



# HOSPITALS AND HEALTHCARE SERVICES OF THE FUTURE



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## **Future challenges (and existing ones) for European hospitals and health care**

**“Prediction is very difficult, especially about the future.” Niels Bohr**

Some think that experts' predictions are no better than a random guess. Given no-one a few decades ago successfully predicted how the world would be today, we might wonder whether we have any hope of predicting how it will be 10, 20 or 50 years from now. Yet we feel compelled to try, being no passive observers of an unfolding drama, but actors shaping history. As individuals we are all forecasters and visionaries, attempting to read the trends and at the same time to create the future we want for ourselves.

Hospitals and healthcare services are not passive in the face of current and coming challenges, namely greater health needs, fewer resources and changing social values.

The significance of the upheavals caused by transformations in medicine call for critical reflection as well as political, social and humanistic consideration that measure up to the challenges to be overcome. It is all the more necessary to mobilise civil society given the significant ethical impacts of the progress being made. Seen from this stance, and in spite of the growing number of bodies dedicated to these issues, these changes are applied with relatively little collective debate. The reinforced position and role of the patient in healthcare systems, the critical importance of streamlining healthcare systems and the need to promote medical research all require vigilance.

How value is constructed differs across countries, regions and even organisations. However, common components of the construct of value include an element of cost and outcome. While measuring costs might appear relatively straightforward, in reality this practice is fraught with difficulties. The same holds for outcome, whose measurement is arguably more challenging as the outcome indicators vary across countries and organisations.

Society's values will certainly be even more debated: how to balance individual responsibility and solidarity; how to keep universal access to healthcare.

## **Scientific innovation**

Since the 1980s, progress in the IT and biology fields have led to extremely rapid medical advancements. The increase in calculating and memorizing capabilities combined with the miniaturization of components, advances in biomaterials and biomathematical modelling allow us to address the most optimal treatment pathways and to save valuable time, especially as regards cancer and degenerative disease treatment. The development of biotechnologies, medical robotics and nanochips, combined with innovative molecules and genetic therapies, offer an opportunity to modify living organisms. Impacts on health and on life expectancy could be tremendous. Prescription-assistant software and medical simulation tools provide accelerated analysis and data processing capabilities that augment the quantity and the quality of the information controlled (like the analysis of drug interactions). Medical teams are able to resuscitate patients whose brains have been damaged and keep them alive. Prenatal screening for chromosomal abnormalities has become standard practice over the last fifteen years. The use of targeted molecules, GMOs and stem cells for treating certain illnesses is starting to gain ground in practice (Alzheimer's disease, breast cancer, diabetes).

Science, which is at a turning point where our understanding of the molecular pathways of the human genome, is finally reaching the stage where we can translate it into medicines.



Several industries such as robotics, genomics and big data are already benefiting and attracting investment.

For brain implants, labs are developing implants that enable disabled people to move robotic limbs by power of thought. Powered exoskeleton, robotic bones and muscles worn outside the body are already a reality. Bionic solutions bypass the eye and feed information directly to the brain. Biological approaches to blindness include gene therapy and implanting stem cells. With artificial hearts, and synthetic fertility using stem cell technology, new fields are opening up.

The promise of better healthcare through the introduction of new health applications such as wearables, embeddables, ingestibles, electronic health records (EHR's) and even the 3D printing of drugs and body parts raises expectations for improved health and longevity. However, the ability to design and rebuild ourselves raises many questions about how we relate to the environment and to ourselves, and it also challenges us to ensure that increased health through greater accessibility to new technologies is attainable for more than just the privileged few.

At the same time, the penetration of recent innovations in communication technology is being astonishingly rapid but a substantial division exists. The rise of global communication, of our reliance on cyberspace and of big data raises difficult questions about privacy, national security and about the relationship between governments, corporations and individuals.

Technologies are tools, they offer both opportunities and dangers. What we make of them is, as always, up to us.

## **Promoting technological development and medical research**

Innovation and research are key elements for improving the efficiency of European health systems. They lead to advances in medical science, which allow more patients to be treated and quicker. It also reduces the cost of staying in hospitals and increases the efficiency of the health system. But innovation and research come at a cost.

Health Technology Assessment can help where priorities have to be addressed in the promotion of technologies. HTA aims to respond to decision makers' information needs, regarding the introduction, coverage, use or disinvestment of health technologies. Systematic European HTA coordination would be very useful. The forthcoming European Reference Networks (ERN) could become an interesting instrument to test at European level, some innovation in medicine.

Technological advances in artificial intelligence, biotechnology, nanotechnology, robotics and neuroscience have left policy makers, business people and consumers scrambling to understand their full social, economic and ethical implications. How can we ensure that artificial intelligence is used for beneficial, rather than unethical purposes?

## **Robotisation**

Today, robots perform cleaning, disinfect the environment; they transport and distribute medication and meals. Robotisation is becoming a reality in some hospitals to help doctors undertake surgery and provide services to patients.

Robotic surgery has already proven itself to be of great value, particularly in areas inaccessible to conventional and laparoscopic procedures. It has the potential to expand surgical treatment modalities beyond the limits of human ability. Whether or not the benefit of its usage overcomes the cost of implementing it remains to be seen and much remains to be worked out. Probably the solution could be to use surgery robotics in specific centres and for specific diseases.



Another important development in robotics can be seen in the field of chronic diseases and disabled people. It lies in its wide-ranging ability in maintaining and expanding the autonomy of these people not only in hospitals but, above all, in their own homes. Probably “domotics”, the science of “home automation”, can better help to face the broadest challenges in the future and it probably presents the best possibilities expansion.

In the coming decades machine learning is likely to be the primary force behind an explosion of applications in robotics and software automation, as can be seen with robotic rays created from rat heart cells or a stingray robot with living cells which can respond to light signals, paving the way for the development of autonomous artificial creatures that can make decision by themselves.

Nurse practitioners with an intelligent machine at their fingertips can handle work that once required more highly trained professionals. Technical assistance systems could then improve working conditions in inpatient care but would not alleviate care staff shortages.

## **Nano**

Innovations such as nanotechnologies and nanomedicines can meet a lot of medical needs, which are not yet covered, in assisting existing equipment and in helping devices to become more efficient. It will be of particular help concerning cancer and surgery.

Nanotechnology has been attracting much interest in recent years. It is considered as a new key technology, able to change our lives in many ways. In some areas, nanotechnology is still in its infancy, requiring much more fundamental research, while in other areas, products are already on the market and on the public’s radar.

Nanomedicine has been identified as a strategic priority in a number of countries. Improving existing diagnostics and therapies, and using nanotechnology to develop new ones are also priorities. Implementation is focused on improving the quality of patient service, enabling technology to move towards more personalized care, at an affordable cost, offering competitive products with high added value.

In addition to excellence in multidisciplinary scientific research, the transfer of nanomedicine from the laboratory to the clinic requires the care sector to coordinate with other industrial sectors (pharmaceutical, biotechnology, medical technology) and research centres.

Research in nanoscience will hopefully contribute to the development of new treatments, new pharmaceuticals and new medical devices. Research is performed in areas such as neuroscience, oncology and infection biology. In order to grow, this research needs both substantial private and public financing.

However, European healthcare systems are facing economic pressure and many firms are reluctant to invest in these new technologies. A future challenge for European healthcare systems will be to give incentives to manufacturers for them to invest and develop nanomedicine. How to deal with growing technological possibilities and artificial intelligence to overcome ageing?

## **NANOTECHNOLOGIES AND NANOMEDICINES IN SPAIN**

NanoMed Spain brings together over 100 public and private sector organizations in Spain that are focused on developing and transferring nanomedicine to the clinic. Given the multidisciplinary nature of nanomedicine, the Platform first seeks to efficiently represent all the different players - in academia, industry or hospitals - that contribute to this aim, identifying both their contributions and their interests in its challenges. In the current economic situation nationally and internationally, the Platform is committed to working as efficiently as possible with the resources available to consolidate the strong position of Spain, which is in the lead internationally in this emerging area. The Spanish Research Council ("Consejo Superior de Investigaciones Científicas (CSIC)"), develops its activities in a large number of scientific and technological areas all around Spain, where several Institutes have been created by the CSIC.

The Andalusian Centre for Nanomedicine and Biotechnology, BIONAND, is a multidisciplinary research centre designed with the objective to promote and support the development of new systems for diagnostics and disease treatment through the research in one of the most promising fields within the new technological advances in medicine: the nanomedicine. This centre is part of the Andalusian Initiative for Advanced Therapies created by the Andalusian Regional Ministry of Health, which aims to promote and support the research in three strategic research lines, Cell Therapy & Regenerative Medicine, Clinical Genetics & Genomic Medicine and Nanomedicine.

The Institut Català de Nanociència i Nanotecnologia (ICN2 – Catalan Institute of Nanoscience and Nanotechnology) is a renowned research centre. Its research lines focus on the newly discovered physical and chemical properties that arise from the fascinating behaviour of matter at the nanoscale.

## **Personalised medicine**

The development of personalised medicine in European countries brings new challenges. It is clear that it can help society identify the risks in a population and prevent them. It uses research, data and genetic information to determine which treatment or regime will work for a person. It provides better diagnostics and a quicker response. The efficiency of the treatment means that patients are less likely to require hospital beds.

