

Digital integration og dataparadokser:

Dansk praksis i en ny geopolitisk kontekst

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Digital sundhedstransformation i en geopolitisk brydningstid

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POLICYAID

Policy, practice and patient experience in age of intensified data sourcing (POLICYAID)

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POLICYAID

POLICYAID is funded by the European Research Council initiated June 1st, 2016 and is expected to be completed on May 31st, 2021.

ERC projekt: POLICYAID



Debatbog 2019



MIT Press, 2023

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Centre for Medical Science and Technology Studies

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DataSpace

DataSpace is an EU funded project exploring what is driving the establishment of cross-border health-data infrastructures, which types of infrastructures are being established, with which implications for whom.

About DataSpace

Healthcare is increasingly datafied and a wide range of actors - patients, clinicians, administrators, policymakers and industry - want to be able to exchange and access health data across national boundaries. Competing initiatives for fostering cross-border data integration proliferate, and the EU provides major investments, e.g. through the European Health Data Space. These massive investments will influence healthcare, administration and research, but we do not yet know how.

DataSpace explores what is driving the establishment of cross-border health-data infrastructures, which types of infrastructures are being established, with which implications for whom. Furthermore, we wish to explore how these new data infrastructures emerge in tandem with wider social changes where data have become constitutive for the lives we can live. With DataSpace we therefore explore and conceptualize how people experience themselves and the world around them with and through data.

We take the term 'space', empirically present in the EHDS initiative, and reinvigorate it theoretically to establish a vocabulary fit for understanding data-intensive health environments. We suggest seeing data spaces as having both formative and experiential dimensions and explore how they interact. Concerning the formative dimensions, data spaces are enacted through premises, work, and users. Four experiential dimensions relate to what is experienced as right (legally and morally), true (epistemologically), present (phenomenologically) and valuable (economically, emotionally, and socially). This theoretical approach moves beyond problematic and archaic distinctions between the virtual and the real and provides a new understanding of how patients, clinicians, researchers, administrators, and industry shape healthcare with and through data.

Publications

Conference presentations

Other dissemination

Staff

NU: DataSpace



Dataintensiveringen i Danmark

Ambitionen om at bruge flere data og til flere ting

"Formålet er (...) at understøtte en kultur i sundhedsvæsenet, hvor udgangspunktet for sundhedsfaglige og sundhedsøkonomiske handlinger er **baseret på data og viden om, hvad der virker**" (s. 6)

**Foreslår øget adgang til data:
Integration af infrastrukturer**

Data er gået fra at være kliniske værktøjer til...

... at være værktøjer for mange formål

- Klinikere
 - Sundhed
- Policymakers og administratorer
 - Good governance
- Forskere
 - Viden
- Industrien
 - Velstand

Actors/goods	Stated purposes claimed to justify intensified data sourcing
Researchers Knowledge	Clinical research, for example use of patient data to – - document effect of changes in clinical procedures and evaluate effects (and side-effects) of treatments - identify patients for randomized clinical drug trials or experiments with precision medicine Health services research focusing on – - Usage of patient data to identify, e.g., patient needs or patterns of inequality - Usage of patient data to assess, monitor and compare, e.g., different forms of organization Epidemiological research, e.g., use of patient data to – - monitor and predict disease burden and distribution - identify population health problems and new potential causes of disease Laboratory research, e.g., use of patient data and samples to – - validate new laboratory methods - carry out -omics research to understand mechanisms of disease Big data research using population data sets, also beyond healthcare, to – - identify patient pathways and interactions - identify patterns of disease or cause new hypotheses based on unexpected correlations
Clinicians Health	Systematic approaches to ensure consistency when dealing with, e.g. - screening, drug and assessment of needs - follow-up data discontinuation of drugs, side-effects, chronic care, polypharmacy) Optimized treatment options - use of experiences from similar patients to make targeted treatment plans, data in personalized medicine - enhanced monitoring of patients at risk Coordination and easy information exchange - communication and coordination between clinicians, across units and across sectors - communication between clinicians and patients Monitoring of quality, for example by using patient data to – - identify safety problems (data infection rates) and unusual patterns (e.g. in prescriptions or deaths) - document progress or achievement of goals Public health surveillance, e.g. - Pandemic surveillance - Preventive measures
Politicians and administrators Good governance	<i>Political level</i> Establishment of goals, and assessment of whether goals are reached, e.g.: - Less use of physical force in psychiatry or shortened waiting times - equality in health provision and outcome - medical error Preparation for negotiations with, e.g.: - unions - pharmaceutical companies and other suppliers Preparation of governmental reforms, e.g.: - financing and remuneration models - creation of new units of administration Prioritization between areas, e.g.: - psychiatry or cancer, what patients cost when not treated optimally - documentation of effect of services <i>Administrative level</i> Remuneration and budget control - service-per-fee (data General practitioners (GPs), pharmacies and specialists) - value-based care Accountability - to avoid fraud - quality assurance - Efficiency and value for money, including "lean thinking" and measurement of effect
Industry Wealth	Create more efficient products, e.g.: - personalize treatment and prevention and achieve better effect - develop data tools that patients can use for monitoring and intervening in their disease Expand innovation and lower R&D cost, e.g.: - use data as cheap "sandboxes" - minimize costs associated with Randomized Clinical Trials - develop new products, including digital devices Monitor effect of drugs post-marketing, e.g. to: - identify side-effects and drug interactions Expand markets (and profits) with real-world evidence (RWE) e.g., by: - moving indication thresholds or documenting off-label uses to enhance marketing - maximizing value-based pricing through documentation of effect data to differentiate prices To use data as assets in their own right, e.g., by: - delivering data access and analysis to other companies



