

# Minor creations of technological tactics for everyday life with a chronic disease

Cachet biweekly – 07-12-18

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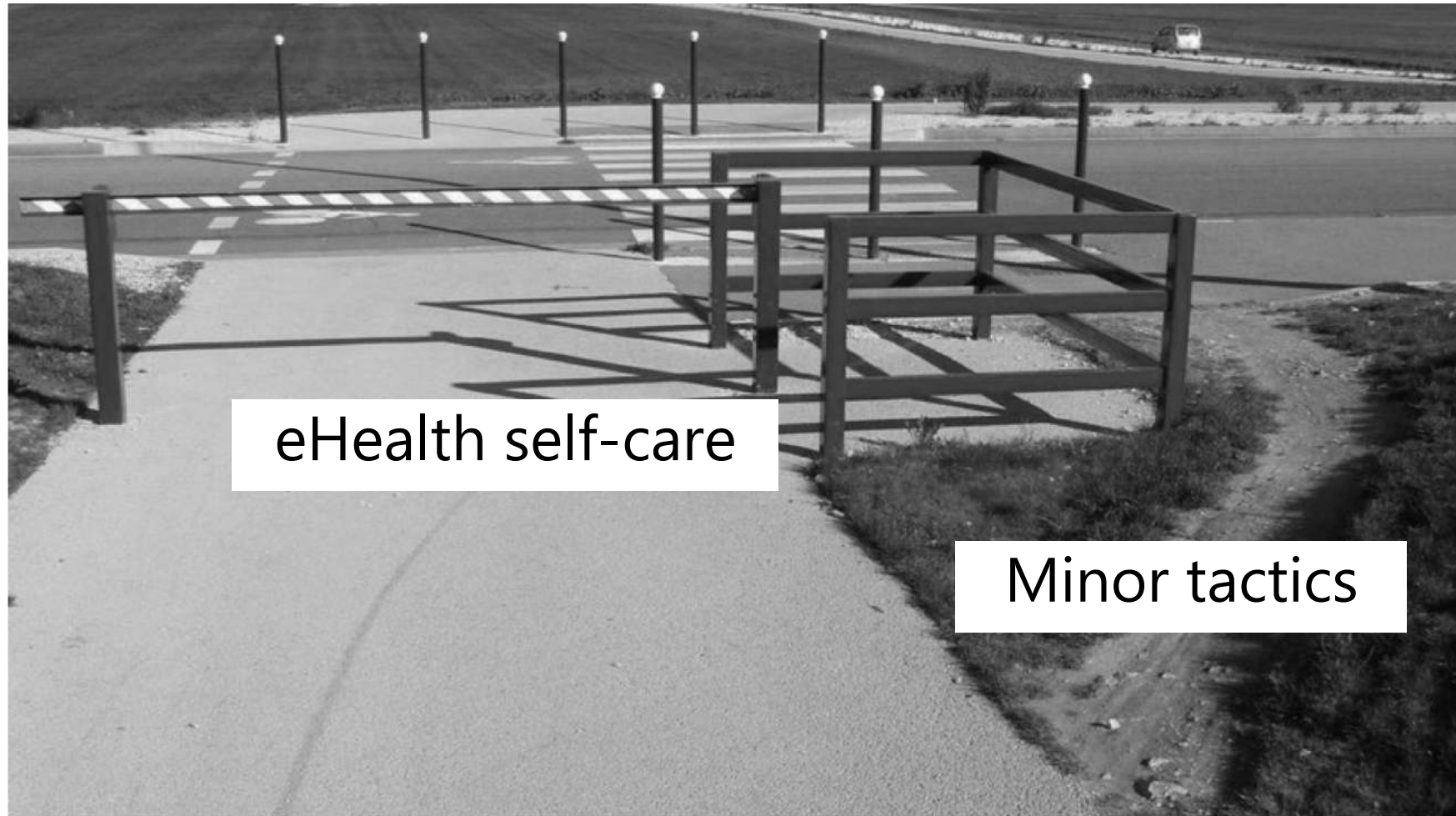
# Agenda

- The overall project
- Findings about minors with chronic diseases
- Critical preliminary insights and questions for eHealth development with minors
- Discussion points