The genomics revolution has allowed us to understand rare disease on a molecular level in a way that was not possible before. These breakthroughs have been accompanied by a second driving force: digital technology. The ability to harvest and analyse large volumes of genomic data are accelerating the hunt for genetic markers of disease and helping identify people with rare conditions.

With genome-based services hospitals can be leaders in prevention and they will have to take responsibility for decisions on prediction tests and treatments for health problems.

With the advent of personalised medicine, the role of caregivers and patients will evolve. Models that enable sharing, ownership and the development of a sense of responsibility towards personal health data, as well as the improvement of personalised medicine health literacy, will need to be generated along with suitable common principles, appropriate policy and regulatory frameworks.

The development of personalised medicine will rely heavily on integrated 'big data' analytics and ICT solutions to generate the required knowledge and infrastructure. Technologies for data capture and management and the development of high quality databases will be instrumental.

Translational research infrastructures and data harmonisation of structured, semi-structured and unstructured data will be a central component of such strategies. This should lead to new analytical methods and modelling approaches as well as innovative decision support tools such as in silico simulations to support physicians' decisions.

To reach its anticipated impact on human health and wellbeing, personalised medicine will need translation of discoveries and communication across the continuum of research. This starts with the integration of all 'omics' data to generate and implement meaningful interventions. Such processes should be supported by re-classifying diseases at the molecular level and by developing preclinical models to validate hypotheses resulting from molecular analyses. The development of new clinical trial designs that are adapted to these new approaches and the integration of preclinical testing with innovative clinical trials may further improve the effectiveness of interventions.

Bringing innovative personalised medicine solutions to the market presents a new set of challenges, one of which is uncertainty. There will be opportunities to support the development of new risk-based approaches for evaluating personalised medicine in a context that encourages systematic early dialogue with all stakeholders, including regulators, funders and innovators, providing guidance for companies on entering the market for personalised medicine. Finally, research on appropriate policy, regulatory and legal frameworks would ensure that the new challenges associated with personalised medicine are adequately addressed from these perspectives.

Personalised medicine needs to rely on a knowledgeable healthcare system that is able to adapt to these new approaches in a timely and socially acceptable way, and that enables the participation of all stakeholders to increase its effectiveness and efficiency.. The starting point for this requirement is the development of training programmes on personalised medicine for health professionals, and promoting the engagement and close collaboration of all stakeholders, including patients. Patients and the citizens will play an increasingly important role in adopting and controlling the use of data from electronic health records and in developing prospective surveillance and monitoring systems for personal health data. To ensure the effectiveness of healthcare systems, health economics research relating to personalised medicine needs to be supported. In addition; a flexible framework for pricing and reimbursement that is fair for all patients needs to be developed, leading to an overall healthcare financing strategy that covers all aspects of personalised medicine.

Developments in technologies for sequencing and bioinformatics continue to be the major game changer in research. The idea of moving from gene identification and diagnostics to therapy development is currently playing out in many rare diseases.

Significant inequalities in access to diagnostic testing services still exist across Europe and the world. Without investment in the development of quality assured genetic testing services, patients will struggle to obtain a diagnosis. There is an urgent need to support access to diagnostic services with integrated clinical care pathways and trustworthy information systems, which will reduce delays and help clinicians support families affected by a rare disease.



## PERSONALISED MEDICINE – THE SPANISH WAY

Precision medicine, also called personalised medicine, is an innovative approach that takes into account individual differences in people's genes, environments, and lifestyles. The future of precision medicine will enable health care providers to tailor treatment and prevention strategies to people's unique characteristics, including their genome sequence, microbiome composition, health history, lifestyle, and diet.

The Spanish Health Minister, Dolors Montserrat, has announced in the Senate that a National Strategy on Precision Medicine will be launched within the current legislature. The Ministry of Health "will try to move forward" this strategy with the collaboration of parliamentary groups and Autonomous Communities «from the coordination and exchange of successful experiences." The Minister also referred to the future inclusion of genetic counselling and genetic screening in the common portfolio of services and the development of a map of genetic analysis by the Spanish Network of Agencies for Health Technology Assessment and Performance.

The new National Strategy will reinforce the development of personalized medicine in Spain. There was an investment of almost €45 million by the Carlos III Health Institute between 2013 and 2016, financing 190 projects related to personalized medicine. Ten research centres in Spain working in the field of exosome research have formed a network of excellence (Network of Excellence for Research and Innovation on Exosomes, REDiEX), an initiative funded by the Ministry of Economy and Competitiveness (MINECO).

The Hospital Clinic of Barcelona understands personalised medicine as the provision of care adapted to the patient's profile. Genetic screening is used for treatment in familial colorectal cancer and melanoma at the Hospital Clinic. They also use remote monitoring for cardiac devices and chronic diseases.

## Digital technology

Healthcare has been slower than some other industries to feel the full force of digital technology. From wearable sensors providing real-time-data on an individual's wellbeing to the ability to sequence a person's genome for a limited cost within 24 hours promise greater visibility over personal health and offer the possibility of earlier, more targeted treatment when people fall ill.

These devices herald the beginning of a big shift towards more informed patients taking greater control over their own health. No longer passive recipients of advice and treatment from doctors, people will have access to their own real-time digital dashboard of medical data.

Digital technology promises to aid drug development by allowing "real world data" from large patient populations to be pooled and analysed. This is opening new ways to assess the safety and efficacy of medicines, potentially streamlining the path to regulatory approval.

Systems must be designed to meet the needs of patients and those who care for them. Many people are already undertaking some health transactions online, such as ordering repeat prescriptions, checking hospital reviews or booking hospital and other healthcare services appointments. For a lot of people, their appetite for using digital technologies as part of their care goes beyond this in ways often not yet envisaged in service delivery.

Health literacy is closely linked to outcomes for patients; and with increasing amounts of health information being presented online, hospital and healthcare services need to ensure that groups with lower levels of internet use, such as older people and more deprived groups, do not miss out. Digital exclusion will need to be addressed, including by catering differently for those who are accessing no, or limited amounts of, information and support online.

There are already a number of programmes where collecting data and comparing performance enables trusts to improve clinical performance. Information technology can also play an important role in improving patient safety, for example, moving from paper-based to electronic patient records.

The technology challenge would allow important information to be shared more quickly and reduce the risk of records being lost or misplaced. However, organisations are often hampered by limited support in the system to build their capability and skills to make best use of digital technology in these ways.

Healthcare organisations must also be better supported to harness technological innovation in order to reduce costs while improving people's outcomes.

## **DENMARK: YOUNG.CONSTANT-CARE.COM**

### **Danish eHealth app for Children and Adolescents with Inflammatory Bowel Disease**

Parents take responsibility for handling their children's disease, but it is important, that children and adolescents learn how to handle the disease themselves. An eHealth application "Young.Constant-Care.com" involved young patients in their own treatment, and resulted in fewer visits to the hospital and fewer days away from school. The aim was to empower 10-17 years old patients with Chronic Inflammatory Bowel Disease.

The participants used Young.Constant-Care.com on a monthly basis and in case of flare-ups. Patients had only one annual pre-planned outpatient visit.

The participants registered symptoms and medication in the eHealth application and sent stool samples to the laboratory for analysis of faecal calprotectin, - an intestinal inflammation biomarker.

A combined score of symptoms and faecal calprotectin represented the patient's disease activity and was shown for the patient in a traffic light system (green, yellow and red colours), determining further action. To ensure proper follow-up, "web-rounds" were performed weekly by the IBD-team.

The project was safe and showed that patients had fewer visits to the hospital and fewer days away from school. Disease activity and quality of life were unchanged. According to the positive results, the eHealth monitoring is now being offered to everyone in the target group. Patients need to be assessed by their doctor before using the eHealth solution.

A new dimension is being implemented into the existing eHealth application called "Here we are and here we come". The aim of this application is to improve the transition and transfer from the department of paediatrics to the adult gastroenterology regimen.

K. Carlsen, MD, V. Wewer, MD, PhD  
Department of Paediatrics, Hvidovre University Hospital, Denmark

## Data

The ultimate need would be independent data capture for all types of clinical, biological, imaging data and records alongside biomarker test results and all therapies received, in databases which are constantly curated and annotated.

Changes require personal health data to circulate. This raises growing concern over the security and the privacy of patients. Indeed, the dissemination of such data can lead to discrimination acts in employment or in the social security sector. Personalised medicine has to be used with precaution. A balance between circulating information and respecting patients' privacy has to be found.

Data quality, consistency and usability in measuring value and transitioning the value-based healthcare ensure health systems are able to generate and use high quality data in order to measure performance and to compare achievements.

There is an increased interest in the use of real world data to support the continuum of evidence generation throughout a medicine's lifecycle. Real world data should enable more efficient development processes, price-setting in relation to the value of medicines and optimal use in daily practice. However, several challenges are emerging, such as how to manage expectations about the use of such data, how to better understand their usefulness and their pitfalls, and how to encourage their optimal use.

Circulating health data also raises important issues about cooperation between different care providers, creation of national quality registries, medical research based on registry data, etc.