Data bliver som tandhjul, der skal køre i flere maskiner på en gang

Paradokser: Forskellige historier, der begge er sande

Eksempler fra bogen

Data gør arbejdet nemmere	...og...	Data giver mere arbejde
Data øger kontrollen	...og...	Data giver forvrænget billede
Data styrker borgeren	...og...	Data truer borgeren
Data flyder alt for frit	...og...	Data hænger fast i siloer

Gamle klassiske indsigter

Berg og Goorman (1999): '**law of medical information**'

- "the further information has to be able to circulate (i.e. the more different contexts it has to be usable in) the more work is required to disentangle the information from the context of its production" (52)

Data øger kontrollen og data giver et forvrænget billede

- "Hvis ikke du har dokumenteret, så kommer der nogen efter dig og beder dig om det. Jeg tror så man kan skjule lige så meget i dag, som man kunne tidligere, for du kan bare indgive dårlige data, forkerte data, så har du dokumenteret. Så der er bare sket et eller andet skred" (sygeplejerske)
- "Hos os får vi et minimum af fejllister - men det betyder ikke nødvendigvis, at vi gør det mest korrekte. Vi har ikke tid til at gøre det ordentligt. Men vi gør det, der får systemet til at tie stille." (lægesekretær)
- "Er der en ting man er, så er det kreativ. Og bliver man presset på noget, som man ikke har en jordisk chance for at opfylde, så snyder man." (vicedirektør)

Fra arbejde lavet sammen med Sarah Wadmann

'Good governance' kan underminere klinisk datavaliditet

- Kommuner, der kræver diagnoser, før de tilbyder specialtilbud, får flere børn med diagnoser

Ikke helt nyt...

...Data styrker borgeren *og* data truer borgeren

- Søren Brostrøm: ”Psykiatriske diagnosekoder er ikke længere medicinsk valide”
- 2009–2017: vækst på 72% blandt unge mænd som afvises på session på baggrund af psykiatrisk diagnosekode

Data flyder alt for frit *og* data hænger fast i siloer

Idealet om "data-drevet styring"

- Vi kan ikke måle performance gennem simpel sammenligning
 - Forskelle kan afspejle variation i baggrundspopulation eller registreringspraksis
- Hvis du måler folk på at opnå bestemte data, ændres registreringspraksis
 - Cambell's Law

En hurtig analyse bliver nemt en dårlig analyse!

- Meget langt fra 'evidence-based medicine'

Nogen gange må man vælge... hvad er vigtigst?



