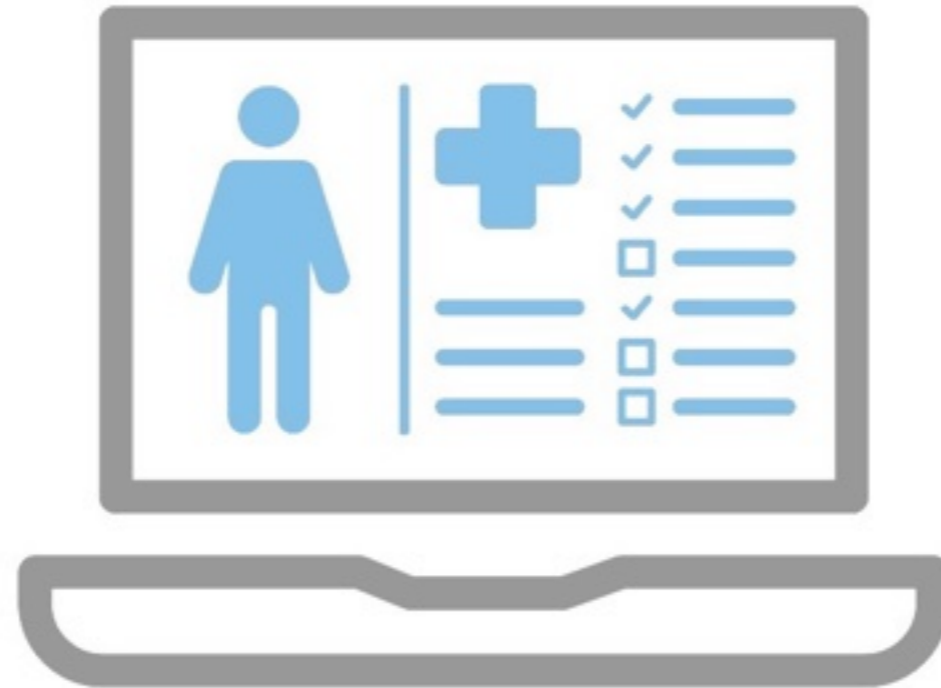


# The Assiduous Patient as Infrastructure of Health Care Systems



IT UNIVERSITY OF COPENHAGEN

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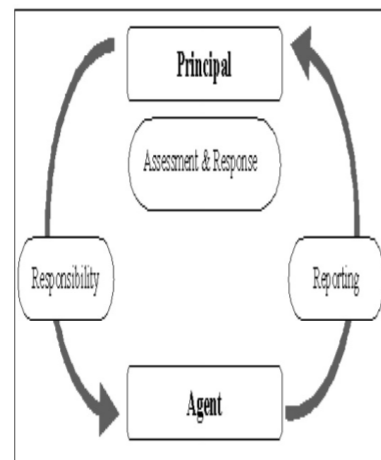
Key note for *IHC, Infrahealth 2017*, June 22-23, University of Aarhus

# Wicked problems

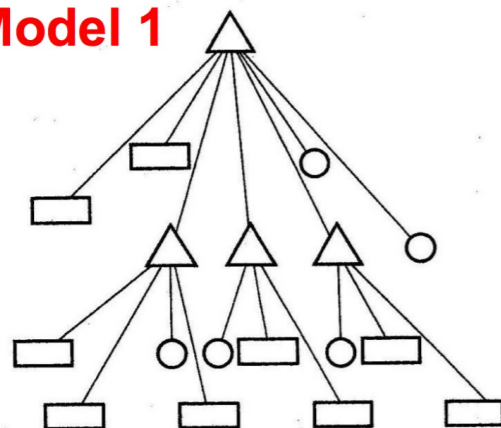
*“involve a large number of variables, conflicting opinions, uncertainties, and dynamics, thus making it hard to predict how they will evolve and how they can be resolved.”*



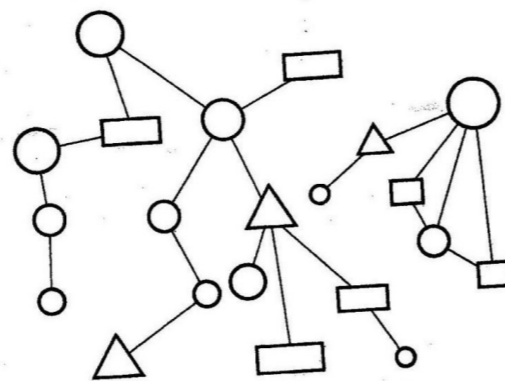
**Model 2**



**Model 1**



**Model 3**



*(Klijn & Koppenjan 2016: 42)*

# Solution =

## Governance through networks

### New Public Governance

- Governance happens where the action is; Among practitioners, patients, and citizens
- All actors are mutually dependent. Their relations are malleable to fit the needs of the situation