Respecting patient personal data has a very high priority. The legislation is up to date but investment in information technology is insufficient. Regarding the lack of investment resources the problem is not going to be solved soon.

Certain advancements are yet to be validated. However, doctors - and more generally scientists - are already able to diagnose disabilities and hereditary diseases before birth. They are also able to treat each person with a specially-adapted, efficient drug and to push back old age to limits that were, until now, inconceivable.

### **ITALY: PATIENT CENTRED INTERACTIVE DIGITAL PORTAL**

The fragmentation of clinical records in many different digital archives is a current problem which hinders fast data consulting. To deal with this, the Italian Veneto Region is creating a Regional digital archive gathering the health records from all the hospitals and the outpatient clinics of its Regional Health System. Patients and health professionals can access this digital archive via a regional internet health portal. Patients will be empowered through an inter-active role in the use of digital facilities.

A key-point for future Healthcare Systems will be their capability to create a digital portal gathering and managing clinical data from the different archives and empowering patients to have an inter-active role using this portal (i.e. digital booking proceeding, ordering medicines using medical digital prescriptions).



Applying the Italian National Directive on Health Records, "Patient Centred Interactive Digital Portal" is based on the following:

- collecting the health records of each patient in a regional digital archive and creating a regional health portal;
- storing records, as possible, both in a legal and in structured way, to get both legal documents (i.e. document signed by doctors) and processable data for a fast clinical approach (i.e. to show sequences of data such as chronological sequences ) and for statistical uses;
- ensuring data protection and patients' privacy. Each access is typically validated with a user name, password and personal card. Every access path remains digitally recorded. For accessing health professionals need to be authorized by their patients;
- allowing health professionals access for consulting the clinical records of their patients, both in a legal and structured way. Clinical records include medical reports, numerical data (i.e. laboratory), images (i.e. NMR), video (i.e. angiography);
- allowing patients access to their health records both on clinical data and on other personal records such as medical prescriptions or communication from Health Local Trust (i.e. date of a biennial screening test);
- creating, an interactive web-site for all individual patients where they can view their health records and act "on line" such as allowing electronic medical prescriptions to be used by an outpatient clinic for a booking or by a regional pharmacy for receiving the prescribed medicine at home.

## **SWEDEN: REGIONAL OPEN COMPARISONS**

Together with the Swedish National Board of Health and Welfare, the Swedish Association of Local Authorities and Regions (SALAR) has for many years published joint annual reports on quality and efficiency in Swedish healthcare. This information is now presented partly in printed form, partly through a publicly available database. These regional open comparisons have been very successful in encouraging debates on quality of care and medical outcomes.

These open comparisons are to a large extent based on information gathered through a system of about 100 National Quality Registries, providing the Swedish healthcare system with a unique opportunity to monitor quality and results. The registries contain individualized data about medical interventions, procedures and outcomes. They are integrated into clinical workflows and have the capacity to generate data in real time. Each registry is supported by an organisation of healthcare professionals, researchers and patient representatives. They are jointly responsible for developing the registry.

### **1177 Vårdguiden – HEALTHCARE GUIDE 1177**

In order to provide residents with high-quality, accurate and easy accessible information, the Swedish county councils/regions are running a joint website and a telephone service for medical counselling (1177 Vårdguiden). The website provides information on diseases, health conditions, health care providers, preventive and health promoting measures etc. Some information is even provided in foreign languages. The website 1177 also offers possibilities (depending on regional variations) to book medical appointments, renew medical prescriptions, read patient record information, and read and send medical certificates to the Social Insurance Agency.

## Organisational Innovation

Europe is at an important turning point: the changes in society and technology as well as the meaning of health call for a radical change in mindset and a reorganization of how we govern healthcare sector in the 21th century.

The WHO paradigm that health is “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” is not enough anymore. There is a need to move toward a more appropriate and modern concept considering health as “a resource for everyday life, not the objective of living. Health is a positive concept emphasizing social and personal resources, as well as physical capacities. As consequence, health promotion is not just the responsibility of the health sector, but goes beyond healthy life-styles to well-being. This changes the role of health sector, of health professionals, of patients, of the citizens and of the other sectors and societal actors including the private sector (WHO, Ottawa Charter). The classical way of governing health (sectorial, hierarchical, focused on cure, based on medical paradigm) is no longer sufficient to address the new challenges. It needs to be people-centred and people-powered, inter-sectorial, networking and not hierarchical, focused on health promotion and not simply in the cure. The classical way of governing has reached its limits with regard to the organization of health care sector itself and, in consequence, it does not produce the health outcomes and health satisfaction our communities would expect.

### DISCHARGE-MANAGEMENT IN GERMANY'S HOSPITALS

Discharge-Management (DM) in Germany has existed for quite a long time. Since 2002 (renewed in 2009) there has been an “expert standard on DM in care” which is applied by most hospitals in a manner which takes into account the individual setting of each hospital.

It nonetheless has been enacted by law and will formally start in mid-2017 on the basis of a framework contract agreed on by the German Hospital Federation and the Federal Association of Salaried Doctors. This contract provides that for every patient who is discharged from a hospital, a formal DM applies. Prerequisite is the consent of the patient to receive DM and in the use of personal data for this purpose.

DM is planned by a multi-professional team, e.g. doctors, nurses, therapists, social service, etc. The individual needs of the patient for organised care after the discharge will be assessed by the hospital detecting those who have a higher risk for post-discharge complications. Hospitals will have to make a DM-plan, which demonstrates all individual aspects of planning and its implementation. For DM-planning, hospitals may contact the following: relatives or carers of the patient; professions who have the responsibility for the continuity of care like doctors, physio-, ergo- or logo therapists, rehabilitation homes, ambulatory care services; health and care funds.

Hospitals will supply patients on discharge with documentation and materials. This includes a discharge letter and a medication plan. Additionally, e.g. when the patient is discharged at the beginning weekend, drugs as well as means for cure and aid can be given to him/her.

When the framework comes into effect in July 2017, hospitals will be responsible for prescribing drugs, means for cure and aid, home care, socio therapy and they will be entitled to declare a patient as incapable of work. Prescriptions may be given for a maximum period of seven days and in the cases where the patient cannot go to the primary care doctor directly after discharge.

Hospitals also will have to offer a call-service (Monday till Friday from 9 a.m. to 7 p.m., weekends from 10 a.m. to 2 p.m.) and give advice to patients on how to use drugs or means for cure and aid. Additionally, hospitals will have to give support to patients when applying for rehabilitation services. Finally, hospitals will have to publish comprehensive information about the application of DM on their websites.

## **Integrating care**

The majority of European Healthcare systems have a silo structure. There is a fragmentation between health and social system, between hospitals, primary care, social services and other stakeholders. This fragmentation impedes the coordination of care and is a barrier to the creation of better pathways for patients.

With the ageing of the population and the emergence of chronic diseases, the demand for new forms of care is increasing in the EU. Chronic disease implies not only long term treatments but also constant follow-up and supervision. In order to avoid “bed blocking” in hospitals, there is a need to adapt health services provided, from cure to care and from short-term to long-term treatments. One challenge will be to organise continuity of care for patients. Hospitals will move to more complex activities with minimum number of cases with a shift to other healthcare providers.

Although many acknowledge the need for healthcare to change and become more integrated and personalized, there is still a lack of practical understanding of how to do this. This extends from the macro to the micro levels of service delivery. How should we proceed, where should we begin, who should make this change come about? Structured improvement is complex and takes time and, unless the conditions for success are in place, is unlikely to achieve set objectives. Changes to care are stalled by the lack of evidence-based specific recommendations, guides and models for implementation coupled with political inertia, ideological divisions and the inability of politicians to make long-term decisions.

A holistic, personalized approach to healthcare requires improvements in cohesion, coordination and communication between systems. Patient safety incidents are no longer related only to episodic errors and failures in procedures at specific times, but also to cumulative failures throughout a patient's journey within a health system. Significant numbers of healthcare service users report that they feel unsupported and that there are gaps between the different elements of their care.

This fragmentation is driven in a number of ways. Funding is usually provided to different providers rather than on the basis of integrated pathways: hospitals are responsible for and get paid for one kind of treatment, GPs another and social care through a different budget altogether. Different healthcare sectors are staffed by diverse groups of professionals with differing cultures and expectations of their role, which reflects disparate educational backgrounds.

To meet the challenges facing healthcare (particularly those arising from ageing populations with chronic physical and mental health co-morbidities) cultural, structural and process issues of fragmentation and its impact on quality will have to be tackled from micro (organizational) to macro (national policy) levels.

The use of information and communication technologies (ICT) in healthcare is highly variable within and between different countries. Although its use is growing, and there is some suggestion that low and middle income countries could overtake high income countries in its adoption, under-utilization is a barrier because it makes it difficult to target services while maintaining the scale of



provision. The effective use of ICT has the potential to transform healthcare if we can increase its use in situations where it will make the most difference (e.g. telemedicine to allow health professionals to monitor large numbers of people, even if in remote locations, which are at high risk of deterioration and to provide directed coaching and interventions).