Nu vil vi integrere sundhedsdata globalt

Sundhedsvæsenets data er begyndt at leve globale liv

Meget er sket fra man først udviklede dokumentationspraksisser

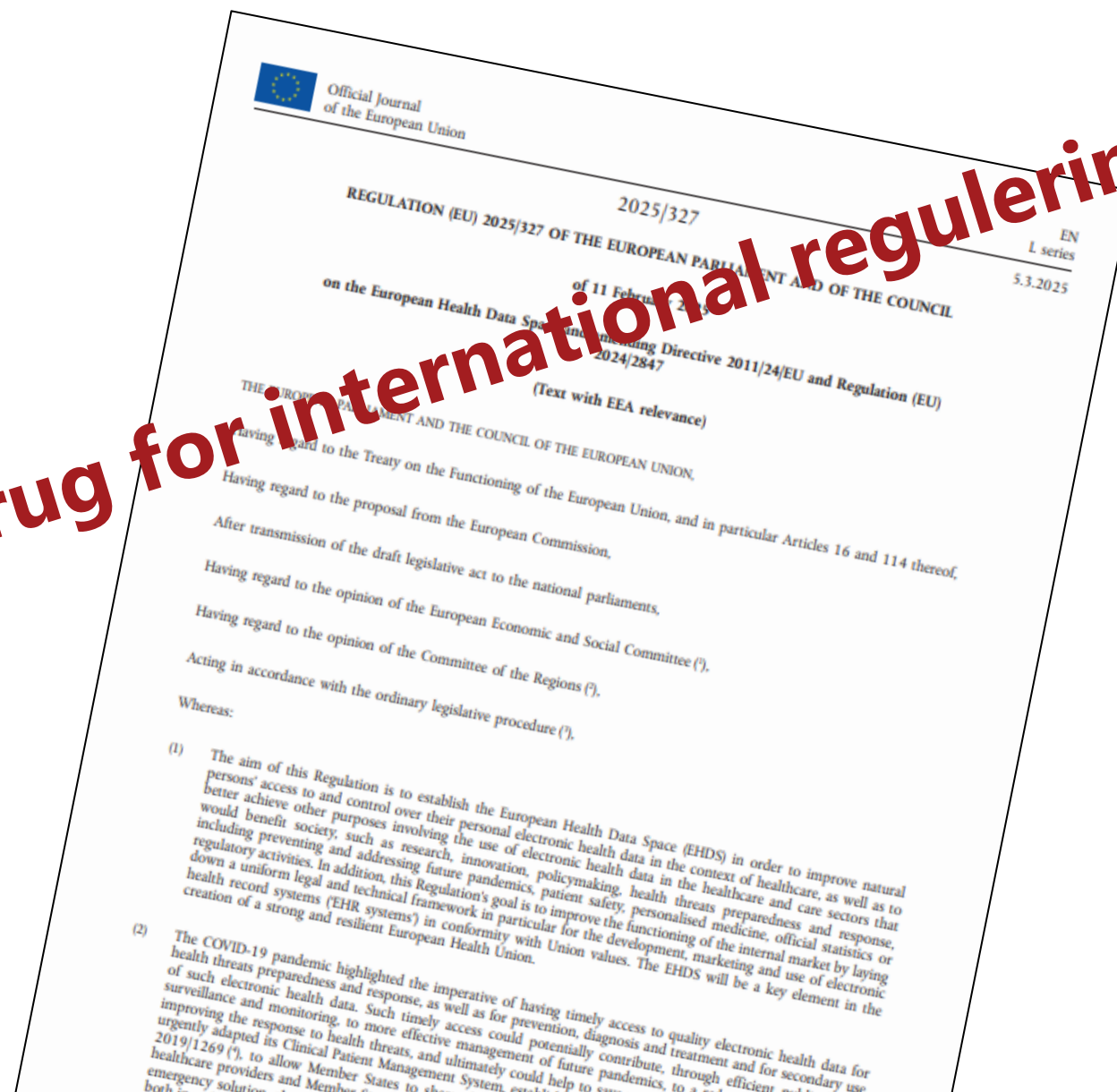
- Fra personlige relationer til globale systemer
- Fra huskeredskaber til kommunikations-redskaber og mange andre formål
- Fra narrativer til datapunkter
- Fra papir til strøm

➡ Så hvilke infrastrukturer bygger vi nu?

