

Danish E-health in a Welfare Research Perspective

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VIVE - The Danish Center for Social Science Research

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VIVE – National Center of Social Research Copenhagen - Aarhus

<https://vive.dk/>

- Research related to the Danish Welfare State
- Interdisciplinary, evaluation studies (benefits & cost)
- In Health: MTV, MAST
 - 7 Domains: Health problem and characteristics of the application
2. Safety 3. Clinical effectiveness 4. Patient perspectives 5.
Economic aspects 6. Organisational aspects 7. Socio-cultural,
ethical and legal aspects
 - Ex. Internet based cognitive therapy for depression, ‘NoDep’
- Research group in Digital health
 - Ethnographic and qualitative methods

Stinne Aaløkke Ballegaard

Senioranalytiker, mag.art. i etnografi, ph.d.

Stinne Aaløkke Ballegaard er antropolog med speciale i sundheds- og velfærdsteknologi samt stor ekspertise i kvalitative studier af organisering og patientperspektiver.



Morten Bonde Klausen

Senioranalytiker



Sarah Wadmann

Seniorforsker, cand.scient.san.publ., ph.d.

Sarah Wadmann har bred erfaring med kvalitative analyser af styring og organisering i offentlige organisationer, typisk inden for sundhedsvæsenet. En gennemgående interesse i hendes arbejde er, hvordan data og dokumentation spiller en stadig større rolle i styringen af sundhedsvæsenet og det daglige kliniske arbejde.



Helle Sofie Wentzer

Seniorforsker

Helle Sofie Wentzer har stor erfaring med informations- og kommunikationsteknologiers rolle i innovation af sundhedspraksisser, herunder mediering af samarbejde, identitet, kvalitet og patientforløb.



Stinne Aaløkke Ballegaard. Anthropologist, PhD

Research traditions: Ethnography, STS, CSCW, Participatory design

Research interests: Healthcare technology, digitalization and transformation of healthcare

- Production and use of health related artifacts by patients, healthcare professionals and management
- Work practices, organization of work and transformation of healthcare professions
- Self-care and perspective of patients and relatives
- Collaborative practices and (re)distribution of responsibility between patients, healthcare professionals and institutions/sectors



Meaning, friction, negotiations, collaboration...

Agenda

Zoom out:

- Danish Healthcare System*
- Digital Denmark on the World Map
- Developments in Danish Health Care
- Challenges to the modernization of Health Care infrastructure: data work

Zoom in: Welfare Research Perspectives on *'infrastructuring'*

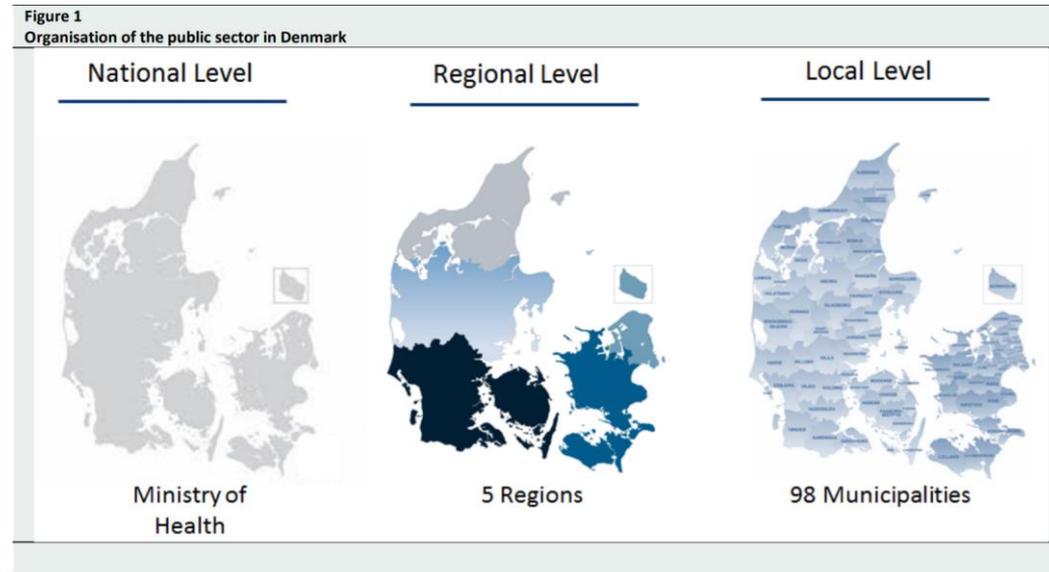
- Learning cases: digitalisations in Hospitals, General Practices & Municipalities ↔ pt. care path with chronic diseases
- Data work: invisible or transparent?
- Safe(ty) in digital roles and relations as patients, clinicians, management/owner?
- Evidence of ehealth?

* 'Healthcare in Denmark', 2017, <http://www.sum.dk>

The basic principle of the Danish welfare system

- The Danish healthcare system is universal and based on the principles of free and equal access to healthcare for all citizens.
- The healthcare system offers high-quality services, the majority of which are financed by general taxes.
- The healthcare system operates across three political and administrative levels: the state, the regions and the municipalities (national, regional and local levels).

Organization



- The state holds the overall regulatory and supervisory functions in health and elderly care.
- The five regions are primarily responsible for the hospitals, the general practitioners (GPs) and for psychiatric care.
- The 98 municipalities are responsible for a number of primary healthcare services as well as for elderly care.