# The overall project

# Discrepancy between eHealth imposed self-care and minors daily life with disease



eHealth self-care

Minor tactics

# Research question

What consolidated ecology of illness-management relations and practices are eHealth solutions embedded into,

and

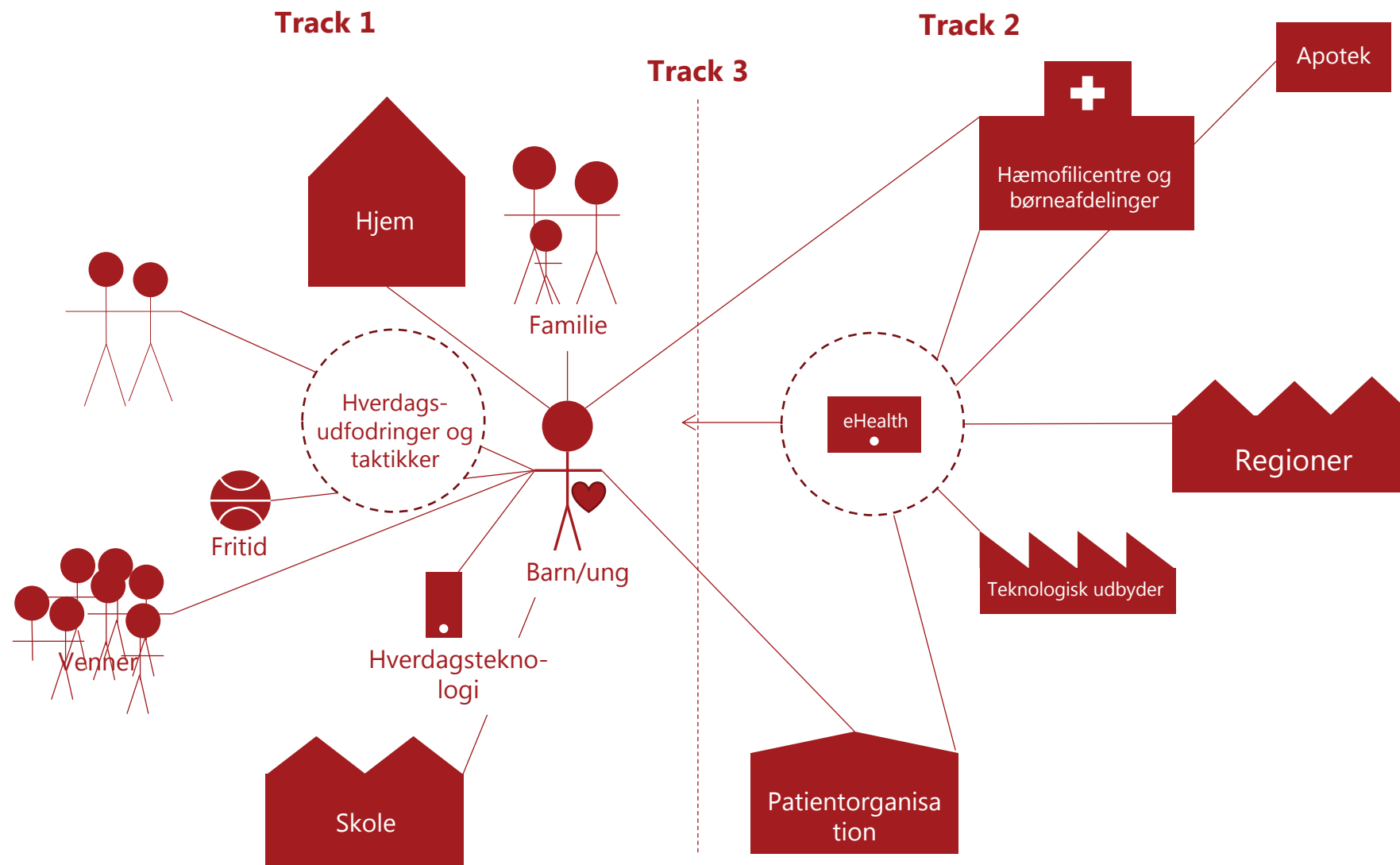
how can we optimize the fit between eHealth solutions and the lived realities of children and young people living with a chronic illness?