# Infrastructures for health care in the New Public Governance paradigm?



*Partnerships*



*Data*



*Experimental institutions*

# The patient as infrastructural component

Citizen involvement and co-creation as a means to find solutions to public sector challenges:

**‘The patient as partner’**

Scholars from STS and CSCW scrutinise the new role of the patient:

**‘Being patient’ vs. ‘being autonomous’**

# Work is delegated to the patient

- Delegation by health care institutions (Domenech, Bjørn, Møller)
- Personal web based health records (Langstrup, Winthereik)
- Blood sugar measurement devices (Mol, Danholt)

## IT...

- ... Enables care at a distance
- ... Requires that patients generate data


# 'Active' and 'passive' are properties of patients in different situations

Properties of patients are 'folded into' each other in curious and unpredictable ways in patient trajectories.

**Certain liberties gained**

**Certain (new) constraints emerge**

# Pregnancy care

A stethoscope with silver tubing and white earpieces is positioned on the left side of the image. To its right is a silver tablet computer with a black screen, lying flat. The background is a dark grey wooden surface with vertical grain lines.

Introduction of an online pregnancy record that could be accessed by midwives, general practitioners, hospital staff and the pregnant woman.

The ambition was to turn pregnant women into **active managers of risk** by involving them in real time information exchange with care professionals.



# Pregnant women as mini-bureaucrat

## Unintended effects

The pregnant woman emerged as an **assiduous user** of an information infrastructure, which she considered incomplete.

Filling the gaps in the records, she became a delegate of the Danish healthcare bureaucracy.

# A failing experiment?

It rendered responsible the pregnant woman beyond her own body and beyond the primary care situation.



What is a successful encounter between state institutions and citizens?



# Example from a different sector:

## *Udbetaling Danmark*

Ambition:

to reduce the number of communication channels available to those seeking access to social benefits  
(Østergaard Madsen)

A transfer from face to face, internet, telephone interaction to digital self-service.

But communication channels can work as fences rather than points of interaction between state and citizen.

# Example: Frustrated citizens is the result of digitalisation of communication



*Have sat for 3 fucking days, trying to log on to EasyID at citizen.dk to confirm that I am still a single provider.*

*But every time I have tried, the system has only let me type the password from my key card, and then shown a message that "an error has occurred".*

*And then you are in trouble as a citizen. But of course I can try again by phone tomorrow during breaks at work.*

*"Ulla"*

- was interviewed by Christian Østergaard Madsen as part of his study *The Citizen as Case Worker*.

# Infrastructural competence

*“an individual’s use-oriented relationship to infrastructure that combines social ability, goal-orientedness, and leveraging of digital and material resources in a way that enables one to generate a functional, operable, and personalized, if patterned or routinized, set of sociotechnical practices to accomplish a necessary task or set of tasks.”*