“The Danish ehealth-Field”, www.SUM.dk

- The Danish healthcare system is characterised by **extensive digitization, electronic communication between healthcare providers and systematic use of data and digitized working procedures.**
- Public hospitals and general practitioners (GPs) systematically collect data, and their contact with the patient is sustained over long periods of time. This **permits large-scale monitoring and analysis**, while records in the national patient register and medication databases permit a significant degree of, for example, patient compliance monitoring.
- The prevalence of **common IT standards** facilitates electronic communication between healthcare providers – hospitals, GPs, specialists, laboratories, local authorities, home care services and others:
 - All GPs keep electronic health records (EHRs), and 98 per cent exchange records electronically.
 - GPs receive all laboratory test results from the hospitals electronically.
 - 99 per cent of all prescriptions are sent electronically to the pharmacies.
 - 97 per cent of all referrals to hospitals are made electronically.
 - All referrals to medical specialists and psychologists are made electronically. Information and communications technology (ICT) and digital workflows are fully integrated in the healthcare system.

⇔ According to the benchmarking information of the European Commission and the OECD, EU’s ehealth deployment indicator, **Denmark ranks as one of the front-runners in the deployment of e-health.**

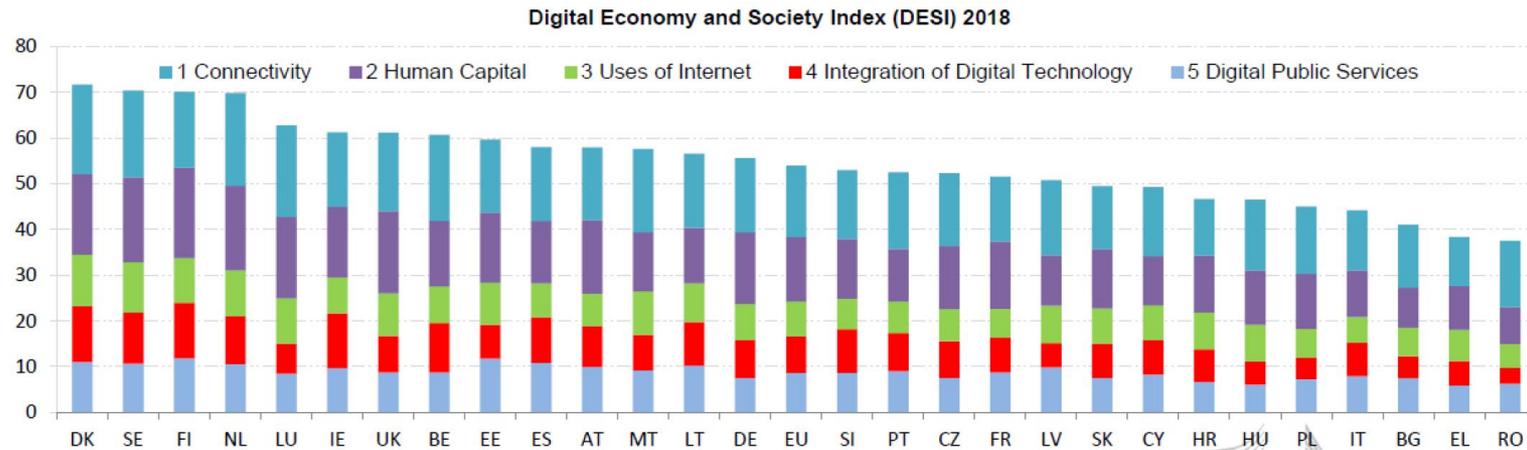
Denmark: A digital front-runner...



- Considerable investments in public sector digitalization since the 1980s
- Implementation of electronic medical records since the 1990s
- Citizens able to view information from medical records through a national digital platform since 2003
- Current attempts at more data integration and real-time monitoring
- Long tradition of state-controlled data registration
- Fairly liberal data regulation