The adoption of ICT in healthcare has not always been easy with positive, negative and mixed results. Although ICT can be a powerful tool for service improvement, it will not achieve lower healthcare costs and improved quality of life if it is simply added on to existing ways of working. Rather, a systems approach is needed to ensure a shared vision across providers and to avoid foreseeable pitfalls and ensure sustained benefits.

As the use of mHealth and telemedicine grows, providers will no longer need to be in the same country as the people they serve. This will improve efficiency and access to healthcare but it also raises issues of confidentiality. Where will data go, who will see it and what will they do with it? The lack of harmonized and transparent legal standards and remedies for data use may also be an obstacle to their adoption.

This raises several questions. Will hospitals be more results-oriented, sharing results and good practices? Will not be defined by the physical structures but organised to deliver services at different locations? Reference centres for process and technology innovation and healthcare services design? What role for lean, for hospital-based health technology assessment? How to integrate research and education? Role of translational research and ways to develop those activities? A more active role for leading professionals in care management and improvement also for the collaboration with the different actors?

With remote health management mobile apps, sensors and medical devices will increasingly monitor and improve health and well-being, patients will be more active with health professionals being mediators.

It is vital to streamline organizations, to open up healthcare establishments to their territory and to provide a place for branches and networks in cooperation with all competent professionals. This also involves defining new organizations in the area, which are more focused, which provide outpatient facilities and shared, multi-purpose technical platforms central to treatment/care. The shift to outpatient treatment/care, which is long overdue, addresses a real public expectation.

The hospital of the future is not just a hospital. It is an interconnected network of providers delivering coordinated care across the continuum. In this environment, hospitals will assume new roles, in many cases serving as organizing and financing hubs that bring together all the providers in a community—including primary care physicians, specialists, post-acute care, and ancillary providers such as pharmacy, nutrition and wellness coaches—to seamlessly monitor, guide and treat a person's health from the moment they are born to the end of their life. This clinically integrated network will be accountable for managing outcomes and total costs of the population, each paid on a sliding scale based on how effective they are in achieving these goals.

Care, treatment and support services need to be delivered in a range of ways, across a range of settings and by a range of professionals, all working in collaboration. It is clear that all parts of the health and social care system, and the professionals that populate it, have a crucial role to play in developing and implementing changes that improve patient care and meet the needs of communities.

Achieving this vision will require radical changes to the structure of our hospitals and ways of working for staff.

## **TioHundra – A JOINT COMPANY FOR HEALTH AND SOCIAL CARE IN SWEDEN**

In Sweden, a lot of initiatives have been taken to improve cooperation between different providers – between health care and social care providers as well as between hospitals and primary care/outpatient clinics – and to encourage teamwork between different professional groups. One interesting example is TioHundra which is a company responsible for both health and social care in Norrtälje (a municipality north of Stockholm). The company is owned jointly by Stockholm county council (50 %) and Norrtälje municipality (50 %). In Sweden, the county councils are responsible for health care and the municipalities for social care.

## **SHARING ANTE-NATAL PATHWAY IN ITALY**

Hospitals and Outpatient Clinics are using the same digital clinical record in an on-line platform managed and protected by the Italian Veneto Region. This allows the same information to be shared all over the Region, sharing clinical data and producing epidemiological information “just in time”. This initiative was created with the aim of monitoring pregnancies “just in time”.

The monitoring regards both the single pregnancy (single clinical data) and the total pregnancies (epidemiological data). Hospitals and Outpatient Clinics share a same “clinical sheet” that is an obstetric data base collecting the main information about each pregnancy (risk factors, blood tests, ultrasound scans, obstetrics reports). It is updated every time it is accessed (normally 6 times per pregnancy). The “clinical sheet” is accessible on a digital platform created and managed by Veneto Region, in accordance with privacy and data protection laws.

Clinical files are consultable and upgradable in each establishment (hospital and outpatient clinic) of the pathway network and at any time during the pregnancy, even in the hospital emergency rooms in case of emergency.

This allows pregnant women throughout the region to access an updated database: in the outpatient clinic close to her home, in the hospital of her delivery, in emergency hospital in case of an emergency. Epidemiological Units of the Veneto Region get “just in time” epidemiological tables launching a specific program (i.e. number of ongoing pregnancies, risk factors, premature conclusions).

## **The design challenge**

People’s need for care, and their lives, have changed radically. But healthcare services largely operate as they did decades ago, when the predominant need/ expectation was treating episodic disease and injury rather than providing long-term, often complex, care. Health care systems need to redesign services so that care becomes more integrated, person-centred, coordinated, community-based and focused on supporting people’s wellbeing and preventing crises.

Care is often still organised according to ‘physical healthcare’, ‘mental healthcare’ and ‘social care’, with each being delivered often by separate organisations and groups of professionals.

People do not recognise these distinctions, frequently have need of all three forms of support, and often end up required to do all the work as their own 'service integrator'. The difficulties and distress caused to people through care being delivered by separate, poorly coordinated organisations is powerfully described by service users and carers. There is growing evidence that outcomes and experience suffer because of the siloed nature of care provision. Conversely, service users, patients, carers and their organisations have described what it is that people would experience if this kind of care works well – in the narrative for person-centred, coordinated care.

Beyond social care, there is also often a lack of coordination and integration between healthcare services and other local services such as education and voluntary and community organisations. Put simply, we are still a long way from all parts of the system working in an integrated way towards the same shared outcomes for health and wellbeing.

The vast majority of contacts take place in community settings, and this care and wider support needs to be redesigned to support people's lives. This demands an imaginative approach, which involves collaborating more widely than just the healthcare services, thinking about non-health-based solutions, and using the assets and capabilities of people with long-term conditions and disabilities, and their families and communities. We need to do much more to support and enable people with long-term conditions to lead healthy lifestyles and take action to meet their social, emotional and psychological needs and to prevent further illness or accidents.

The importance of working with people as individuals in their family context, with assets and capabilities of their own, to determine what support they want – which leads to better health outcomes and less reliance on costly and high intensity health and social care. Evidence of what support people want, and its value, continues to grow; different models, involving different agencies, will be required to suit the particular needs of specific communities. Not only is supported self-care what many people want, it also supports good outcomes and is cost effective.

Provision of health services in settings in the community, close to – and in – people's homes, is not always adequate to meet demand – as shown by rising delays in people getting the support they need to leave hospital. The need for system-wide changes if models of care that are more community based are to be implemented; their work also highlights the potential for such models to reduce emergency hospital admissions. Specialist expertise is more often needed in settings outside hospitals. Specialist medical teams should work in partnership with primary, community and social care.

Where care in communities – including support for self-care – is not meeting people's needs, this generates huge pressure on hospitals. More community-based care is needed to support hospital care itself to remain sustainable. While some people will experience better outcomes in hospital, a large proportion of the patients cared for in hospital could have better outcomes and experience of care if they were treated outside hospital.

The hospital sector accounts for the largest proportion of all pending and a very significant part of the assets, both in terms of estate and staff, remain invested in a heavily hospital or institutionally-based model. Hospital beds and the duration of patients' hospital stays have both fallen as the hospital sector manages rising demand through efficiency. The acute sector will need radical solutions to address the pressure from the increasing number and complexity of patients, as well as to manage the short-term risks of shifting resources away from hospitals, particularly maintaining quality and ensuring alternative services manage demand so that people have less need for hospital treatment.

At the same time, there is growing concern that the lack of continuity of care outside normal working hours, across hospital, community and primary care settings, negatively affects patient outcomes and experience. One example of this would be the evidence of increased mortality



rates for people who are admitted to hospital at the weekend. This represents a clear case for moving towards a seven-day health and care system. In developing seven-day services, solutions to financial, service design and workforce challenges will need to be found.

Poor access to preventive services (from primary, community and social care services) is likely to be an important factor in the rise in the overall rate of emergency admissions for conditions that are potentially avoidable – such as asthma and pneumonia.

Despite the limitations of the way care is organised in many places, it can be very challenging to secure support for changes from patients, the public and staff. Change cannot be credible without close alignment of patients, local communities, managers and staff around the vision for change. This requires early, genuine and constructive engagement; this is not easy and requires time and money. Change should be based on what local communities need and evidence of what works, and should enable and facilitate the health and care system to be more effective.

## **FINLAND: IT FOR HEALTH**

In the near future of Finland, the development of medical and IC technology gives new possibilities to diagnose and treat patients. Understanding of disease mechanisms gives tools to prevent and cure diseases instead of alleviating symptoms. This will have remarkable impact on the structure of social and health care systems. Patient can be diagnosed and treated at home without a doctor visit.

Doctor/therapist and patient communicate face-to-face via digital channels. Psychotherapy is given using this kind of video-technology in Lapland. Non-invasive methods replace blood samples and physical measurements. Devices to measure blood glucose through skin by the patient are in use in primary care. The information obtained will be carried automatically from the device to the electronic patient record using mobile technology. This method is in use in our hospitals and will be expanded to homes soon.

Specialist consultations can also take place at home using communication technology. Ambulatory control visit can be replaced this way. Doctor-to-doctor consultations, meetings etc. already take place using video connections.

Biobanks have been built to facilitate the development of personalized medicine. We already have genetic markers that direct the treatment. The prognosis of breast cancer has improved dramatically due to targeted therapy. The significance of surgery will decline. Same development is expected not only in other cancers, but also in metabolic diseases.

