

A photograph of a doctor with blonde hair and a stethoscope around her neck, wearing a patterned white and black shirt, looking at a tablet held by a patient. The patient is seen from the side, wearing a green top. They are in a clinical setting with anatomical models and a bookshelf in the background.

FUTURE AGENDA

Open Foresight

THE FUTURE OF PATIENT DATA
A Danish Perspective

DTU Business
Executive School of Business

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The Future of Patient Data

A Danish Perspective

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We would like to thank DTU Business Healthcare
for hosting the June 2018 Copenhagen events

Denmark is recognised as one of the leading nations for healthcare and is at the forefront of digital transformation in the sector. As new challenges and opportunities emerge over the next decade this article considers what the core drivers of change may be and explores how developments in the availability and use of more and better patient data may impact the Danish health system. Linking together previous research, a recent related Future Agenda initiative and insights from a number of expert discussions in Copenhagen, it then examines the pivotal issues that will affect healthcare providers in the future and considers how the wider sharing of exemplary data can change delivery models.



Denmark in the Global Context

Quality of life in Denmark is very high. With a GINI index of just 28.8, Denmark is one of the most equal societies in the world.¹ It is consistently seen as one of the happiest and is also one of the richest.² In 2017 Denmark's GDP was \$51,387 per capita, 20% above the OECD average. From a wealth distribution perspective, average income tax is running at around 45%. Although predominately urban, with approximately 88% of the population living in cities, two thirds of Danes meet WHO recommendations for daily physical activity.³ From a telecom infrastructure point of view it is also a leader - jostling with South Korea to be the world's most connected country. Some 97% of Danes have internet access and average internet speed is 3 times the global average. Mobile phone use is close to universal with 129 subscriptions per 100 people.⁴

Given all this, it is unsurprising that many see that the Danish healthcare system is, without doubt, one of the best in the world. Indeed, the comparative statistics tell a clear story of a well-funded, universal access approach that is delivering benefit to the whole population:

- **Well-funded:** Relative to population size, Denmark is one of the 5 top spenders on healthcare in Europe and the 16th highest globally. According to OECD / WHO / World Bank data in 2014/15 Denmark spent over €28bn or 10.8% of its GDP on healthcare.⁵ This was equivalent to €3996 per head, more than both the OECD average of €3773 and the EU average of €2781 per person (9.9% of GDP). In 2014 there were 3.7 physicians per 1000 population – around the European norm and 40% more than in the US. In addition, there are twice as many nurses as the EU average.
- **Universal:** As with several other countries, Denmark provides universal healthcare coverage for all of its population. Notably however, public sources account for over 84% of Danish health spending. This is the highest in Europe, where the average is 37%. Correspondingly, in 2016 only 2% of Danes had private health insurance. Within this context generic drugs supply over half the market and Danes are the least likely in Europe to use A&E for primary care.⁶

- **Impactful:** In terms of outcome indicators, average Danish life expectancy is running at 80.8 years – comparable to both the US and EU averages. However, in more specific areas, five-year survival rate for breast cancer is one of the best in the EU, as is in-hospital mortality. Waiting times for hip replacements are among the lowest globally, 98% of cataract operations are undertaken as a walk-in service – 3 times the EU average - and, at only 4.3 days, the mean stay in hospital is the shortest in Europe. Denmark also has one of the lowest infant mortality rates in the world while smoking rates have dropped by two-thirds since the 1980s.⁷

But it's not unflawed. For example, and in common with other Nordic countries, although levels have decreased significantly over recent decades, regular drinking of alcohol, especially binge drinking, is still one of the highest in the EU. In addition, COPD admissions to hospital are also among the peak in Europe and 50% above the average.



The Danish Health System

A fundamental principle of the Danish welfare system is that all citizens have the right to good health and healthcare, regardless of income – which is often summarised as ‘free and equal access’ and ‘universal coverage’. By law patients are guaranteed a health assessment within 30 days. Consequently, the system is heavily financed by public funds, experiences little inequality and has notably high levels of user satisfaction. However, privately-funded health insurance has recently become more widely offered to company employees as a supplement to the public system - this is starting to introduce a potential social divide around the free and equal access principle.