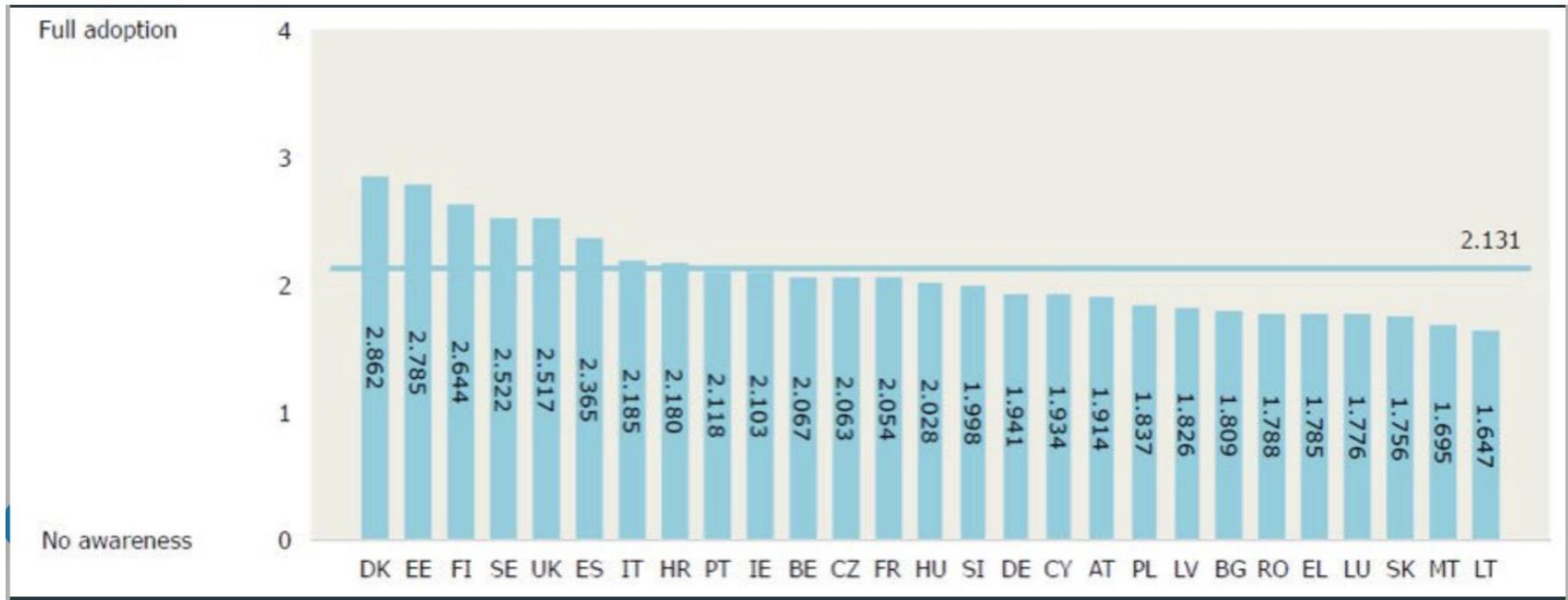
Denmark Digital Frontrunner

Danmark er i front ift. digitalisering og teknologianvendelse



Digital Frontrunner: General Practice,

(Lisbeth Knudsen. Sundhedsdatastyrelsen, esundhedsobservatoriet 2019)



Communication between the sectors

Denmark has a long tradition for the healthcare system. Extensive digitisation over time. The following IT solutions

- Implementation of the so-called the health system.
- Establishment of the **health data** providers.
- The **web portal Sundhed.dk** with registers, electronic health records patient's GP.
- The **Shared Medication Record** electronic record of each citizen
- The Shared Medication Record health authorities (e.g. municipalities)
- Across the healthcare system,

The vision* is to achieve a single, cohesive health system in which IT and digital processes support continuity of care across hospitals, GPs and home care services.

so that existing patient data can be accessed by different healthcare professionals and care staff, irrespective of where in the health system the data were originally registered.

ts who are in contact with the and the course of their disease e also won international acclaim: ch of the communication within ation between all healthcare dical data from national health a can also be accessed by the essionals access to a complete eneral practitioners and local us IT solutions more seamlessly

*www.SUM.DK Healthcare in Denmark – an overview

Telemedicine

- In recent years, Denmark has implemented several telemedicine pilot projects to a more coordinated and efficient use of resources. Telemedicine in actual operation includes:
- The National Telemedicine Centre (NTC) is coordinating and implementing telemedicine initiatives, and is also responsible for developing and pioneering future telemedicine initiatives.
- Examples of cross-sectoral telemedicine initiatives carried out are TeleCare Nord (North Denmark) and TeleCare South (South Denmark).
- **A national infrastructure for telemedicine is being implemented on a large scale.**
 - This includes standards for data exchange between the entire healthcare system, covering all types of data, including text, audio, video, and images.

The goal* is to have a digital infrastructure and IT architecture in place within the foreseeable future, so that relevant information can be exchanged across the healthcare system and other sectors

telemedicine pilot projects reflecting the needs of the population. Five specific telemedicine programmes to be implemented are being rolled out. This is part of the large-scale implementation of the entire healthcare system, covering all types of data, including text, audio, video, and images.

*www.SUM.DK Healthcare in Denmark – an overview

Status: Visibility of results ↔ more access and multiple use*

Denmark has a long tradition for collecting and using data on both quality of care, activity and costs, and the healthcare system has a **comparatively mature infrastructure** for data collection and for storing data in national healthcare databases. This provides a **potential for better use of data and for realising the benefits of greater transparency of outcomes**. The visibility of results reform will contribute to:

- Better treatment and care through systematic monitoring and benchmarking of results and outcomes leading to the dissemination of best practices
- Relevant patient information through easy access to comparing quality of care, waiting time and outcomes, including patient rated outcomes across hospitals and care providers;
- Increased access to healthcare data for citizens, journalists, researchers and others who study and compare, for example, variations in treatment standards and quality of care
- Increased data based management through the systematic use of data to benchmark results and outcomes in order to support a more efficient and outcome oriented healthcare system.

*www.SUM.DK Healthcare in Denmark – an overview

‘Health data programme’: A new governance model

As part of the “visibility of health data” programme, the Health Data Programme was established in 2014 to run over a four-year period. The programme tracks is defined to support the vision:

- New data model and user interface. A modernised data model and easy accessible user interface to relevant healthcare data for healthcare professionals and citizens.
- Modernised infrastructure and data management at the National Health Data Platform. A secure infrastructure for national health data management, including a modernised data platform.
- Better data quality. Enhancing quality of the healthcare data by establishing a new national governance model for monitoring data quality in order to support higher validity and reliability of healthcare data.
- **Better cross-sectorial cooperation.** A new governance model for health data management to support cross-sectorial cooperation.