Neurological and other diseases (Parkinson, diabetes) can be cured by tissue/stem cell transplant technology. Good results have been already shown in clinical trials.

Advanced technology with the 4P qualities (predictive, personalized, preventive, participatory) will restructure hospitals, both the need of space and the procedures. Future hospitals are compact “hot hospitals” with special diagnostic equipment, intensive care unit and operative facilities

While current structures, nationally and locally, should not be set in stone, the temptation of major, top-down restructuring must be avoided. Major structural re-organisations are costly and it can take years for new organisations to become fully competent after they are created. They also distract attention from improving models of care and hinder the ability of local leaders to work together and build the strong relationships that are crucial for large-scale service change.

High-quality leadership is crucial at times of challenge and when transformational change management is required. This is true at both a national and local level.

Evidence shows that consistent leadership gives confidence to staff, stakeholders and regulators and is important in embedding change. Continuing to increase the engagement of clinicians in leadership will also be crucial. Addressing these issues will need to be part of ongoing efforts to strengthen leadership. Many examples already exist of the types of leadership approach that will be needed. National government, and national bodies, must allow local leaders the space to continue to develop these approaches, which would be stifled by top-down, performance-management approaches.

## **CLINICAL NETWORKS**

Clinical Networks are important instruments in many countries for managing patients in an integrated way. Different networks are described in literature and their common feature is “sharing clinical data”. Today, most of them are sharing by internet or, when they need a specific protected way, by a specific intranet line. They are run in different ways, depending mainly on their aims and their ages, dealing with a single disease or groups of diseases, connecting only hospitals or only outpatient clinics or both.

Clinical Networks represent an important opportunity for the future Health Systems for managing in a more punctual and prompter way the health of their citizens. As much as possible, Networks should have the following main characteristics:

- Involving all the establishments interested in the management of the clinical disease of the network: hospitals, outpatient clinics, rehabilitative centres, home care;
- Sharing the same organizational protocols, same clinical guidelines.
- Storing data both in legal and structured way. Storing in a legal way means creating archives containing legal documents (i.e. reports digitally signed by doctors). Storing data in “structured” way means to create archives which can be elaborated and seen in a logical order (i.e. sequences of glucose levels). These kinds of storage are pre-requisites for the next key-points.
- Facilitating consultancy. Today and more so in the future one of the main problems of doctors is “how to manage so much clinical data”. This means having an easy and fast searching system and a logical presentation of the data. This means that health professionals should be able to see the data of their interest in a logical order such as chorological data sequences or fast comparison of pictures/graphics.
- Facilitating epidemiological works by means routine studies (i.e. epidemiological surveillance) and by means specific studies on emerging problems.

## **The outcome challenge**

Variation in clinical practice is now well documented and associated with poorer health outcomes, increased costs, and disparities in care. Despite the efforts to reduce unnecessary differences in practice patterns they have been difficult to overcome. How to cope with heterogeneity and gaps in clinicians' knowledge; economic incentives for undesired clinical behaviours; autonomy of physicians; communication and decision support tools? Good clinical practice must sometimes vary to reflect a patient's specific social, environmental, and biological situation. Sometimes a standard practice would not be best for a given patient.

Healthcare systems should of course focus on delivering health outcomes, directing our resources to what improves health and quality of life. This may have a positive impact on healthcare system sustainability by identifying and reducing useless spending.

The transition to outcome-oriented healthcare systems has started with the investment made in integrated healthcare systems including their health information systems.

### **PATIENT SAFETY AND QUALITY IN SLOVENIA**

The need for safety and quality care in Slovenian hospitals is well-known. Some indicators are followed on national level and are published in public. All hospitals were obliged to gain one international accreditation certificate. Some hospitals are participating in EFQM process of excellence. Some of the hospitals have also gained ISO 9000 certification.

### **SWISS MEDICATION SAFETY**

A project on medication safety was one among others on the medication part of a national strategy: <http://www.patientensicherheit.ch/fr/th-mes.html>.

The second national pilot programme for patient safety was centred on the admission and discharge from hospitals, times of potential risks of errors in medication. To avoid these mistakes, systematic verification systems have been put in place in other countries. Drawing on those experiences, verification will now be systematic in Switzerland. It includes two elements: a comprehensive list of drugs taken by the patient before being admitted that will serve as a reference for all further process; the systematic use of this list for each prescription. The verification is conducted at all stages of the hospital stay: admission, transfers and discharge.

## Human resources

### Demography

Europe will have to face a lack of health professionals. It is expecting a shortage of doctors and nurses which will not cover the demand of care. More than 3.2 % of the doctors are for example expected to leave the profession each year by 2020. This phenomenon, together with geographical inequalities (lack of infrastructures, medical deserts), will increase the inequality in the access of healthcare in Europe.

Recruiting new and highly qualified healthcare professionals is a major challenge, although there are regional differences. But this is not unique to this sector or these professions. There is also a need to recruit new teachers, new social workers etc.

One first important task is to educate enough new health care professionals. Another task is to make healthcare jobs attractive, improve working conditions and showing young people all the possibilities that the health care sector offers. In this way, sick leave could be reduced and more healthcare professionals will be encouraged to stay, return or retire later. Thirdly, there might be reasons to review the division of labour between various professions and to shift tasks, to encourage more patient involvement etc.

To meet this demand, health professionals will also have to retire later and work longer. So, the need to adapt the tasks for health professionals who will not be able to do their job anymore is increasing.

### Migration

Another issue concerns healthcare professionals' mobility. The Directive on the mutual recognition of professional qualifications is fostering the mobility of health professionals in the EU. The migration of health workers was supposed to rectify the labour market imbalance between different EU countries. The challenge for EU healthcare systems is to ensure a high quality and safety of care even if health professionals' backgrounds differ.

However, the Directive has negative effects on some countries facing a shortage of health professionals due to their migration for better working conditions or salaries. How to manage circular migration will be a challenge for EU healthcare systems.

### Adaptation to innovation

Moreover, with scientific and technological progress, new methods and techniques are developing. Health professionals need to learn to harness these innovations to be more efficient. A challenge for European healthcare systems will be to ensure the constant education and appropriate training of health workers and medical students.

## SWISS CLINICAL NURSE

The implementation of clinical nurses is a project by the cantonal hospital of Winterthur in the canton of Zurich. It involves clinical nurses taking over activities conducted so far by medical doctors. The project is limited to the Department of surgery and evaluated by the University of Applied Science of Winterthur. The tasks are equivalent to those of doctors in the post-surgery phase. The clinical nurses order further diagnostics (x-rays) or therapies (physiotherapy) and decide when a medical doctor is called in.

There will be a need to increase development of non-technical competences, patient communication, team management and conflict management. There will also be a need of new professional roles for disease management, personalisation of care with genetic counsellors, follow up, more engineers for process improvement, information analysts.

It is of great importance that healthcare providers embrace new medical methods and techniques. That requires healthcare professionals to be open to innovation and obtain appropriate training, but also hospitals and other health care providers need to invest in new technologies, further education for their employees etc. Some new methods and techniques will be generally used; others will encourage medical specialization.

Constant and continued education is a requirement for all those health professionals who need a license for their work – medical doctors, dental medicine doctors, registered nurses, registered midwives, pharmacists and physiotherapists. In these cases continuous education and training go beyond basic education and training, including specialty training. This of course includes renewing knowledge on all the different technologies used in their respective professions and in health care as a whole.

Hospitals have traditionally been the centres in and around which all the agents in the healthcare sector gravitate. However, this situation is changing for a variety of reasons. The reasons include the fact that primary healthcare centres are being reinforced and are taking on a higher profile, that alternatives to traditional hospitalisation, such as hospital care at home and hospital support centres, are being developed, and that developments in telemedicine and new technologies mean that only patients who cannot be dealt with by external means are sent to acute hospitals.

More fundamentally, the changes that are affecting acute medicine further challenge this traditional model as social complexity, clinical multimorbidity and the need for coordination of care change the way services need to work.

The current model of outpatient care does not support this approach, and while emphasis on shifting outpatient care in medical specialties to primary care has increased, it is not clear that primary care has the capacity, time or skills to assume this task. Redesigning the role of specialists in diabetes, heart failure, cognitive impairment and COPD will be a key part of any effective future model. Longer appointments for the most complex patients, multidisciplinary assessment and case conferences involving social care and other agencies may be required.

## **Carers**

Ageing of the population in the EU has consequences on society and in particular on carers. The increase in demand of care and the lack of adapted structures to accommodate elderly people is increasing informal and formal care in the EU. Both are helping people to receive home care treatments. Informal care has been decreasing following a change in the traditional family structure, the labour of women, the development of mobility and the ageing of informal carers. But carers will have to face to an increase in the demand of care due to the emergence of poly-pathology.

A change in the approach that specialists take in managing risk is also required; the new models involve sharing this between patients, carers and other healthcare professionals rather than this having to be assumed solely by the specialist. Payment systems and regulation will have to adapt to this approach.

The question is also how to coordinate care and support of patients in the community (pre-admission and post discharge) so that the 'value' of care is increased, or more specifically the risk of acute hospitalization is reduced.