The Danish healthcare infrastructure is well established. With a total population of 5.8 million, Denmark is separated into five regions and 98 municipalities, each of which cover at least 20,000 inhabitants. Structurally, its health system has three political and administrative levels: government, the regions, and the municipalities:

- While the national government provides central coordination, legislation, policy and overall framework for the health system, much of the accountability is at local level.
- The regions are, for instance, responsible for providing hospital care, taking on tasks such

as owning and operating hospitals and prenatal care centres. They also allocate finances that pay for many core healthcare professionals including primary care GPs, specialists, physical therapists, dentists, and pharmacists.

- The municipalities are mainly concerned with preventive care, rehabilitation, treatment of drug abuse and long-term elderly care.

Within this there are areas of deep local collaboration. For instance, managing more home-based treatments and achieving low average hospital stays both require close partnership and coordination.

In terms of access to healthcare, more than 90% of the Danish population contact their doctors each year. Annually, around 1.1 million people are admitted to hospital for inpatient care and over 14 million outpatient procedures are conducted. While the number of hospitals in Denmark has decreased in the past decade, hospital visits have risen, bringing facilities to near capacity and thus providing incentives for more efficient methods of treatment. In recognition of the growing healthcare challenge, over €7billion is being invested in 20 new or renovated modern acute care hospitals.⁸



Structural Challenges



Denmark's health system is very much vertically, rather than horizontally, structured. Several experts believe that, compared to some other nations, this makes it unwieldy and difficult to adapt to changing circumstances. Given the challenges ahead, healthcare professionals we met are concerned that their ability to work efficiently will be hampered by the existing divisional silos. Finding more appropriately qualified health workers is also a burgeoning issue: Curating a supply of doctors and nurses is a central challenge across the system and, moving forward, recruiting, training and reskilling the right healthcare talent pool are therefore all concerns.

As in most 'developed' countries, financing the future healthcare budget in Denmark will not be easy. Pressures on the system are building, particularly as the number of the elderly is expected to double over the next 40 years. In 2015 a third of persons aged 80 and over received permanent support, either in their own home or in sheltered accommodation. Currently comprising 19% of the population but absorbing recently over 30% of hospital expenditure, as the number of over-65s rises to one in four by 2050 many expect a corresponding increase in costs. At the same time, public expectations around better survival rates for complex conditions such as cancer all adds to the pressures; finding sufficient funding to be able to offer expensive treatment for all will be a constant strain. Given these challenges and the search for solutions, advocating the use of more and better health data as a catalyst for change is increasingly defined as a core future ambition.