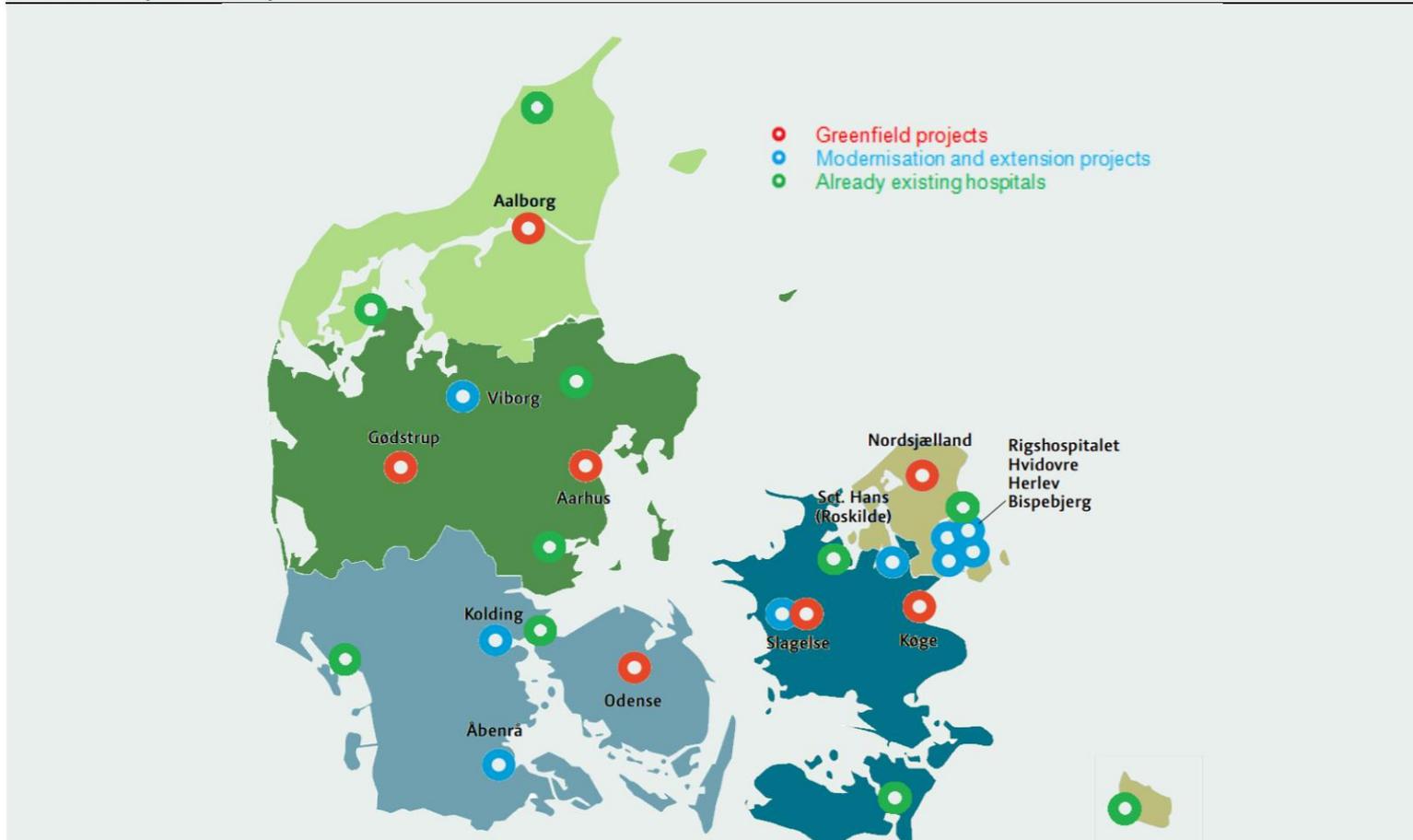
The vision* of the Health Data Programme is to create “better healthcare through better use of data”

Modernization: The expansion of the Danish hospital infrastructure

- New hospitals and sustained hospital services structure
Denmark is investing EUR 6.4 billion in 16 new hospital projects.
- The goal is to ensure national access to modern health services and to improve quality across the entire healthcare system.
- Designing the new hospitals **involves broad-based collaboration** with research institutions and private businesses in the field of health.

