



2084

- EDITORIAL, *C. LOVIS*
- HOSPITAL OF THE FUTURE, *M. KEEN*
- FUTURE MEDICINE, TODAY'S HEALTHCARE, *S. HEINEMANN*
- LET'S CHANGE BEFORE WE HAVE TO, *M. CABRER*
- SMART CONTRACTS IN HEALTHCARE, *S. JANIN*
- PATIENT HEALTHCARE PORTALS, *M. PETERSEN*
- LABS OF THE FUTURE
- FUTURE OF AUGMENTED REALITY IN HEALTHCARE, *D. MADISON*
- CHALLENGES, OPPORTUNITIES OF TOMORROW'S RADIOLOGIST, *D. HILMI*
- UTILITY OF ARTIFICIAL INTELLIGENCE IN RADIOLOGY, *R. VIDAL-PEREZ*

TOP HEALTHCARE TRENDS
2018

THE FUTURE OF MEDICINE
BOOK, *P. BRONSON ET AL*

VISIONARY LEADERSHIP,
D. CORTESE ET AL

WOMEN IN RADIOLOGY,
S. BAKER

ROBOTICS: A CHANGE

MANAGEMENT CASE STUDY,
L. ROBSON

AWARD-WINNING 'DOCTORS'
ASSISTANTS', *S. MCNALLY
ET AL*

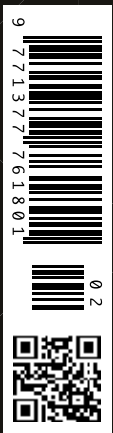
3D PRINTING AT THE JACOBS
INSTITUTE: AN UPDATE,
P. MARCUCCI

DEEP INTEROPERABILITY IN
HEALTHCARE *C. BUCKLEY,*

VIRTUAL REALITY CLINIC: A
CASE STUDY, *B. WIEDERHOLD*

MACHINE LEARNING FOR
BRAIN TUMOUR DETECTION,
D. CORONADO

ARE RANKINGS THE BEST
WAY TO DETERMINE
HEALTHCARE SYSTEMS?
A. LAYLAND ET AL



Leading the way in patient healthcare portals

There is no “one-size-fits-all” approach to patient portals

With the European Commission's eHealth Action Plan 2012-2020 for wide digital health implementation in the works, sundhed.dk explains how to make a success of a health data portal.



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Can you summarise the current work and objectives of sundhed.dk?

sundhed.dk works according to the overall national strategy within eHealth as the state, regions and the municipalities, the funders of sundhed.dk, define it. The work and objectives of sundhed.dk are more specifically set by the strategy of sundhed.dk 2016-2018, which is defined by the political board of sundhed.dk. The strategy for the portal in the years 2016-2018 is:

- Display of more data on sundhed.dk
- A better, more user-friendly and focused portal
- More users to sundhed.dk
- Digital security and reliability of data

The number one priority is to have more patient data for general practitioners and the municipalities' home care nursing sector for more satisfied users in these fields. The last point, especially, has shown to be a tough job in Denmark.

Within this work - and as an add-on to our existing strong public sector data world - the focus for sundhed.dk is also to find a way to handle the citizens' own data extracted from wearables. There is no easy solution and the challenges for sundhed.dk is to be confident that data stays within the ownership of the general public and the citizens. This has to happen in cooperation with the public health sector and players in the private sectors, since they are designing and delivering the devices such as cell phones, tablets, smart watches used by citizens to register and collect their own data.

The next step is to find out what to do with this data. Can it be used by health professionals in combination with other personal health data generated in the public healthcare sector systems? I'm sure this kind of data will improve quality of treatment this way and will lead to more efficient treatment. sundhed.dk could play an interesting role here as a platform for uploading personal data – and a

platform for accessing data.

Within this development, it will be even more important for sundhed.dk in the years to come to consolidate our role as a 'safe place' for the citizens' personal health data. We refer to it as “safe harbour.”