- Her er eksemplerne på hjemmesider fjernet af hensyn til copyright

EHDS har ikke fundet på det med at dele data over grænser

Der er god brug for international regulering



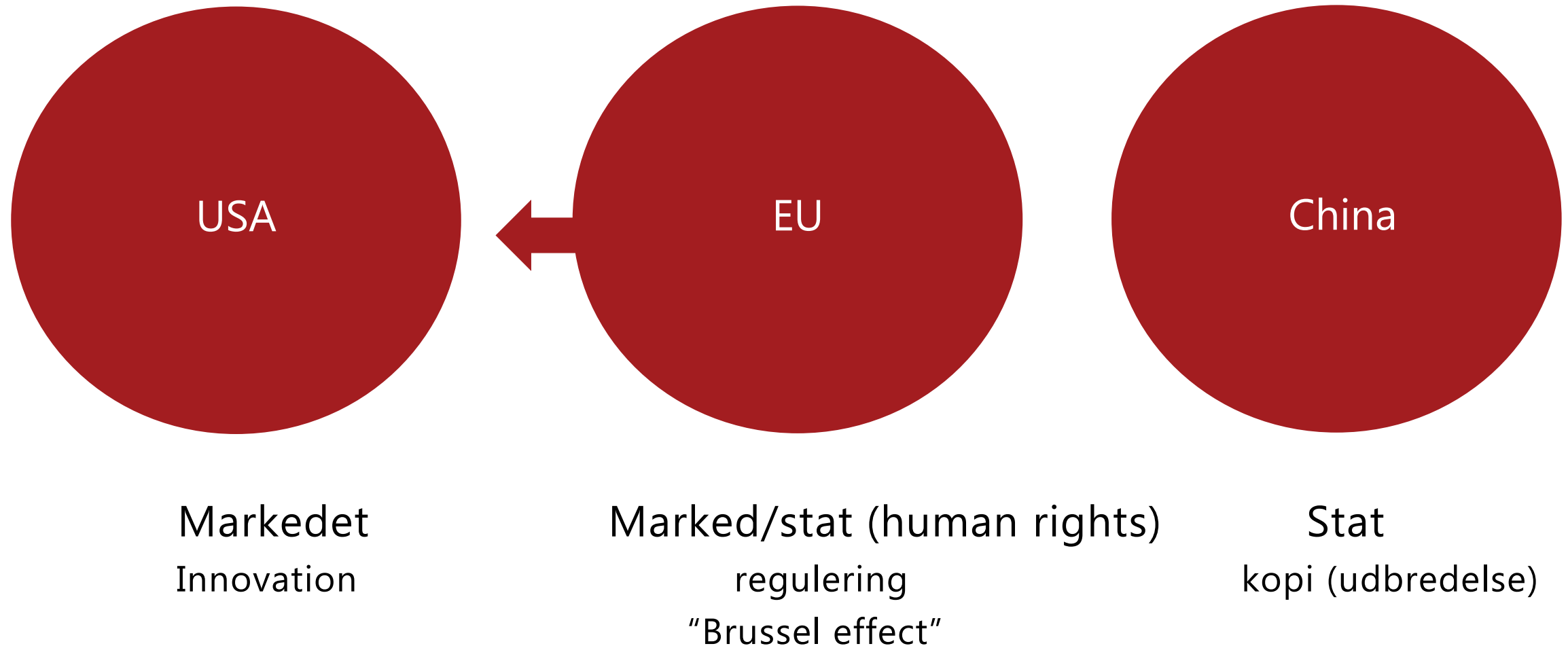
Data som økonomisk vægtstang – geopolitisk kamp

- "From resources for health to assets of wealth"

Rapporter fjernet - copyright

Den bredere geopolitiske kontekst... som den var

Alle kæmper for 'digital sovereignty'



Økonomi, sikkerhed og sundhed er sfærer, der glider sammen

- Hjemmesider fjernet - copyright



Geopolitiske skift – fra økonomisk konkurrence til sikkerhed

- En ny geopolitisk situation
- Hvem kan dele data med hvem?
- Billeder fjernet - copyright

Sundhedsdatas nye geopolitiske afvejninger

Solidaritet

Nationalstaten

Hvilket "vi"?