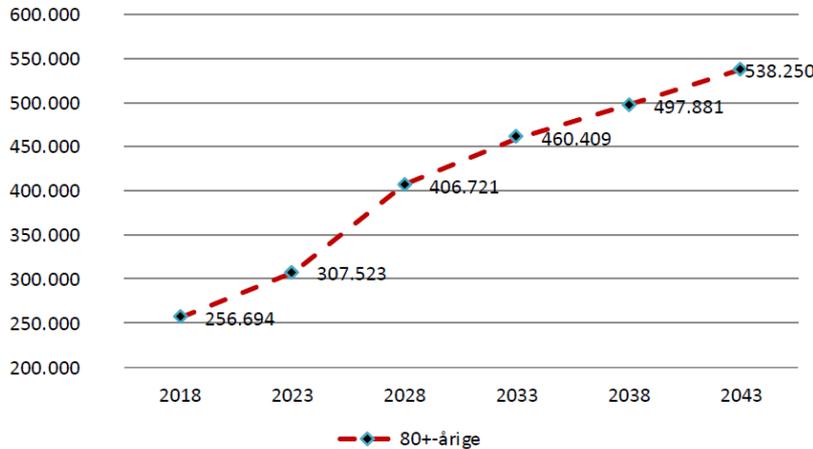
Fewer hospitals, less beds ⇔ *infrastructuring*

Figure 4
The new hospital landscape

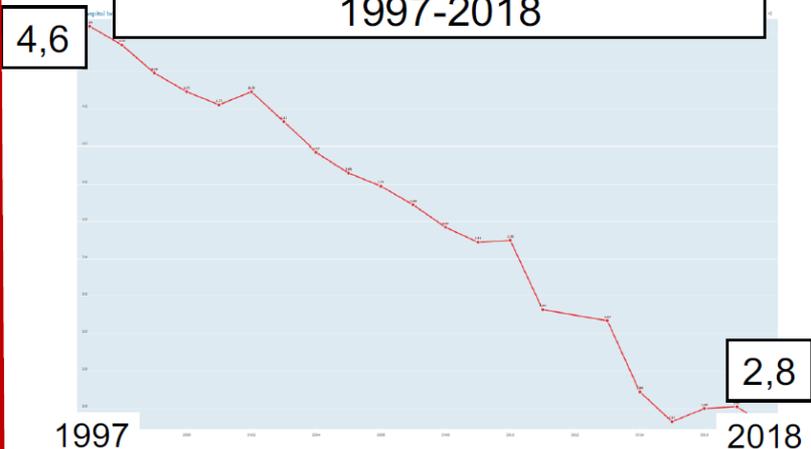


More elderly, more multi-morbidities, more demands for care and treatments in *primary care settings*

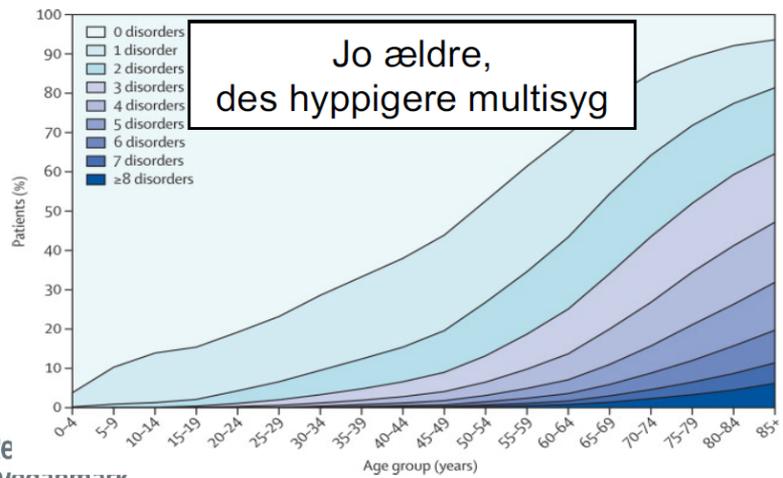
Fremskrivning 80+-årige 2018-2043



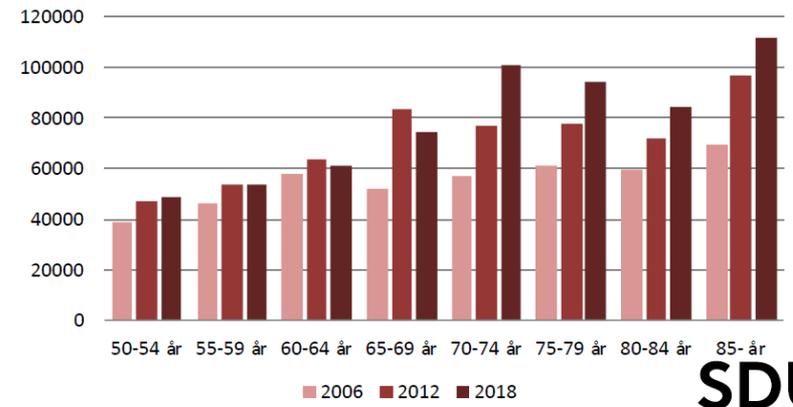
Hospitalssenge pr. 1000 borgere 1997-2018