Health Data in Denmark

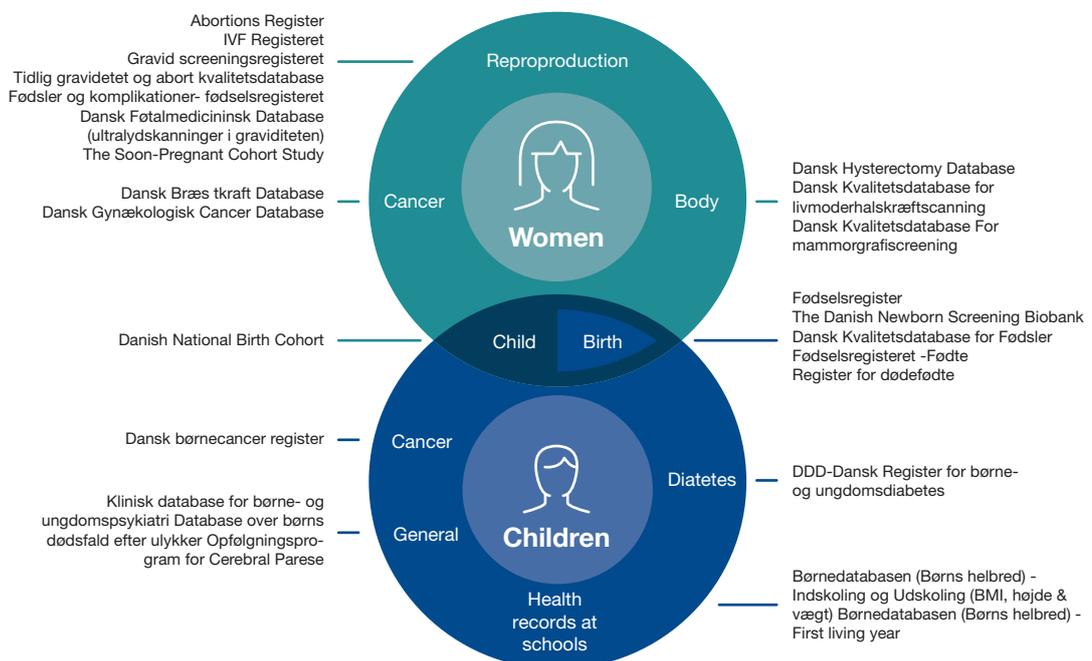
A broadening portfolio of countries including Canada, Finland, France, Israel, New Zealand, Norway, Singapore and Sweden are all now seeking to offer their citizens access to the entirety of their personal health data. Though, as of 2017 there were only four countries - Australia, Denmark, Estonia and Iceland - where such a facility already exists. The Danes were the first. Indeed, as part of a wider public sector digital transformation, for many years Denmark has been very much at the forefront of a more data-driven approach to health information. A central driver in this has been the widespread use of a unique personal identifier that has been adopted across multiple sectors to aid integrating digital processes. This was introduced in Denmark way back in the late '60s – decades ahead of other EU and G7 nations.

With a strong track record in public innovation, the country has also been at the forefront of several specific health IT innovations and, as the majority of these initiatives are based on a common infrastructure, they have already helped create one of the most patient-centric health systems in the world. The way healthcare for women and children is managed is a good example of just how complete the Danish health data set already is.

At a wider, full population level, Sundhed.dk is the unified Danish eHealth portal providing both access to, and information about, all the available healthcare services. It is unique in that it brings the entire sector together online and provides an accessible digital forum. All Danes can use this platform, thus enabling patients to both communicate with healthcare professionals and also gain clear overview of a full set of up-to-date relevant information. Likewise, doctors, nurses, consultants and care providers have secure and controlled access to data regarding the patients they are treating.

Sundhed.dk was initiated in 2001 by the Association of County Councils in Denmark, the Ministry of Interior and Health and others. It followed on from MedCom, established in 1994 to provide access to some limited health data. Since its launch in 2003, Sundhed.dk has provided quality assured health information and access to medical records and medication. It creates links between existing data sources, opens up data sets to new user groups, and facilitates communication between healthcare providers and citizens. This eHealth portal not only provides a secure infrastructure with good search optimisation and slick user interfaces, but also supports the development of numerous new services.

Example Danish Health Databases for Women and Children



An early and comparatively modest investment in this shared-system infrastructure has resulted in the development of services that are used widely within municipalities and regions all over Denmark. Within this, the regions handle citizen health data securely and are also very open with patients about how they use their information.