The last thing is the ongoing work with constantly modernising the portal. In recent years this work has been focusing on re-building the portal to ensure access to information and health data from all mobile devices. The development of sunded.dk and the technical framework is always user driven. sundhed.dk has to quickly adapt to new tendencies in the public in technological development and in the healthcare sector to keep adding value to both citizens and health professionals.

How is the work aligning with the EU eHealth 2020 aims?

The work of sundhed.dk is aligning quite well with the EU eHealth 2020 aims. We recognise the challenges presented in the EU eHealth 2012-2020 plan and, even though we have come far with the development of sundhed.dk, Denmark still faces the same challenges: striving for a more efficient healthcare sector and higher-quality treatment through use of technology while keeping the public budgets down.

As highlighted in the EU eHealth Action Plan 2012-2020, Denmark is also experiencing a decline in the number of healthcare personnel, a higher incidence of chronic diseases and growing demands and expectations from citizens for higher-quality services and social care. sundhed.dk shares the perspectives in the EU plan which are as follows: “eHealth can benefit citizens, patients, health and care professionals but also health organisations and public authorities. eHealth, when applied effectively, delivers more personalised ‘citizen-centric’ healthcare, which is more targeted, effective and efficient and helps reduce errors, as well as the length of hospitalisation. It facilitates

socio-economic inclusion and equality, quality of life and patient empowerment through greater transparency, access to services and information and the use of social media for health”.

The overall work of sundhed.dk is in some ways reflected in the EU eHealth Action Plan in terms of its aims of empowering patients and healthcare workers, to link up devices and technologies and to invest in research towards the personalised medicine of the future. This means providing smarter, safer and patient-centred health services. Given the fast-growing uptake of tablets and smartphones, the Action Plan also includes a special focus on mobile health (mHealth).

“ CITIZENS AND HEALTHCARE PROFESSIONALS ONLY USE A HEALTH DATA PORTAL IF IT BRINGS VALUE TO THEM ”

sundhed.dk provides information and data for both healthcare professionals and citizens focusing on ‘patient empowerment’. sundhed.dk has gone ‘mobile’ to match the growing uptake of tablets and smartphones and keep bringing value and provide safe and patient-centred health services – which also support personalised medicine in the future. Personalised medicine has high priority on the political agenda in Denmark and a national strategy for personal medicine was published recently. sundhed.dk has an important role here, also in the future, supporting patients.

On the subject of personalised medicine, it is also worth mentioning that we have experienced a shift from “system data - out” (data-generated in the healthcare system and shown to citizens/health professionals) to “system data - in” (data-generated in the public, by use of devices and optionally displayed to health professionals and maybe integrated to the public healthcare systems).

When it comes to the technical implementation of sundhed.dk this approach does not necessarily correspond with the course of action defined in the EU Action Plan.

sundhed.dk has been implementing a flexible approach without a national framework and national standards to follow, but fostering a spirit of innovation. sundhed.dk recommends encouraging small pilot projects and letting them evolve in their local, innovative settings in different parts of the country in

cooperation between health professionals, users and administrators.

Another key learning to be prepared is regarding data security, associations of healthcare professionals and so on. Do not step aside for arguments for keeping valuable health data a secret and do not reinvent the wheel. Instead keep a pragmatic approach. The technical solution might be the easiest part of digitalisation.

What role did sundhed.dk play in getting the Danish populace’s cooperation for eHealth implementation? What would you say is the most important factor in gaining the support of the population?

sundhed.dk is established and is continually being developed from a user-centred perspective. This approach is reflected in the strategic aims of sundhed.dk: working for a more user-friendly portal. sundhed.dk was established to bring value not only to the healthcare sector – but to the people: to Danish citizens and healthcare professionals. They only use it, if it brings value to them.

sundhed.dk works with user-centred design, service design and invites citizens and health professionals to be a part of designing solutions. The aim of sundhed.dk is to meet the needs and wishes of the citizens and the health professionals.

sundhed.dk offers ‘one entrance’ and easy access for the individual to health information and personal health data. sundhed.dk provides transparency within the healthcare sector and empowers citizens to take part in their own treatment, plan their next visit and so on. Data can be accessed only through a high-security level and the citizens have access to “my log” which is a service that shows the health professionals who have had access to data.