Jo ældre, des hyppigere multisyg



Akutte indlæggelser 2006-2018

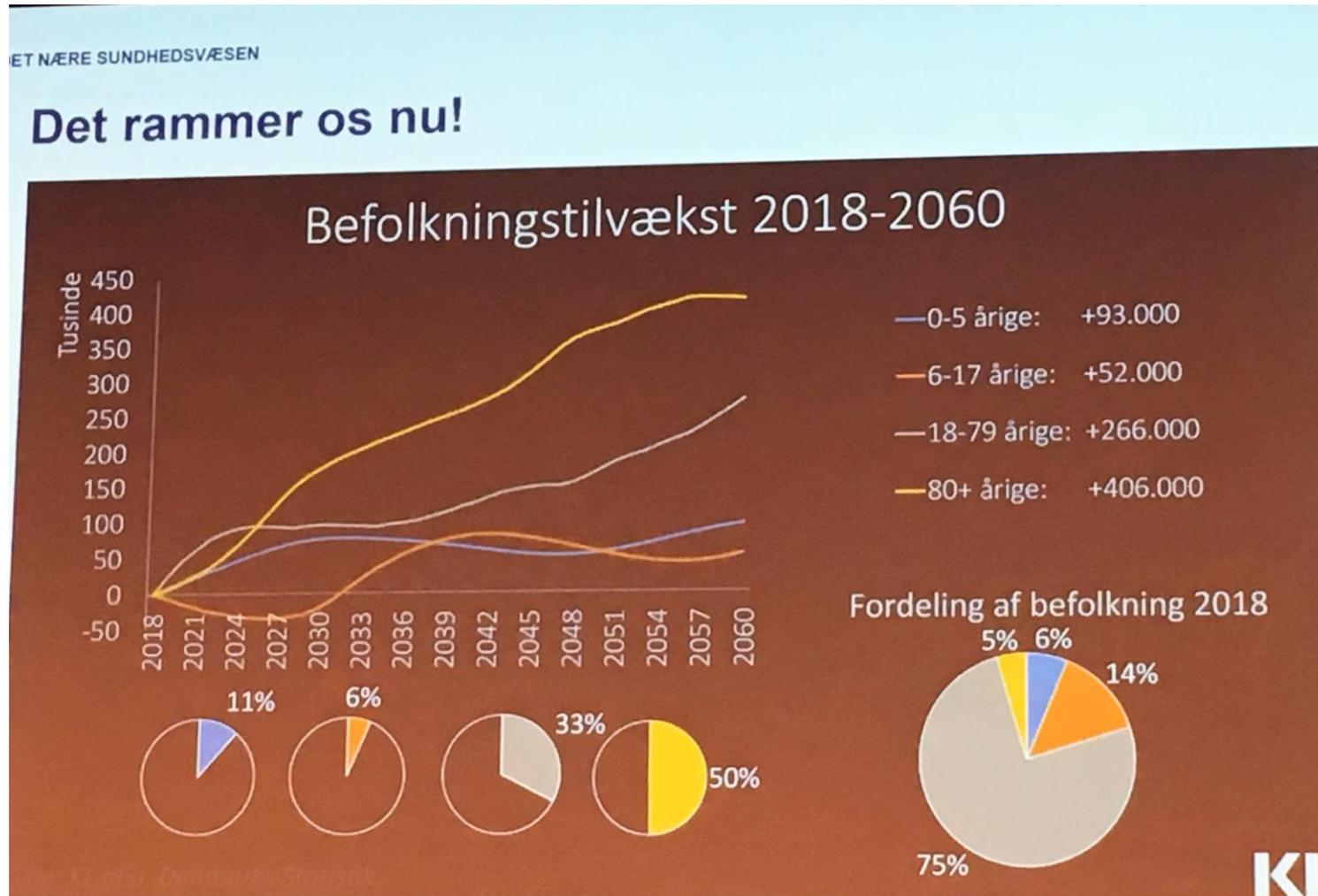


<http://2019.e-sundhedsobservatoriet.dk/program/>

- Development in Health Care. Hospitals and 'Det nære sundhedsvæsen'. Chr. Hørsløf, KL. E-sundhedsobservatoriet 2019

	1980	2000	2014	2020*
Udskrivninger	916.000	1.130.000	1.150.000	1.500.000
Ambulante besøg	3.295.000	4.405.000	7.900.000	10.700.000
Sengepladser	42.500	20.592	16.400	13.000
Organisatoriske enheder	128	78	30	21
Gennemsnitlig liggetid	10	6	3,7	2,7
Ad *) Estimeret.				

Demographic developments in DK



Acceleration and transformation of Patientcare paths of elderly to primary care sector:

Increased demands for:

- Collaboration between hospital, GP, and municipalities (Homecare, nursing homes, rehabilitation unites) an citizens' homes
- Digital dependence for exchange of information and data
- Data produced by many, different groups, for different purposes and values
- GPDR, ethics and conflicts
- Research support/facilitate negotiations between many stakeholders

Challenges to the social sustainability of data infrastructures, Sarah Wadmann 2018, 2019

Two Danish experiences:

1. The rise and fall of a data infrastructure in general practice (1990s-2014)
2. Implementation of the Epic platform in the hospital sector (2013-2019)