## Financial sustainability

In the EU, health expenditure represents on average 9% of GDP with 70% of funding coming from public funds. The tendency is to increase health expenditure since it increases GDP. However, with the financial crisis a lot of questions appeared about the financial sustainability of the healthcare system.

The gap between funding for the health system and the rise in demand is making it increasingly hard to see how the current model can be sustained without more radical change.

There is a clear need to shift resources into community settings, which will require a managed transition. This will need to include investing in change, and addressing the short-term risks of shifting resources out of hospitals – particularly maintaining quality and ensuring alternative services manage demand so that people have less need for hospital treatment.

Health economists have shown that redesigning services to be fundamentally more productive could fill a large proportion of the funding gap. However, service change alone will not fill all of what is a huge funding gap and releasing savings will not always be straightforward. Further options for responding to the funding gap are limited and involve tough choices. Savings so far have relied heavily on cutting the prices paid to providers, reductions in administrative staffing and wage restraint – rather than redesigning services to be fundamentally more efficient. There is also some limited scope to make further efficiency savings through better procurement, though this could only fill a relatively small proportion of the overall funding gap.

As a number of experts have highlighted, the tough choices required in order to bridge the increasing gap between flat funding and rising demand mean we need an open and honest debate about the future levels, and sources, of funding for health and social care.

There are several key research questions related to future European ageing research in the area of the quality and sustainability of social protection systems. Which measures can make current pension, health, social and long-term care systems more sustainable over time? What are the most effective social and economic policy models in this respect, and how are they interrelated? Which role do education and training play, as 'nonmaterial resources of social protection', in improving the sustainability of social security systems? Which impacts would banning the mandatory retirement age have at micro, meso and macro level? How can an adequate level of service quality be achieved, in times of budget constraints with an ever-growing population in need of long-term care? Which trade-offs and alternative pathways exist between the urgent need to reform and modernise current social protection systems and their long-term sustainability, especially in countries with most traditional welfare cultures? Which role are the current trends of economic globalisation playing with regard to the sustainability of existing social security systems? Will payers be able to purchase outcomes and value and be able to evaluate all the process of care and the health status? How will risk-sharing models develop with payers and the industry? The development of payment by results? What about revenues generated by preventive services?

## Climate change

The link between environment and human health has been evidenced, and European countries now have growing concerns about climate change and pollution. Climate change is largely caused by human behaviour, industrial waste and the concentration of greenhouse gases. It has direct and indirect effects on human health such as the impact on food, the development of water-borne diseases, and the emergence of pathologies linked to the quality of air. These consequences put a burden on health systems as they increase hospital admissions and health expenditure.

Climate change relates to uncertainty and investing in environmental issues is risky as it does not necessarily mean that you will benefit from it. However, in a socioecological approach, health systems need to take care of their natural environment. A challenge for the hospitals and EU Health systems is to promote sustainable and environmentally-friendly hospitals. “Green Hospitals” and “Smart Hospitals”, which save energy and decrease the amount of carbon emissions, are flourishing in some EU countries. They mobilise hardware and software to become “paperless hospitals”.

Climate change poses a major threat to health and healthcare. Changes in the earth’s surface temperature, sea level, rainfall and extreme weather events will put the well-being of billions of people at risk and challenge the preparedness and resilience of health care. The temperature rise is likely to be greatest in higher latitudes but the profound health effects will be felt by those with the least access to resources.

Heat waves will cause increased mortality from respiratory illnesses and heat stress in at-risk populations. The changes in global temperatures will also affect health through the altered spread and transmission of water and rodent-borne illnesses. Pathogen maturation and replication within mosquitoes, the spread of insects to new geographies, and the likelihood of being infected are all affected by temperature rise: malaria, dengue and tick-borne diseases will become increasingly widespread. Poor nutrition from reduced food availability, the psychosocial impact of drought, and the displacement of communities will have further impact on the demand for health care.

Hospitals and other healthcare providers consume a lot of energy and other resources, produce a lot of waste and use equipment, liquids etc. that are (potentially) dangerous for the environment. For that reason, hospitals and other healthcare providers – which can be expected to serve as a good example in health promotion – should develop strategies for reducing their climate impact.

Such strategies should include:

- construction and use of energy efficient buildings and equipment and of renewable energy sources;
- use of safe and environmental friendly products, materials and transports;
- proper waste management including waste separation and reuse of materials and products that are suitable to recycle;
- substitution of harmful chemicals with safer alternatives;
- reduction of water consumption;
- purchase and serving of sustainably grown and healthy food;
- appropriate prescription, safe management and proper disposal of pharmaceuticals.

## Socio-economic factors

### Inequality of access to healthcare

Equal access to the health care available is not yet been achieved in the EU Member States nor between them.

Evidence suggests that inequalities in health are caused by differences in the socio-economic determinants of health, such as occupation, income, education, housing and access to transportation. One of the most prominent publications in the field is the Marmot Report “Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health,” published by the WHO in 2008. The publication reveals that the patterns of global and regional health distribution follow the social gradient: the wider the gap in socio-economic health determinants, the wider the gap in life expectancy and health. This phenomenon exists among, but also within countries and even cities and it can only increase with recent migrations. In any geographic unit, considerably shorter life expectancies are found in the more disadvantaged population groups compared to those who are better off.

There are still significant health inequalities, including by age, ethnicity and socio-economic group. People living in the poorest areas, will, on average, die seven years earlier than people living in the richest areas. The average difference in disability-free life expectancy is even worse: 17 years between the richest and poorest neighbourhoods in some countries. Evidence shows that people living in deprived areas develop multiple conditions earlier than people in more affluent areas – and many people of working age have multiple conditions.

One group particularly affected by health inequalities is people with a mental illness, who are almost twice as likely to die from coronary heart disease as the general population, four times more likely to die from respiratory disease, and are at a higher risk of being overweight or obese. Many of these factors are interlinked, and a person’s overall wellbeing will affect their ability to adopt healthy behaviours, as well as their mental health.

### **SLOVENIA: INEQUALITY OF ACCESS TO HEALTHCARE**

Equal access to health care has many dimensions. Economic equal access is mostly ensured in Slovenia through provisions in the Health Care and Health Insurance Act. The situation is more complex in the case of waiting lists and in receiving the actual information on the waiting times at registration for a visit or a procedure. Waiting lists are big issue

. There will be special attention paid to the different problems, from shortage of staff, to mobilization of resources at different levels and adequate training to identify these needs.

A particular systemic inequality problem in Slovenia is a co-payment system for almost all services covered by compulsory health insurance. Co-payment varies between 10% to 90% of the price of service (even for the most expensive services like organ transplantation and expensive drugs). There is private insurance offered for co-payments which is the same amount for all people regardless of their social status. Many poor citizens cannot afford the insurance for co-payment and co-payment itself so they have limited access to the public healthcare services.

## Health literacy

Health literacy is linked to literacy and entails people's knowledge, motivation and competences to access, understand, appraise and apply health information in order to make judgments and take decisions in everyday life concerning health care, disease prevention and health promotion to maintain or improve quality of life during the life course.

EU health systems are facing a weak health literacy level in the population. Limited health literacy is driving to riskier behaviour and less healthier choices, leading to increased hospitalisation and health expenditure. On the contrary, a sufficient health literacy rate will lead to healthier behaviour and patient empowerment.

Health literacy is varying between different social groups, but more and more people seek information about diseases and health conditions on the Internet. Health literacy has an impact on the patients' abilities to benefit from a treatment, understand the doctor/healthcare staff and take in the information that the health system provides.

Following WHO considerations, it is necessary to remember that Health Literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their ability to use it effectively, health literacy is critical to empowerment. From this point of view, in modern countries, there is a new way to have a problem of "Health Literacy": too much information could be a problem. For instance, Internet information could be a problem. Information on the web is often old, incorrect and often contradictory. The correct use of Internet is a key issue such as the difficult access to health information for some type of people.

Promoting health literacy also means considering the different life phases which are associated with different risks of experiencing inequality and poor health literacy: childhood and adolescence, middle life, older age could need different and specific approaches. Last but not least, it is necessary to work both with professionals and with communities.

Health literacy is more than information: it is about being able to seek out, judge and use health information to make good health decisions in all areas of life. Low health literacy affects health and can reinforce other inequalities. It is an individual challenge but also a systems challenge: healthcare professionals, organisations and systems are often difficult for people to "navigate": they need to adapt so that all users, including people with lower health literacy, are able to understand and easily access the services they need.

Looking ahead, healthcare leaders and professionals will need to be ready to work with patients who will want to be more involved in decision making around care. The present day practice of having healthcare professionals lead decision making related to care that is driven by information asymmetry, will become obsolete because of greater information in the hands of the patient.

This necessitates better integration of health care into everyday life. Patients will expect seamless and on-demand support. Patients will also be looking for more everyday support from their healthcare teams and integrated solutions.

Patients will increasingly move beyond self-diagnosis on websites and draw on social connections to inform their health related decisions. In the future patients will use social connections to advise them on everything from which doctors to see to which therapies to explore. Both patients and healthcare providers will use social media to make a diagnosis. Patients will also become part of learning communities where they share information through virtual discussions and other online resources.

