innovation, and sharing ours.

Resoucrses

DG CONNECT has financed 6 studies about using big data for public health policy making
[Read more](#)

- Contribution to the public consultation on Transformation of Health and Care in the Digital Single Market
[Read more](#)

Additional reading

- Public consultation on the preliminary opinion on 'Disruptive Innovation. Considerations for health and health care in Europe'
[Read more](#)
- Public survey on Net Innovation for the Work Programme 2016-2017
[Read more](#)
- Expert panel on effective ways of investing in health. Disruptive Innovation - Considerations for health and health care in Europe
[Read more](#)
- Regulating the internet giants. The world's most valuable resource is no longer oil, but data
[Read more](#)
- EU policy makers seek views on digital innovation in health and care
[Read more](#)
- Clouds linger over troubled transatlantic data-transfer deal
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- Fitness Tracking Startups Are Sweating Due to EU Privacy Regulators. Privacy regulators worry companies could abuse access to data
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