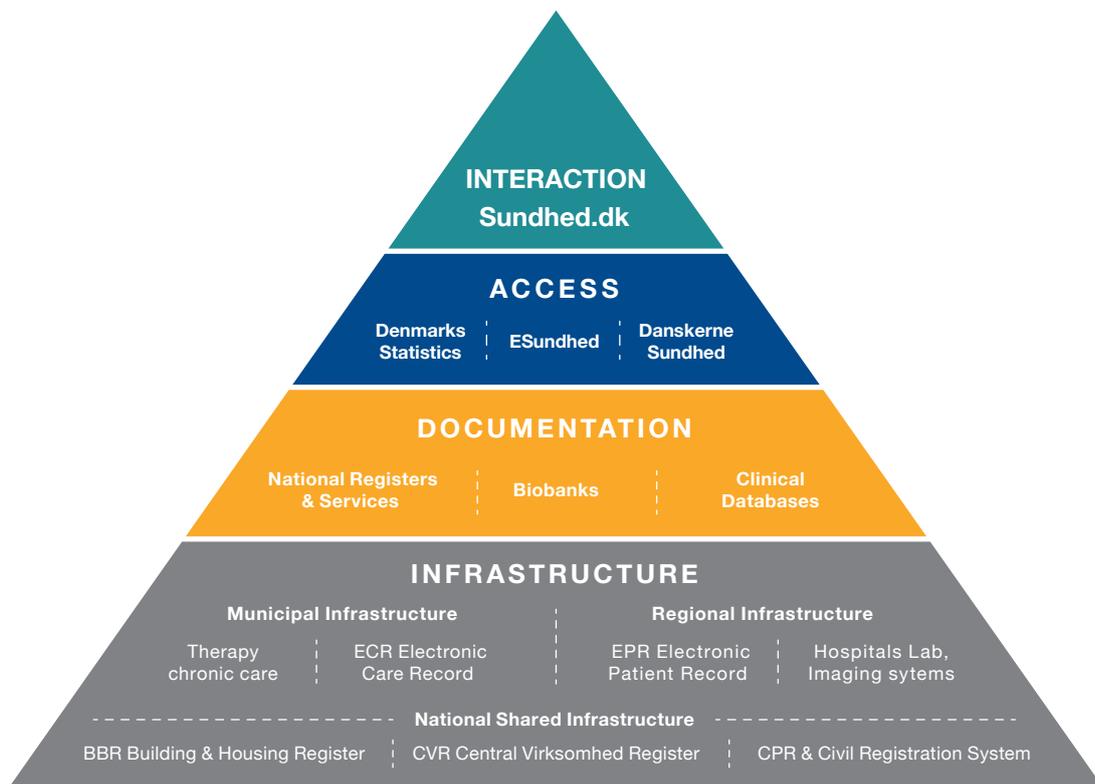
While the sundhed.dk portal initially had only GPs as frequent users, around 2010 public engagement increased to about 45% of the population. Since then, by servicing both citizens and health professionals, the portal enables the two communities to cooperate using the same data. Advocates consider that this both empowers the citizen and gives the health professionals better tools with which to improve care quality.

Consequently every Dane now has their own personal page where they can find accurate and updated health care information. They can all:

- View treatments and diagnoses from their own hospital patient record
- Book appointments
- Renew prescription drugs
- Monitor their own drug compliance
- Survey shortest waiting lists for operations and quality ratings of hospitals
- Register as organ donors,
- Appoint the power of attorney and
- Gain access to local disease management systems in outpatient clinics.

Building on this pervasive base, there are multiple plans for further improvement that are all well documented in the Public Digitisation Strategy, regional policies for the use of health data as well as the 8 National Goals for the healthcare system.

Denmark's Integrated Health Data



Future Implications

Given the overall dynamics, many conclude that Denmark is one of the most connected, well-funded and healthy nations in the world. The advent of more and better health data should therefore have additional impact. So, what about the future? How will the global changes underway impact and enhance the Danish system? Moreover, what will be the national vs regional response?

A recent global project exploring the future of patient data was undertaken by Future Agenda in partnership with leading organisations around the world. Twelve events across many different healthcare systems brought together over 300 experts to debate the primary shifts for the next decade as well as explore their implications. Within this, several shared ambitions in a number of different countries were identified – many of which can already be seen as existing assets of the Danish system: Good quality patient data, common access to it, and means of interacting with both the information and the different communities who form the full care system.