Another key element to explain the success of sundhed.dk within the population is that sundhed.dk is 100 percent publicly funded with no commercial interests. Citizens have great confidence in sundhed.dk.

What have been some of sundhed.dk's biggest challenges and how did it overcome them?

sundhed.dk is publicly owned across three administrative and political levels: the state, the five regions and the 98 municipalities. sundhed.dk is founded in national political strategies and has its own political board and steering committee.

This governance structure is one of sundhed.dk’s great advantages.

Implicit in this model also lies a challenge: everyone has to pull in the same direction, and this can sometimes conflict with agendas and interests. Another challenge is, that the data sundhed.dk shows to citizens and health professionals is displayed directly from the source (the clinical system) or journals written by the doctor. This means that data is presented in “raw” form, without interpretation. This is not always a very user friendly or considerate way to communicate health data. This issue is discussed regularly: on the one hand data should be displayed at once (it is the citizens' own data they should be given access to it). On the other hand a health professional interpretation and comment to supplement data could be more considerate. This “delay” in showing data has gone from three weeks to 72 hours to zero hours at sundhed.dk.

Evaluations of specific services at sundhed.dk illustrate this point of view from the citizens: “data is better than no data” and even the doctors notes are appreciated, even though they are written with another purpose in mind, rather than to communicate directly to the citizens.

Is there anything that could be happening at a policy or other level to make the process of implementing eHealth easier across the EU?

It will be very difficult if you think in terms of overall technological frameworks or standards to be followed and wait for this to be defined and ready. eHealth solutions – also when it crosses sectors or borders – is not, in my opinion “one size fit all”. Technological development moves fast and keeps moving – there is not enough time to analyse, clarify, define, standardise and wait for a ‘great’ framework to be established.

My best advice is to follow the Danish example for one: give citizens login access to their full eHealth data anytime anywhere – worldwide. We must open up and strive for transparency in a secure way. Let the citizens be “in charge” of their own data.

A suggestion could be for EU to focus on bringing people together to exchange experience so that we could learn from each other and from ‘best practice’. Furthermore, we also have to bear in mind, that each country – also within the EU – has a different starting point, different prerequisites and possibilities.

How, in sundhed.dk's experience, does successful eHealth implementation reduce healthcare costs and improve patient outcomes?

You have to look at eHealth as an investment to

support patient empowerment. When you empower citizens, you might bring the number of expensive hospitalisations down.

eHealth provides people with tools that make citizens co-players and co-writers of their own health situation and treatment. eHealth solutions can also support initiatives of prevention and the quality within treatment.

Successful eHealth implementation reduces healthcare costs and improves patient outcomes in numerous ways.

When the number of hospitalisations goes down, healthcare professionals can spend time with critically-ill patients, citizens can stay at home and maintain a higher quality of life and maybe still be part of the work force.

Personalised medicine can reduce costs and bring higher quality in treatment – eHealth can provide different tools to support telemedicine.

What do you think is ahead in the mid and long-term futures for eHealth?

Combining the healthcare sector's data with the citizens own contributions, I think that personal health data collected by the individuals using smart devices will be the core focus in the years to come. The question and the interesting challenge here is how to use this data and how to combine the health data generated in the healthcare sector with the citizens' own data. It fosters, in my opinion, a new co-operation between the public healthcare sector and players in the private market. ■

KEY POINTS



- ✓ sundhed.dk works according to the overall national eHealth strategy as defined by funders the state, regions and the municipalities
- ✓ The health portal stresses being a “safe harbour” for both healthcare professionals and citizens with a focus on ‘patient empowerment’
- ✓ The aims of The European Commission's eHealth Action Plan 2012-2020 align with many of those of sundhed.dk
- ✓ sundhed.dk supports fostering a spirit of innovation through natural evolution of small pilot projects
- ✓ User confidence and trust is essential for healthcare portal success
- ✓ Smart device data will be the focus for eHealth in years to come