

## Precise medicine for better patient outcomes A HOPE roundtable

On 27 September 2018, in Estoril (Portugal) during the 27th European Association of Hospital Managers Congress, HOPE was organising a session « Precise medicine for better patient outcomes », chaired by HOPE President, <u>Eva M. Weinreich-Jensen</u> with speakers from Denmark (<u>Erik</u> <u>Jylling</u>), Estonia (<u>Andres Metspalu</u>), Belgium (<u>Pascal Verdonck</u>) and France (<u>Guillaume Mercy</u>).

Eva M. Weinreich-Jensen introduced the speakers explaining that the session was wanted to bring forth four different perspectives on the topic of precision medicine: regions, hospital federations, managers, and researchers. To shine a light on the various ways that precise medicine affects how we work and what we need to do to make the most of the new possibilities, in order to make the newest possibilities available to our patients.



<u>Erik Jylling</u>, Executive vice president of Danish Regions presented "From Precision Medicine to Personalized Health. The Future Healthcare - New paradigm - New tools", showing first the disruptive forces leading to basic change in health care conditions. In this context new technologies represent a great potential but need the creation of a balanced eco system centered around the patients' needs, balancing security, trust and transparency. The first step is an outpatient strategy so that patients stay at home; diagnostics and treatment take place in the patient's home; the GPs are responsible for treatment of the big chronic diseases and the patient's empowerment is strengthened. "same day surgery" when possible cut down overtreatment and hospitals change from



outgoing to outreach. While telemedicine is technology as "compensation for distance to hospital", coproduction health service model ("Teamwork") is technology taking "advantage of distance to hospital".

There are many considerations for delivering precise personalized medicine/healthcare: a health care system infrastructure (governance), a technology infrastructure (electronic patient record, information systems), a legislative framework (GDPR, Data-ownership), patient consent, patient empowerment (self-management, wearables...), and a digital health strategy. This includes initiatives like: The Virtual Doctor, digital tools for rehabilitation, better citizen control and overview over health data, Digital Pregnancy Journal, digital workflows between different health sector professionals, continuous work on home monitoring, data security and IT, infrastructure optimization and so on. It needs an infrastructure for personal health and new legislation concerning (among others) genomics data and citizen consent concerning the use of health data.

So, in short, the big picture is that the vast new variety of data and information available – with some of them coming directly from patients' wearables – means that we have a much higher possibility of treating the patients individually. If we – as hospitals - manage to catch the information, work closely with the patients and consider their input valuable, we can get better results. But as simple as it sounds it will challenge the way we usually have been thinking of health care and how to deliver it.

Andres Metspalu, Professor at The Estonian Genome Centre, Institute of Genomics, University of Tartu, presented "From Biobanking to Precision Medicine". The Estonian Biobank has worked on a prospective approach, longitudinal, volunteer-based with 52,000 participants (5% of the adult population of Estonia) on health records, diet, physical activity, but also on DNA, plasma and cell samples. It was based on the Estonian Human Genes Research Act that includes a broad informed consent and open for research with clear access rules. In 2018, an additional 100 000 people will be added to the biobank and all will be genotyped with GSA array. The system moved from questionnaires to national registries providing disease trajectories and treatment history for all 50000 people. He then presented the case of familial hypercholesterolemia and of breast cancer. Considering that on average 5.5% of individuals in the population use at least one of the 32 drugs associated with the studied genes on a daily basis, the pharmacogenetic feedback is now based on (semi-)automatic decision support system. He concluded that large prospective biobank cohorts make it possible to move towards personalised risk prediction and to use it in general medical practice, however, there are still many challenges on this road.

<u>Pascal Verdonck</u>, Chairman, AZ Maria Middelares, presented the perspective of a hospital manager on precision medicine. In the health continuum technology is the "driver" and according to him, precision medicine is data-driven medicine. Precision medicine is a medical concept/process that customize healthcare, with medical decisions, treatments, practices, or products being tailored to the individual patient. Precision medicine is "an approach" for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person.



According to him, it is not completely new. A person who needs a blood transfusion is not given blood from a randomly selected donor, but the donor's blood type is matched to the recipient to reduce the risk of complications. Diagnostic testing is employed for selecting optimal therapies based on the context of a patient's genetic content or other molecular or cellular analysis. He mentioned the tools employed in precision medicine: molecular diagnostics, imaging, and data analytics. Concluding on the challenges and requirements, he said that smart infrastructure is needed as well as standardization of the collection of clinic and hospital data. There is a need to design databases to store large amounts of patient data efficiently. Scale is needed because sequencing large amounts of DNA are expensive to carry out. There are ethical, social, and legal issues: privacy and security.

<u>Guillaume Mercy</u>, Fund for Research and Innovation Project Manager, at the French Hospital Federation presented "The Role of Hospital Federations for Precision Medicine." He first listed the current limits to precision medicine: lack of skills, economic challenges (highly specific therapies), storage capability (digital data and biological sample), security (sample contamination, cyber-security, ...), philosophical and ethical, scientific and technical. The hospital federations can manage the lack of skills and lower the cost for precision medicine by sharing resources, best practices and organization (white paper), by providing recommendation for new production structure, by anticipating innovation for rapid adaptation (business intelligence tools). Hospital federations have the potential to organise the innovation to facilitate deployment of new technologies. They can manage and secure data by providing structuration and collection tools for genomic data, by identifying vulnerabilities in the system to correct them. Hospital federations can organise social debates and <u>support research</u>: creating an ecosystem with common values and complementary goals, being a meeting place where skills, knowledge and resources can be shared, mixing different actors to develop new approaches.

Summing it all up in short: we need to think health care and the role of hospitals in a new way, if we want to take advantage of the possibilities precise medicine offers. Even if the citizens are ready to share the data, we must be ready to get their consent, opinion and have the infrastructure ready to manage the huge amount of data that are possibly accessible, not just for patient treatments but for research purposes, too. And that we take both hospital managers, hospital staff, hospital federations, patients, citizens and many more to succeed with that.