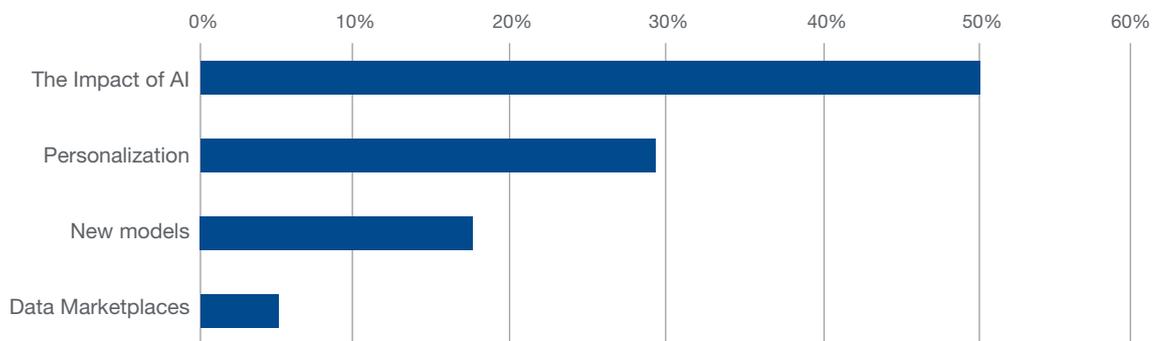
As the first phase of a subsequent series of more regional, national dialogues, in June 2018 additional discussions were undertaken with healthcare experts in Copenhagen to uncover more detail.

The aim was to both respond to the global context from the Future of Patient Data project and debate what the implications may be for Denmark. In particular, a core objective was to identify what are the primary issues for the Danish healthcare system for the next decade.

Opportunities

In terms of key opportunities, as is common with a number of other nations, many are excited about the potential impact of artificial intelligence (AI) and the ability to improve personalisation in healthcare. In addition, others see advantage from the promise of more individualised medicine, getting closer to the patient and a growth in more preventative healthcare.

Which of these four opportunities will be most significant for the Danish Health System?



Challenges

However, before these benefits can be realised, there are several specific challenges to be addressed. In the Danish context, the most significant of these is how connect and integrate data sets. Over half of those consulted in Copenhagen felt that this is a primary issue for Denmark in the next decade.

Due to the efficiency and the public nature of the Danish system, there are exceptionally high levels of trust in both government and the healthcare provided. There is also little current concern about data ownership. Rather, the key question is how to better interrogate and so gain more societal and individual value from the health data that is limited by the way that the current distributed approach constrains broad sharing for full cross-population analysis. Moreover, with a growing health-data ambition, other key objectives include improving prevention, better education, more detailed insight gathering and integrating more unstructured social and patient information.

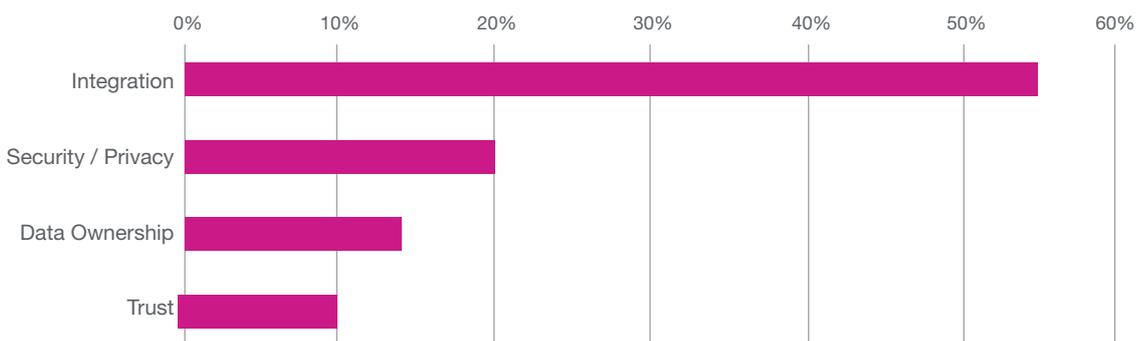
Given that each of the five regions have their own approach to healthcare, despite the existence of sundhed.dk, most information, including varied electronic patient record systems, is presently very much centred around local care and specialised institutions. As such, few fully connected data sets currently exist at a national level. This situation is

driven by both the legacy systems and regulation as well as an ongoing political climate that largely opposes connecting and broadening regional data sets. While local integration and interrogation, including the use of AI algorithms, is taking place, whole country analysis is, so far largely, resisted. Balancing security and trust while sharing access to data across regions is a pivotal concern.