## HEALTH LITERACY IN PORTUGAL

This project “SNS + proximidade. Integração de cuidados e literacia em saúde” aims to: promote and contribute to care integration through the management of people's pathways, especially concerning those with multimorbidity; improve the response to acute disease and acute exacerbations of chronic disease; empower citizens to decide on their health and on proper use of health services, emphasizing the role of health literacy and health promotion across the life-course. The project results from the collaboration of the Strategic Support Centre of Ministry of Health (MH), the Northern Health Administration Region and eight health units in this region, with the participation of some central MH organisations, namely the Central Administration of the Health System. (ACSS), the Directorate General of Health (DGS) and the Shared Services of the Ministry of Health (SPMS).

The project will take place in the Northern Region, in the mentioned eight units, progressing in phases in the course of 2017. It will cover a total of 657,544 health care users (regarding the management of people's pathways with acute illness or acute exacerbations of chronic disease).

Main assumptions:

1. From organizations to people's pathways. It seems clear that there is an urgent need to transform health systems by refocusing them more on people rather than on organizations, and by looking at life course pathways in health care according to the concrete needs at each phase.
2. Multimorbidity and frequent use of health care. This transformation should take place where it is most needed, focusing on segments of the population with health problems and needs arising from multimorbidity, which tend to be frequent users of health care.
3. Management of acute disease and acute exacerbations of chronic disease. It is important to reorient people pathways with acute illness or acute exacerbations of chronic disease, increasing the capacity of primary care through a daily consultation (available to the patient with an acute condition) and improving cooperation between these services with those of emergency in hospitals.
4. Health literacy. The ability of citizens to make smart decisions about their health and the proper use of health services is a critical factor in the good management of health care pathways.
5. Requirements I: Care integration and information systems. The transition from an overly fragmented information system to an integrated one based on the people's pathway, accessible to professionals and citizens, is an essential requirement for the success of the project. From a perspective of the role of the citizen and the promotion of health literacy, a reference digital library is planned. Another initiative is related to a Health Agenda - Health Calendar in the life course, consisting of a set of health promotion and protection messages.
6. Requirements II: Care integration, human capital and new management tools. A number of technical and management tools are being developed for improving health care, from new contracting processes (especially those focused on care integration), to new diagnostic and therapeutic integrated centres, as well as considering relevant areas as "hospitalization at home". At the same time the need to invest in a more diversified human capital in the Portuguese National Health Service (SNS) is recognised. From a perspective of the qualification of the SNS attendance spaces, it is intended to improve the qualification procedures of the public attendance, by the qualification of this assistance spaces, fundamental change, both for the management of the in the health care pathways, and for the promotion of the health literacy.
7. Organizational impact of care integration through the pathways management. In the medium term, profound changes are expected in the organization of health centres and hospitals, through the care integration pathway.



# Patient empowerment

## Towards a Person-Centred Care approach

Patients demand quality of care; they wish to be informed and to get the best medicine available, the best hospital. Patients want to know by whom and in which conditions they will receive care. They want to be able to choose their hospital and be informed about the quality and safety of care. They want to be involved in their own care thanks to a co-decision power between the doctor and the patient. The co-decision gives more responsibility and autonomy to the patient and should guarantee better communication and information for patients.

Patients wish to be considered as more than a health condition. Health care is fundamentally about human interactions. Being treated with respect, dignity and compassion and being seen as a human being with a life beyond one's health condition or status is a starting point of empowerment.

No-one is beyond empowerment, though some people may need more support. The right strategies should be adopted for specific needs, particularly to encourage those who may be in a vulnerable or marginalised situation. All patients should be supported and enabled to have a say in their care, according to their capabilities and wishes, and regardless of their age, gender, ability, ethnic origin, religion or belief, socio-economic situation, sexual/gender orientation, identity, expression or characteristics. If patients wish to delegate a decision to someone else, this should be respected.

All health-related decisions, whether long-term care planning for complex needs or one-off treatment/prevention decisions, should be the result of a shared decision-making process between the patient and the healthcare team. Patients manage their chronic condition themselves most of the time. Patients and professionals need to build a relationship based on mutual respect, share information and engage as equal partners in dialogue about treatment preferences, priorities and values. The information needed is available in an easily understandable format, including health records. Patients have the right to receive information they need and want, in the right amount and format and at the right time, in language simple enough to enable them to make choices according to their wishes. The right not to receive information should be respected. In addition, patients should be able to freely access their own health records and be considered the co-owner of their data, having a say in how that data is shared and used. Information for patients should be co-designed with patients to ensure good quality.

Individual patients' need to manage their care and life in the context of their personal values, goals, family and other circumstances. Therefore they should be at the centre of a joined-up approach to care. Patients and families should be offered all relevant options in order to make meaningful choices, and the health/social care team should include the right roles, skills and knowledge to support elective self-management. Self-management education should be made widely available in the community as part of integrated chronic disease care.

The patient experience should be adopted as a key metric in assessing the quality of healthcare. This does not mean tick-box exercises such as "satisfaction surveys", but meaningful – including qualitative – patient-centred measures. Indicators for assessing the quality of healthcare should be defined also by patients themselves, and not only by what providers assume is important for patients. Patients' feedback should be actively encouraged, listened to, and acted upon.

Meaningful patient involvement is based on the premise that patients have a unique expertise and knowledge: only the patient sees "the whole journey." Patients can identify gaps in provision, but also superfluous or unwanted services, helping make healthcare more effective and efficient. Patients also have a fundamental democratic right to be represented at all levels of the planning, delivery and review of healthcare services, policy and legislation; their involvement should be built into formal structures and processes, and it should be valued.

Individual patients can be powerful advocates based on their own personal experiences and circumstances. In addition, patient organisations put forward views representing a constituency of patients, through a consultative, democratic process. Patient organisation representatives are chosen to represent patients' views at the policy level, and they understand that they are representing a broader perspective. Patient organisations should be systematically supported, including financially, so they can accomplish these tasks effectively.

Equity and empowerment go hand-in-hand. To be an empowered patient, one first needs access to high-quality care. Many patients are not getting even basic treatment. Our vision as a patient community is for all patients to have equitable access, without discrimination, to high-quality health and social care that is designed to meet their needs. This requires political change to ensure the rights of all patients are respected, to fight the inequalities that persist in health across the EU, and to make health a priority in all policies at national and EU levels.

## Demography

### Ageing of the population and rise of life expectancy

The highest life expectancy recorded for women anywhere in the world has risen by a year every four years since 1840. This inexorable advance in longevity is the most important of all the changes to human life in the past two centuries.

Between 2015 and 2030, the number of people in the world aged 60 years or over is projected to grow by 56 per cent, from 901 million to 1.4 billion. By 2050, the global population older than 60 years is projected to more than double its size, reaching nearly 2.1 billion (UN World Population Ageing 2015). In 2030, there will be approximately 40% of elderly people (persons aged 65 or over) in the EU. Eurostat projection states that in 2060, there will be 15% fewer adults of working age in the population and almost one dependent elderly person to two working persons. According to the EU Ageing report 2015, the ratio of persons aged 65 or above relative to those aged 15-64 will increase from 27.8 % to 50 % until 2060. Although the trends are very similar, those averages hide important differences between countries. In any case this implies that the EU would move from having four working-age people for every person aged over 65 years to about two working-age persons. The ageing trend will have an impact on potential economic growth and on labour market and social security systems in a number of important areas, such as the availability of labour force, dynamics of skills structure, capacity to support labour market transitions and maintaining social security standards across Europe.

Demographic change also raises questions in terms of the risks of secular stagnation, with labour making a negative contribution to GDP growth from the mid-2020s onwards, skills and competences needed to raise productivity (resistance to changes vs. adaptation to changes, new technological developments, new production patterns, more mobility and new forms of employment, lifelong learning needs). At the same time, ageing will exercise higher financial pressures on social security systems: including sustainability of pensions systems and increasing healthcare needs. Ageing will also result in increasing demands on the care economy and the need to take into consideration its specific features such as pay levels, job quality, prevalence of female workers, etc.

Demand for health and social care, and wider services that support people's wellbeing, is rising inexorably. People are living for longer, partly because of the successes of the health systems and other public services. This is of course a good thing.

As the population ages, a growing number of us will experience longer periods of ill health and have greater support needs.

People's care needs are also becoming more complex. 70 per cent of health and care spending is on the 30 per cent of people with long term conditions. By 2025, millions of people will have at least one long-term condition and a growing proportion of the population have more than one long-term condition.

Care for people with multiple long-term conditions is often very complex and, as their number grows, so does the impact on demand for services. It has been suggested that at least 30 per cent of all people with a long-term condition also have a mental health problem.

More adults are living with disabilities. It is estimated that by 2030 the number of younger adults (aged 18–64) with learning disabilities will have risen by 32.2 % and the number of younger adults with physical or sensory impairment by 7,5 %.

All of this means increasing amounts of ongoing care, social care and other forms of support needed by a growing number of people, who often have complex needs and multiple long-term conditions, a growing proportion of whom are very frail. The ongoing failure to prevent or delay disease and ill-health is exacerbating the rising demand for care. There has for a long time been insufficient action on prevention, health promotion, early intervention and tackling the wider determinants of poor health (such as education about healthy choices and poor housing).