Rise and fall of a data infrastructure in general practice

Data from GP records compiled in national database

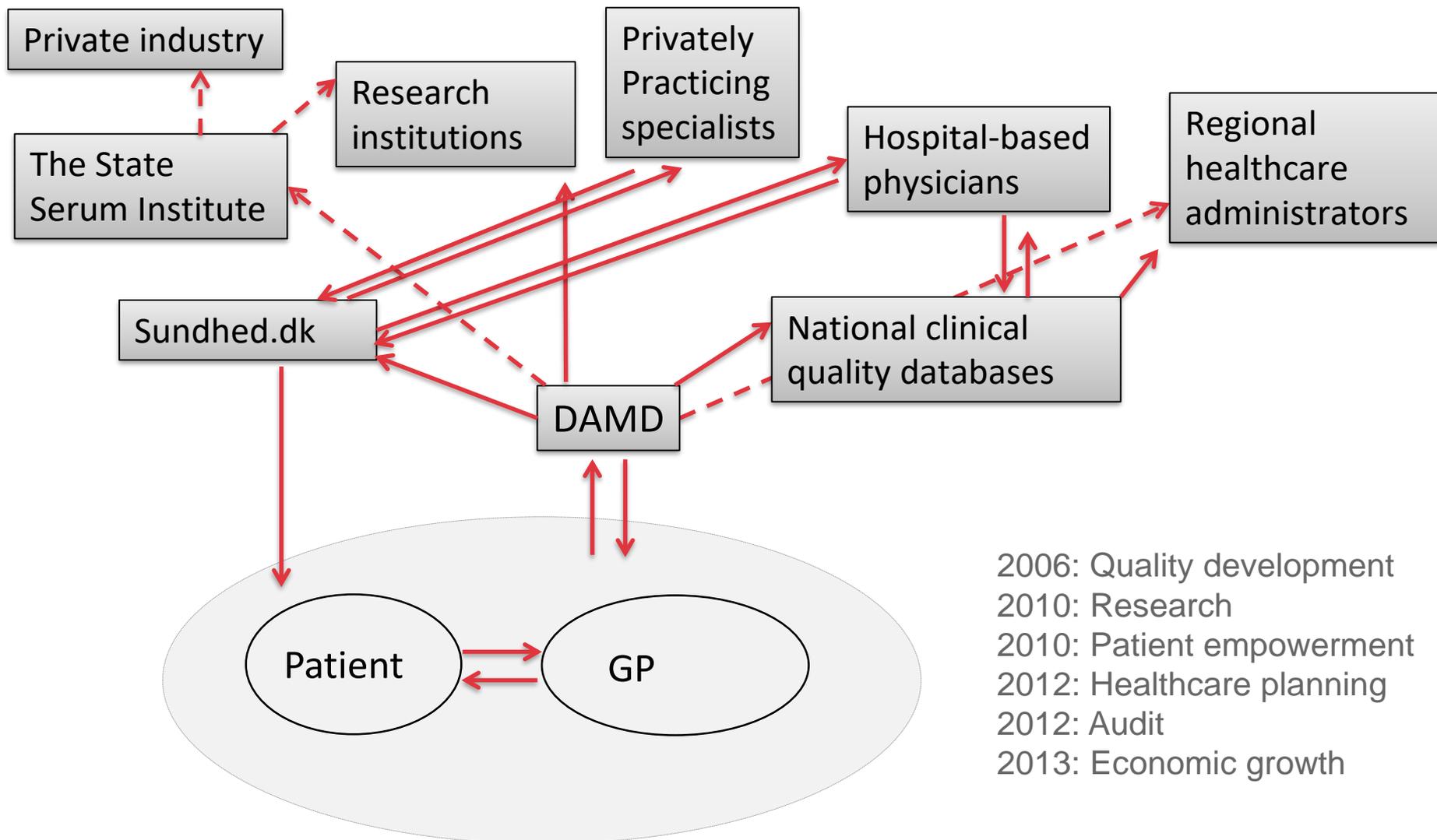
Data collection and processing were:

- Standardized
- Automated
- Centralized

Enabled seamless and efficient data flows.

“About the best thing happening in Danish healthcare for years.”

Purposes of data use multiply



Seamless repurposing lead to value conflict

- Patient privacy
- Professional autonomy



- Efficient use of public resources
- Economic growth



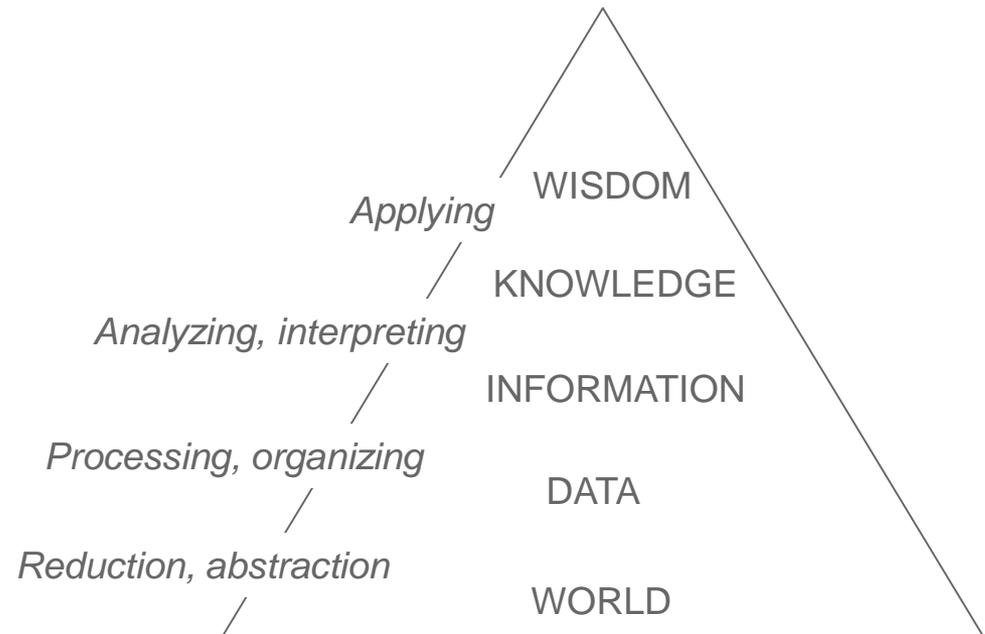
“For ten years, I have quietly looked after my business. I’ve been a good doctor, coded everything and all this until I suddenly realized this... this invasion of the professional authority or whatever you’ll call it.”