“The Danish healthcare system is a gold mine of data due the excellent data quality and density available. But the data is trapped in organisational silos and data architecture is not designed for collaborative use at scale, so there is an urgent need to build unified data interchange protocols and allow faster turnaround for data mashups to happen.”⁹

From the global point of view, this appears rather ironic given that, as mentioned previously, one of the unique assets for Denmark is a truly full 100% population healthcare data set. Other countries only have information on a sub-set of the population – and often biased to the predominantly healthy, wealthy or the sick, depending on the nation. By contrast the Danish system is one of the few in the world to have all the data about every single citizen going back decades from conception to death. It may be in multiple silos, but it does exist.

Which of these four challenges will be most significant for the Danish health system?



The Big Tech Challenge

Those we met in Copenhagen see that Denmark could, and moreover should, capitalise on these health data assets before the window closes and big tech takes over. Many of the major US tech firms such as Alphabet (Google), Amazon, Apple, Facebook and Microsoft all see Denmark's full population data for nearly six million people as an ideal test-set for their latest algorithms, while the likes of GE are already paying billions to access subsets of it for their own analysis. As others outside the US, such as Alibaba, expand reach and numerous startups continue to scale, many believe that Danish health data will become increasingly attractive and valuable.

But timing is imperative. Going forward, access to more personal data by the technology firms may well challenge existing systems and change the view of what should be the main focus of a healthcare system. As one workshop participant put it "we currently offer services to people who need it – they might offer services to people who want it." This raises questions both about where value can be gained and who it is for. It's a philosophical issue and

several are concerned about letting high value health data move to the big tech companies.

Dealing with the big tech challenge is no easy task – and the best choice of which options to follow is clearly politically-charged. Therefore, some question whether or not Denmark can remain resistant to wider sharing and continue to maintain such a distributed, but arguably secure and protected system. Advocates for change see that, if benefits can be proven and the political will shifts, then the country could embrace key emergent opportunities earlier than other nations and so enable its world-leading health data to be further leveraged for the wider benefit for all. Notably, some consider that, in the same way that historically it initiated world leading standards for nationwide debit cards, common secure log-in and GSM interoperability, Denmark could also be at the fore in the use of health data. Several even see that the nation could apply its proactive industrial-policy setting to become a globally unique hot-bed for new start-ups in health-data and AI.



Future Transformation

In terms of the future opportunities, many of those already summarised in the wider global research assume well informed and health-literate patients and greater digital connectivity and data access – all of which already exist in Denmark. However, notable in comparison to other systems is a lack of enthusiasm for other developments such as new business models and the rise of data marketplaces. Indeed, in a country where there is such a rich resource of high-quality population data within a public healthcare system, the notion, supported elsewhere and particularly in the US, that there is money to be made from trading and monetising health information was firmly rejected in the Copenhagen discussions. High levels of trust in the system may well be linked to an implicit assumption that health data will not be exploited monetarily. However, some see that, rather than financially focused marketplaces as planned elsewhere, perhaps societally-driven data exchanges could have impact in Denmark. In addition, the issue of data sovereignty, the storing and therefore owning of data in different national jurisdictions is not seen as a major issue. In a country where major data sharing is not occurring nationally, concerns around limiting international sharing are not yet on any radar.

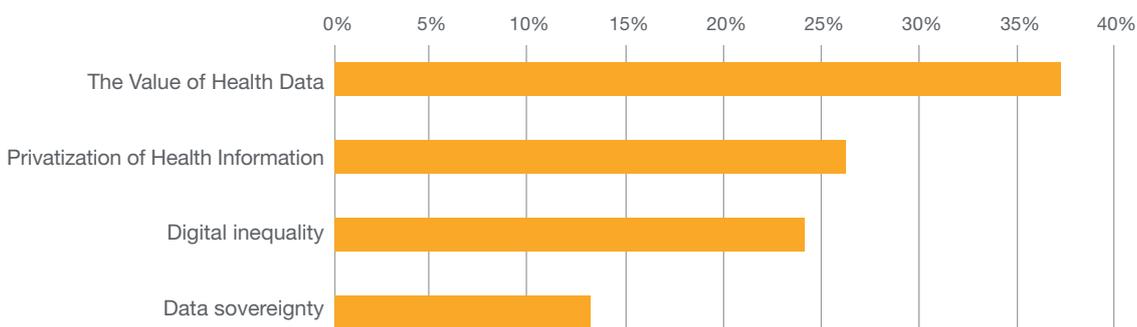
could, some argue, take an even more proactive approach than is being suggested in the UK with the Future Care Capital platform.¹⁰ However, despite sitting on far better information, the regulation and politics that defines the Danish system is potentially blocking more significant progress. Because of this and despite its many advantages, several experts see that in 10 years Denmark could slip behind others and be a follower rather than a leader in the digital transformation of healthcare.