EU-alliancer

Menneskeheden

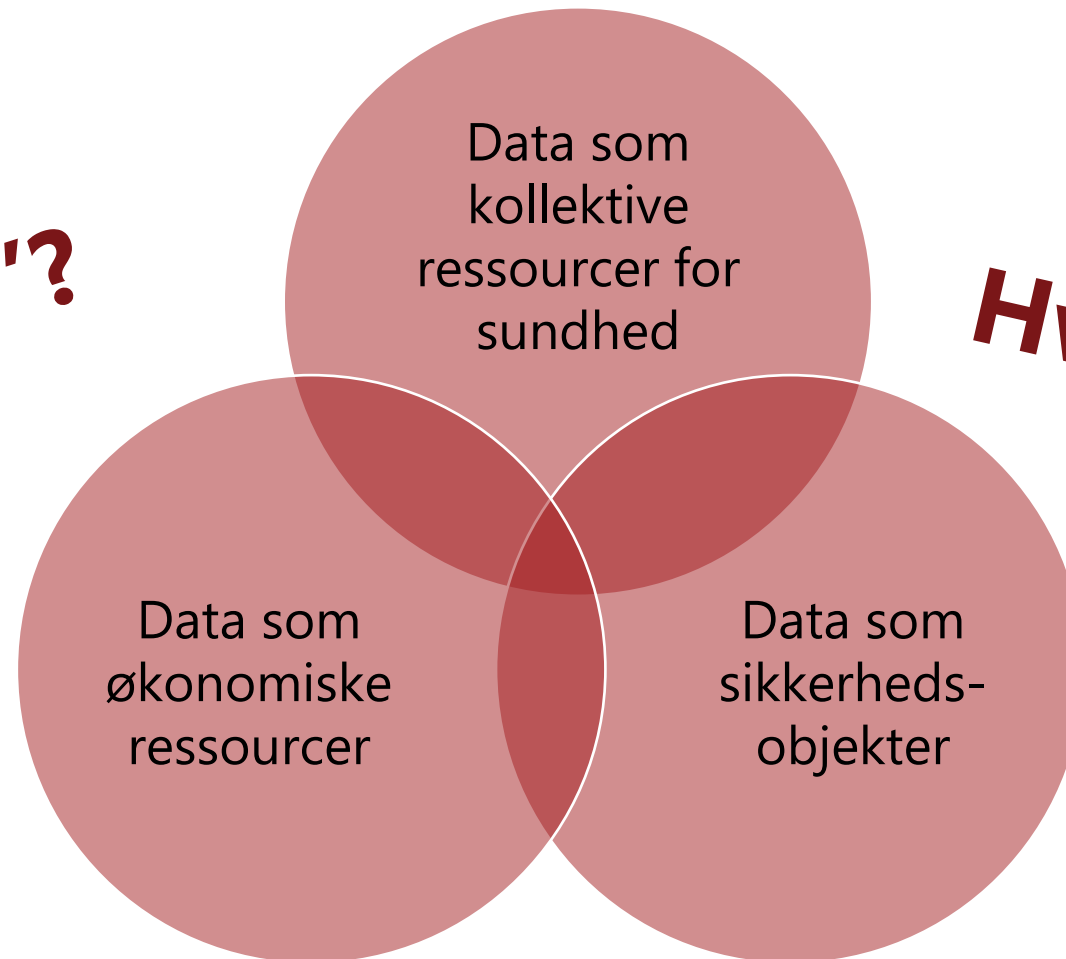
Suverænitet

Velfærdsstaten

Hvem er "truslen"?

Alliancepartnere

Firmaer



Nogen gange må man vælge... hvad er vigtigst...



Konkluderende bemærkninger

Konkluderende bemærkninger

Vi har brug for realistiske forventninger til data:

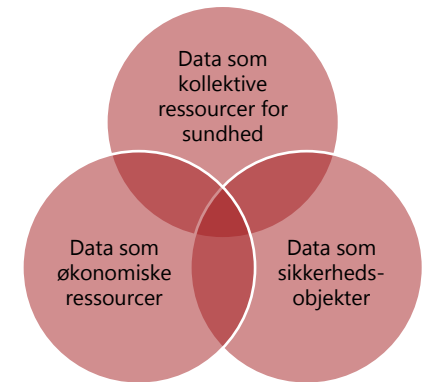
- Genbrug af data kræver mere end *adgang* til data
- Nogle typer sekundær brug underminerer primær brug
- Dataintegration kræver derfor afvejsninger

Vi skal ikke være datadrevne – men *bruge* data

- Det forudsætter dømmekraft – og dialog

I den nuværende geopolitiske situation bliver afvejsninger og valg kun endnu vigtigere

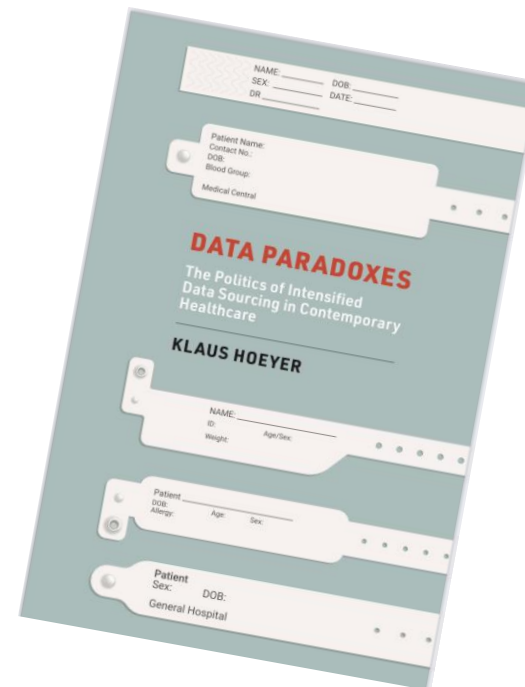
- Der er desværre ingen sikre valg



Tak for jeres opmærksomhed



www.policyaid.ku.dk
www.dataspace.ku.dk



Tak til kollage-kunstner
Lisbeth Søgård-Høyer