General practitioner

Epic as the solution to problems of fragmentation

- Professionals worked in different electronic records and needed to log into many different systems
- Medical secretaries played an important role in keeping it together
- Epic offered digital integration of 30 IT systems

Technological aid
does not reduce the
need for data work.
It redistributes it.



Standardized work-flows and real-time data

- The business case: improved patient safety, quality of care and lower IT operation costs

- The design of the Epic platform provides for:
 - Stricter work divisions
 - Greater interdependence among professional groups
 - Redistribution of work from secretaries to physicians.

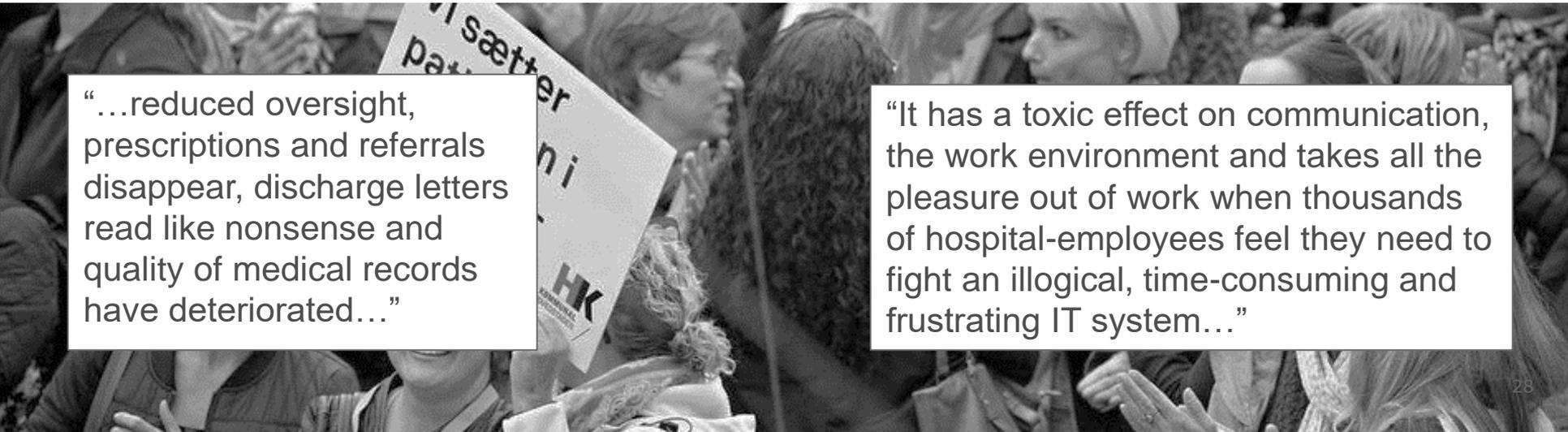


Secretaries were let go to realize the economic scenario of the business case

Decision-makers underestimated the resources required for “invisible” data work

Hospital productivity went down. Data validity too poor to estimate how much

- Time-consuming for physicians to write notes and order tests – they are not using the pre-defined options
- Coding errors resulting from physicians’ lack of training (and interest) in coding
- Loss of administrative expertise resulting from decentralization of specialized secretary tasks to physicians



“...reduced oversight, prescriptions and referrals disappear, discharge letters read like nonsense and quality of medical records have deteriorated...”

“It has a toxic effect on communication, the work environment and takes all the pleasure out of work when thousands of hospital-employees feel they need to fight an illogical, time-consuming and frustrating IT system...”

Infrastructure and sustainability: Danish lessons

- Digital integration is interlinked with organizational transformation
- Valid information rests on mundane and often “invisible” data work
- ‘Big bang’ implementation strategy vs. gradual development
- Reuse of data can create value conflict
- If reuse is seen as illegitimate by data producers, original purposes of data generation may be distorted
- Sustainable data infrastructures require more than digital integration and user satisfaction. Attention must also be paid to political and moral concerns.

Future research in ‘infrastructuring’ for efficient care processes and cross-sectorial patient care paths:

- **Where:** Data-work in clinical care settings, i.e. in the new hospital, at the GPs (patients with chronic diseases), municipalities and elderlies homes:
 - Research questions: how is data produced, used and negotiated by patients, health professionals, and management ↔ social and technical solid data (algorithms and automation)
- **What:** Different digital solutions (apps, platform, wearables, sensors, video), tasks, competences, organization, literacy
- **Why:** Need knowledge on use and effects in practice,- and development of evidence-based ehealth, i.e. evaluation studies to secure quality, costs and safety
- **Digital Bildung:** Development of ethical awareness: GPDR, ownerships and rights in private and public co-produced data

Thank you for your attention

Contact: hewe@vive.dk

- Collaborative learning infrastructures of Danish ehealth:
www.esundhedsobservatoriet