Pivotal here is the opposition to wider sharing of data. This seems very much at a system level rather than for individuals: In an Oslo workshop, one participant suggested that in Norway “sharing data is liking paying your tax” and is a good thing for everyone to do. The same view may well apply in Denmark. Some propose that, this way of thinking might instigate the formation of a “new logic” away from universal informed consent to a reverse “active non-consent principle” where citizens are, by default, donating certain health data to a common platform. They could be required to opt-out rather than opt-in to sharing their health data.

So, there seems to be a clear conundrum in Denmark. The country has one of the best, if not the best, high-quality and properly full-population healthcare data set on the planet, but it is presently politically, and so possibly culturally, unwilling to allow it to be combined and mined at a national level, and beyond. Other countries, such as the UK, have been permitting partial data sets to be analysed by the likes of Google DeepMind and IBM Watson in the anticipation of greater and earlier diagnosis and hence treatment of key diseases. With such high-quality data, Denmark

From the discussions to date, in Denmark there is widespread local government “fear of misuse” of data at a country level and therefore the regions and municipalities are reticent about allowing patient data to be aggregated, shared and analysed nationally. This may be sustained by the lack of a nationwide vision around how best to manage health data. As a result, in the absence of top-down collaboration, many are turning to more localised bottom-up data analysis.

Which of these will drive greatest future change for the Danish Health system?



Future Possibilities

If this obstacle could somehow be overcome, then the experts we engaged with see multiple future possibilities for even greater health support and thus a more efficient and impactful approach. Specific examples of potentially significant change that could have impact include:

- Individualised medicine
- The impact of AI
- Personal data stores
- Getting closer to the patient

Individualised Medicine

National integration and simultaneous connection to growing personal wellness and proxy data would allow for more individualised analysis that can enable better and earlier diagnosis and treatment. We could see a world in which more personalised care is driven by greater interoperability across existing systems and delivers more cost-effective support, decreasing admin burdens as well as more specific risk analysis and categorisation. Increased access to more individualised data, linked to new analytics could meaningfully help to deliver more customised treatment that is both more agile and efficient.

The Impact of AI

If we then add in better analysis from the application of machine learning and pattern recognition followed, in turn, by more sophisticated deep and self-learning AI, then the presumption is that we can connect clinical, behavioral and personal data in totally new ways - and so deliver focused health support more specifically across the Danish population. More accurate, accessible and automated predictive diagnosis, in particular, will be a pivotal issue – and one which, as neighbouring Sweden has already started to demonstrate, can also positively impact the financial planning of healthcare.

Personal Data Stores

Implicit within this is the assumption that patients will increasingly control, if not fully own, their individual health data – most likely through the wider adoption of personal data stores. Regulation is, however, key to enabling this - alongside building trust in new platforms. Returning to the political obstacle already identified, some see that this shift from system to patient control of data may well be the change that unblocks sharing in Denmark and allows citizens to better embrace new models for healthcare.