*(Erickson, Sawyer and Jarrahi, in press)*



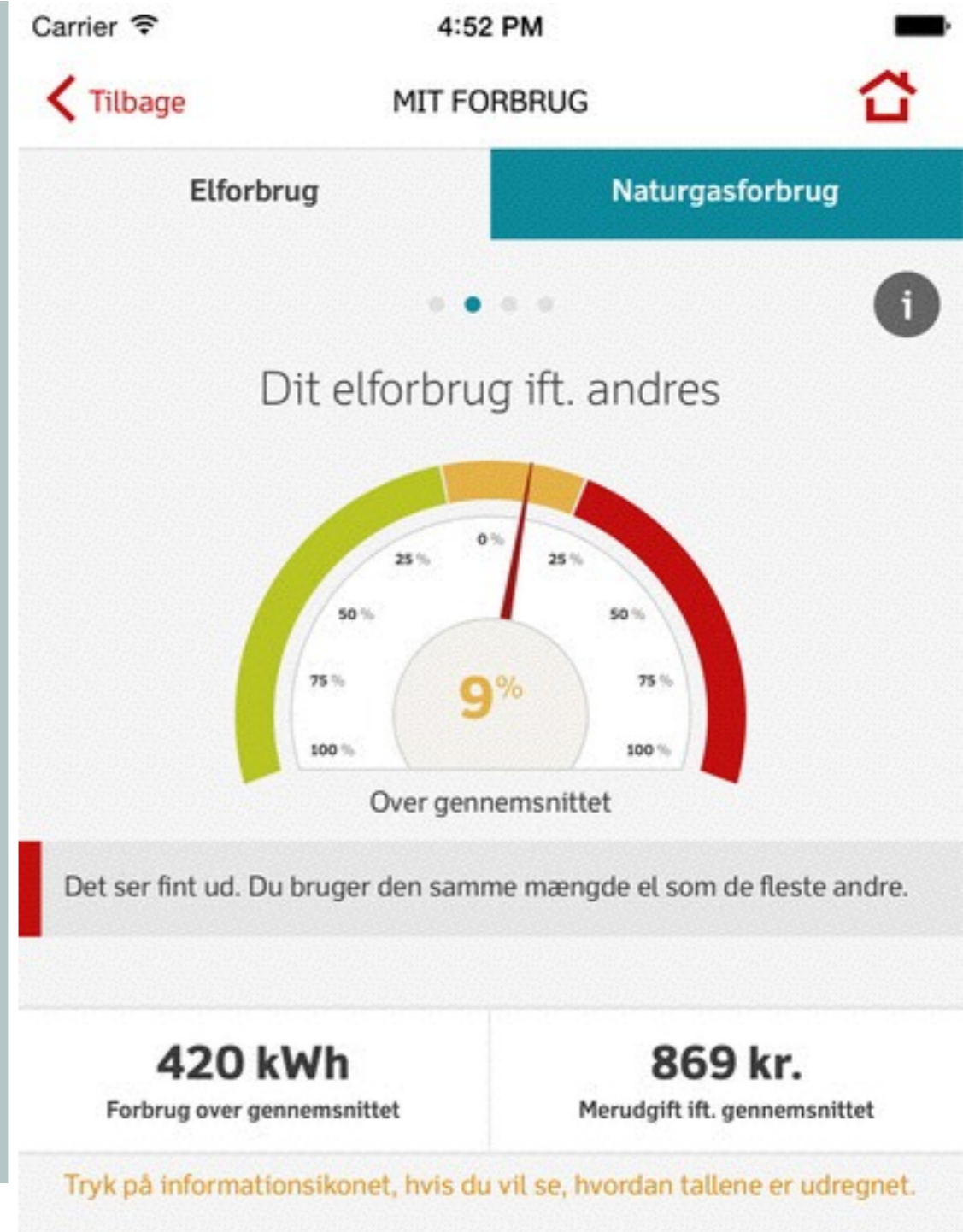
# Comparing health care and energy sectors

Empirical and theoretical comparisons  
to the issue of governance networks

# The “cost-insensitive consumer”

Energy companies take measures to make consumers responsible for their household consumption:

- Make household consumption visible
- Adjust prices: Pay less when there is much available electricity.
- ‘Load sharing’ - sharing economy





# Solution - make the consumer responsible

A lightbulb with a hand inside, symbolizing an idea or responsibility, with two cartoon figures below it.

This form of sharing “(...) is opposed to the implied selfishness of denying others access to underused time and assets confined to the private sphere”  
(Wendy Brown)


# Who is responsible and accountable in a governance network?

A vision in governance networks is co-responsibility. But if patients are rendered responsible for quality of care as well as for care costs, questions emerge:

**What can the patients expect in terms of resource?**

**Inequality as an effect?**

# Are there still infrastructures around?

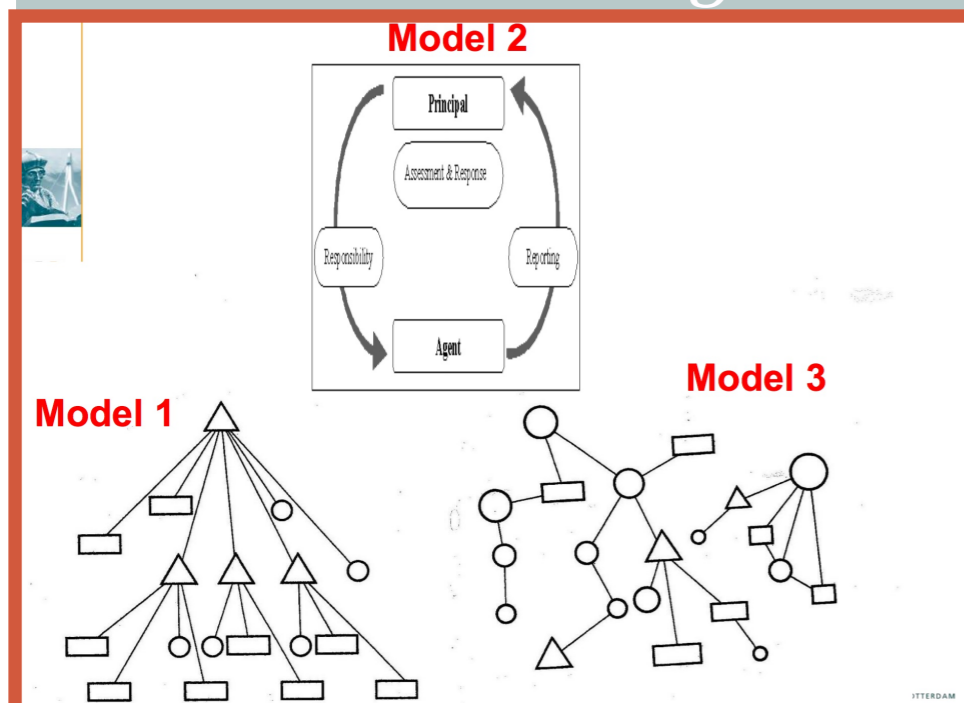
An illustration on a blue grid background showing a hand pointing at a laptop screen. The laptop screen displays a medical dashboard with a line graph, a circular profile picture of a man, and text. Surrounding the laptop are various medical and digital icons: a syringe with red liquid, a smartphone with a white cross on a red background, a red and black pill, a hand holding a document, and a hand holding a tablet. A faint world map is visible in the background.

A patient has emerged, whose participation and interactions with health care institutions are distributed across a digital landscape.

**Can we even talk about a patient being a part of an infrastructure?**

# The experimenting organisation?

*“(...) more or less stable patterns of social relations between mutually dependent actors which cluster around a policy problem, a policy programme and/or a set of resources which emerge, are sustained and are changed through a series of interactions.”*



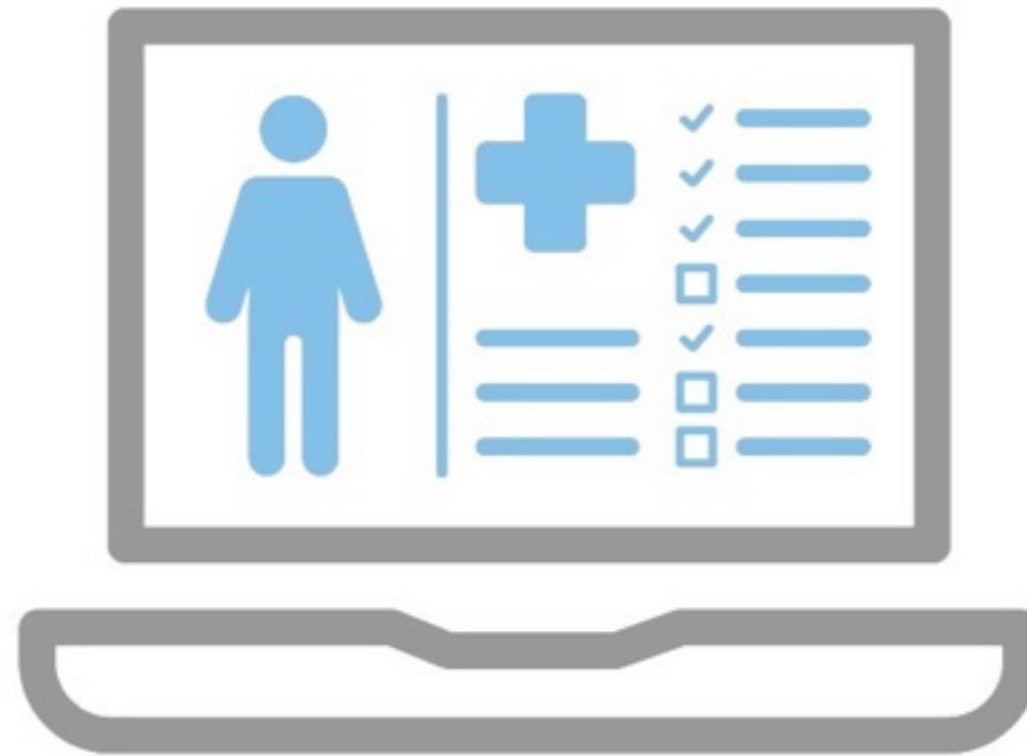
*(Klijn & Koppenjan 2016)*

# In conclusion

1) Study how online environments call patient assiduity into being in governance infrastructure characterised by mess and incoherence.

2) Trace processes and technologies through which patient assiduity is turned into responsabilisation.

# Thank you!



Title:

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Key note for “*Infrastructures for Healthcare*” conference, June 22-23 2017, University of Aarhus