What reforms can make the European social security models sustainable whilst ensuring that they remain adequate in the light of the expected ageing of population? Not all health care systems are ready to face this challenge. But in all of them it will affect the service that the system can provide. This can lead to more prioritisation and not all expectations will be met.

Prioritizing is nothing new in health care. It takes place every day – now and also in the future. Increasing life expectancy is basically something very positive. But the increase of elderly people and the altered age structure, in combination with higher ambitions and new technological advances that increase the demand for healthcare services, is and will continue to be a major challenge – not just for the healthcare systems, but also for the social care and more generally the overall social protection systems.

But there have not been everywhere serious political discussion or decisions on it. With economic situations continuing just as bad as it has been lately, there might be a need to put that issue on the agenda.

We just do not know how much expectations and demands of services will increase. Ageing is just one reason. There are also other factors like better knowledge of services, legislation (also at EU-level), patients' right to choose, immigration etc.

Lifestyle choices often contribute to the burden of disease too: smoking, excessive alcohol consumption and obesity are proven to increase the rates of preventable diseases. The cost for treating these associated conditions is estimated at a cumulative €100 billion each year. While some progress with some public health issues has been made, such as smoking, other trends, are heading in the wrong direction. This is the case with rates of obesity.

This progressive ageing is accompanied by the high prevalence of people suffering from two or more chronic diseases. These patients use high rates of healthcare resources and, in order to improve the quality of the attention they receive and the efficiency in the management of the healthcare and welfare resources available, they need a systematic management of their care.

Although the ageing of the population is a topic that has been discussed over many years, not all systems are ready to face this challenge. Health services are going to be very affected by these demographic changes since they will require significant changes in many aspects (technological, organizational, training, etc.). Prioritization is essential.

## **Palliative care**

The ageing of the population is also connected to death and how to die decently. In the EU, governments are debating about euthanasia and palliative care. It raises many issues such as dignity, respect and confidence between the doctor and the patient. This is relevant in all national situations. Several solutions have been identified to tackle this today and in the future.

## Epidemiology

In the coming years “health” will continue to become a more holistic concept, and “disease” a more fluid category as definitions change, knowledge increases, and stakeholders (patients, pharmaceutical companies, payers and providers) contest the scientific objectivity of disease categories. While the discovery and development of cures for acute diseases will remain an ongoing challenge in the future, learning to properly manage chronic diseases will be the larger issue. Chronic conditions challenge us to view health and disease not as opposites, but rather on a sliding scale. In the future patients will need holistic care that improves health and wellbeing as well as innovative cures.

While recognizing that modern medicine is about the quest for newer, better and more precise treatments, this has an impact on the design of future treatment places. As we continue to develop more adaptable technologies and health sensors, to apply big data and health analytics, to integrate holistic treatment options, and to design more appropriate and efficient services, our conventional medical understanding of biological systems and treatment approaches will be expanded and transformed.

### EARLY DETECTION IN SLOVENIA

In the past a very successful program for early detection of risk factors for cardiovascular diseases was launched and resulted in earlier diagnosis of hypertension and hyperlipidaemia. Consequently, there has been a steady and sharp decline in premature mortality for ischemic heart disease. Between 2003 and 2009 three organized cancer screening programs were launched – cervical, breast and colorectal. They have all resulted in decreasing the stages at diagnosis and the colorectal and cervical screening programs. This has led to a lower incidence for the respective cancers. In 2016, the screening program for colorectal cancer was extended to include the age group 70 to 74 years of age.

## Non-communicable disease

With the ageing of the population and the development of the consumer society, chronic diseases and lifestyle diseases have been growing. However, a larger part of non-communicable diseases can be avoided by developing prevention policies.

Chronic diseases and lifestyle diseases are on the rise. Unhealthy lifestyles (i.e. smoking, drinking too much, lack of physical exercise, eating both wrong foods and too much) contribute considerably to increasing numbers of patients diagnosed with lifestyle-related diseases. Many diseases could thus to a large extent be prevented by healthier ways of life.

More resources and efforts should be spent on preventive health care and health promotion. Lifestyle habits are often established early in life. For that reason, it is important to prioritize children's and their parents' habits and living conditions. Such efforts must also be directed to those who have the biggest risks of falling ill, since differences in lifestyle are significantly dependent on the social environment, education level, economic conditions and place of residence.

Hospital and healthcare services will work on services for the chronic care management. They need new ways of funding and new ways of working in collaboration and coordination:

prevention, diagnosis, monitoring, intervention and remote management.

Regarding prevention, it is necessary “to build a healthy public policy” as foreseen by Ottawa Charter for Health Promotion. It means putting prevention and health promotion on the political agenda, informing policy-makers about the health consequences of their decisions and to accept their responsibilities for health. It also means working by means of intersectorial actions, creating “health promoting setting”: health services and hospitals have to collaborate with institutions in their communities such as municipalities, schools and workplaces to create advocacy for health. Promoting healthy lifestyles, promoting prevention and the early detection of some types of cancer (breast, cervix, colon-rectal) are important issues in national and regional prevention plans. To put this into practice also means creating some indicators regarding this matter and using these to evaluate the managements of the hospital trusts and health local trusts.

The current organization of health services, which focuses on the resolution of acute pathologies, stimulates episodic care of health problems with a curative approach, while giving little value to preventive aspects of care, the perspective of care, or the responsibility of persons to care for themselves. The lack of coordination between levels of care (primary care/specialized care) and between health and social systems is one of the main determinants of inefficiency in providing, developing and managing healthcare resources.

## **CHRONIC CONDITIONS IN CHILDREN IN PORTUGAL**

Children with neurological and developmental disorders face many challenges. Different services therefore need to join forces to deliver an adequate solution. To achieve this, Development Centres were set up following a report by the by the National Committee of Child Health, presided by Professor Torrado da Silva in 1993. One such centre is the Centre Torrado da Silva for Child Development at Hospital Garcia de Orta (Lisbon and Tagus Valley) which has developed an experiment to reorganize the promotion of equity, efficacy and efficiency.

The goals are to:

- set up a multi professional centre to assist children with neurological/developmental problems;
- provide adequate research, evaluation and treatment/intervention;
- reinforce links and cooperation with the community;
- train professionals in different areas (health, education, social security) through specific internships and training actions;
- create an applied research and testing hub for technical devices and new technologies.

Its methodology is to:

- aggregate the human and technological resources from the different Hospital services;
- change the traditional medical model for team work, where the intervention from other professionals is fundamental;
- empower the families to try and find their own resources that will help deal with a permanent condition.



The results show an increase in the number of consultations in different specialities (10 861 in 2016); multidisciplinary consultations for complex pathologies; interventions in different areas. Training activities involved medical internships (paediatrics, neurology, neuroradiology, child psychiatry), psychologists, nurses and other technicians coming from different areas of the country; training actions for parents and technicians in different areas: health, education and social security. Scientific activity led to clinical research work and projects; national and international communications and articles published in specialized journals.

The reorganization of existing resources led to improved accessibility with a significant increase in the number and differentiation of care, fewer resources used, better use of families' time and a less time off work.

Considering that there is still a lack of public services to deal with chronic conditions, it would be fundamental to replicate the centres with similar organization but with different levels of differentiation, depending on the hospital to which they are aggregated in order to provide a multidisciplinary network of assistance for the chronic conditions.

## **Communicable disease**

With more new health threats (SRAS, H1N1, EBOLA, ZIKA...), healthcare systems need to be reactive. We have to be responsive to new health threats – but also to the possible return of “old ones” (tuberculosis, polio etc.). It is a very relevant issue, especially from the perspective of International Public Health.

Furthermore, in order to organise health services so that they can deal with such diseases, there needs to be international health cooperation and mechanisms for surveillance and control.

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Chief Executive: Pascal Garel

Avenue Marnix 30, 1000 Brussels  
Belgium

Tel: +32 2 742 13 20

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## CO-AUTHORS

Mrs. Dr. Sara C. PUPATO FERRARI, President

Mr. Nikolaus KOLLER

Mr. Willy HEUSCHEN

Mrs. Dr. Todorka KOSTADINOVA

Mrs. Dr. Ružica PALIĆ KRAMARIĆ

Dr. Petros MATSAS

Dr. Roman ZDÁREK

Mrs. Eva M. WEINREICH-JENSEN

Dr. Urmas SULE

Mrs. Dr. Aino Liisa OUKKA

Mr. David GRUSON

Mr. Georg BAUM

Dr. Yannis SKALKIDIS

Mr. Eamonn FITZGERALD

Dr. Domenico MANTOAN

Dr. Jevgenijs KALEJS

Dr. Dalis VAIGINAS

Mr. Marc HASTERT

Mr. Denis VELLA BALDACCHINO

Dr. Jaroslaw J. FEDOROWSKI

Mrs. Prof. Ana ESCOVAL

Dr. Dan CAPATINA

Prof. Marián BENCAT

Mr. Simon VRHUNEC

Mrs. Asunción RUIZ DE LA SIERRA

Mr. Erik SVANFELDT

Mevr. Drs. Margot VAN DER STARRE

Ms. Elisabetta ZANON



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