Getting Closer to the Patient

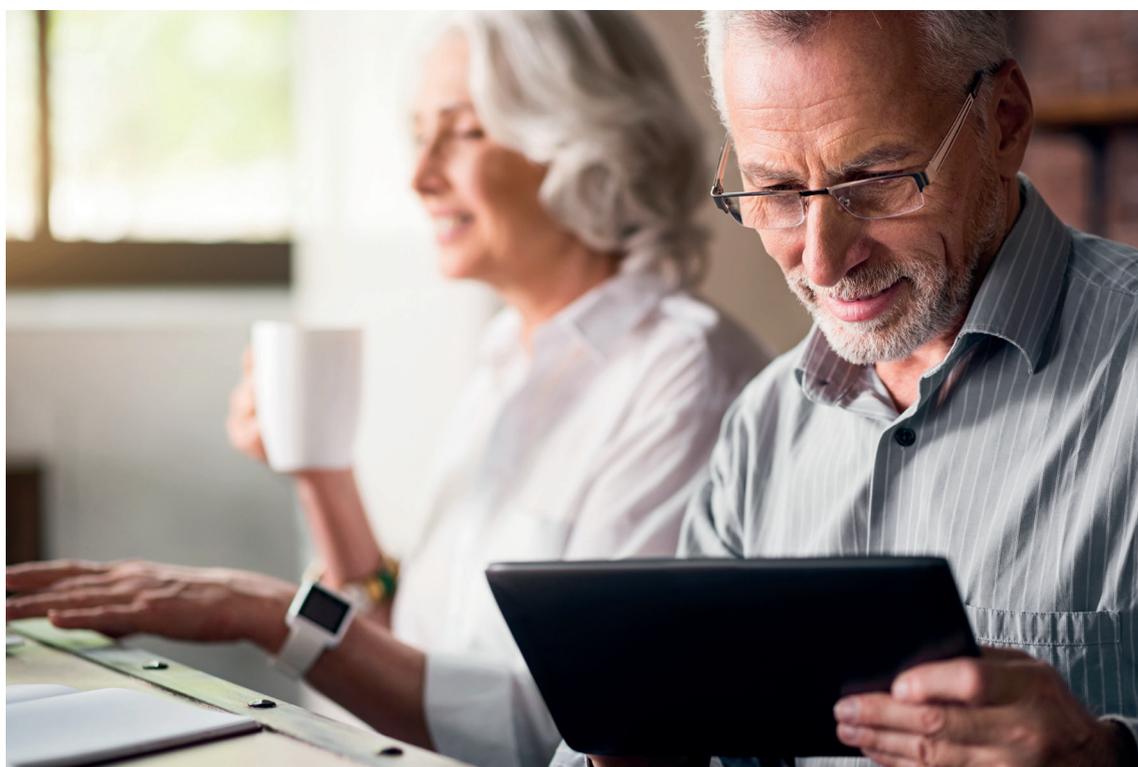
Lastly, some suggest that we could see a shift away from the delivery of healthcare in separate silos that prioritise hospitals, municipalities and only then the patient, to mirror this system. Here the patient can be at the centre, with the municipalities and hospitals working in support to collaboratively deliver better healthcare, prevention and, if needed, sick-care. Moreover, much of this care can be provided in the home or on the move rather than within the hospital or doctors' surgeries. The view was that Denmark is ready to make the changes "driven by realism and idealism" and so meet the rising demand from patients. Using the data to better structure the system around the patient is certainly viable.

While political discussions about handling data and who should be in control of it pervade the health debate, change could well be accelerated, especially if, as some suggest, the voice of informed healthcare professionals are listened to more. A number of organisations have already mapped the Danish health system and future data implications while others have explored different future scenarios for Denmark.¹¹ Implicit within many of the recommendations is a call for wider sharing and analysis.

The Way Forward

Denmark already has a healthcare system the likes of which many other nations can only dream of. Ensuring that it continues to lead and take advantage of the changing patient data landscape is a priority. The country is indeed unique on many levels and one that is rightly proud of the superior quality of its healthcare as well as the wider social support provided by its culture and services. Providing the optimal benefit to all individuals within society is very much part of the Scandinavian DNA. Moreover, with high education levels and good data awareness, it is well positioned as a country to develop new digital solutions. As several workshop participants highlighted “innovation is part of the Danish mindset.”

However, through more open and sophisticated analysis of health data generally - and patient data in particular - many see that we could be at an inflection point: The future of healthcare may well increasingly be about the future of patient data. As such, ensuring that the world-leading high-quality Danish health data is used effectively, and not siloed, is an evident need. How, where and within what framework this can occur is the open question. This seems to be a significant topic for further dialogue.



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For more information about the global Future of Patient Data research please see www.futureofpatientdata.org



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