# Ethnographic fieldwork

- 1. Everyday challenges and tactics for minors with chronic diseases (JRA and Haemophilia)
- 2. eHealth development practices (Self-empowerment app and decision supporting tool)



# Fields



# Findings about minors with chronic diseases

# Fieldwork amongst minors with hemophilia and Juvenile Rheumatoid Arthritis



# Establishing frames and routines for home treatment



# Home treatment is scripted and ritualized



# *Interembodiment* assemblage of treatment



# Minors perform treatment on dolls and teddy bears



# *Imitation games* of the link between medical devices, treater and the treated



# The greatest challenges to minors with chronic diseases

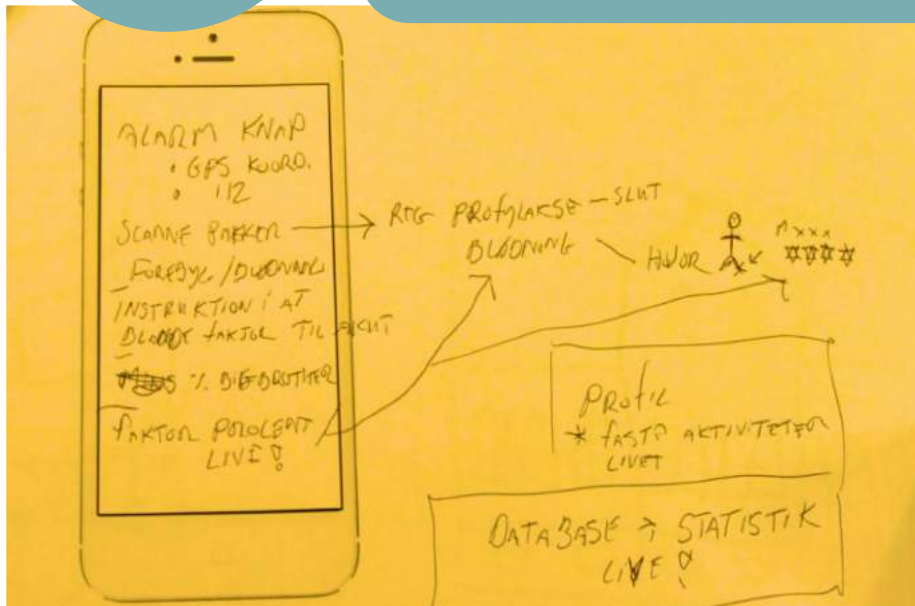
- Relations to peers
- Not having the disease take up too much space
- Domestication/management of "dangerous" treatment equipment
- Learning to take part in treatment

# Critical preliminary insights for eHealth development with minors

1

## Whose challenge are you solving?

Does the solution solve a **challenge that families experience**? e.g. limiting visits to the clinic, or limiting how much space the disease take up.



## 2

## Instead of *treatment compliance* focus on “*reality compliance*”

Make the solution comply with already established tactics and routines for disease management



## 3

## Focus on haptic process of learning about treatment, disease and body, instead of results

Successfulness in **disease management** for minors is *felt*, not measured. Help minors **explore best practices** for them



Telenor DK 13.58 97 %

Ny registrering  
**Blødning**

Hvilken type blødning  
er der tale om?

**Traume**

Blødning opstået i forbindelse med  
aktivitet, fx. ved et slag, stød eller  
overbelastning

Spon

Blødning der opdages  
relation til aktivitet eller

4

Telenor DK 13.57 97 %

Ny registrering  
**Placer blødning**

Hoved/hals

Mave/bryst

Højre arm

Venstre arm

Underliv

Højre ben

Venstre ben

Is it “self-care” or should it actually be termed  
“health care”?

“self-care” and “registrations” are not compatible in families’ everyday life  
management



5

**The framing of community-solutions are critical;**

Minors have **no practices of diseases sharing in social forums**; they wouldn't know what to get out of sharing and there are specific norms for minor life online

## 6

## Gamification design might contradict how serious minors are about the disease

Even though the minors play “imitation games” they are very serious about the disease.



# Discussion points

## Discussion points

- Who is the participant in *participatory design*?
- How to include insights about everyday life, challenges and tactics in an eHealth design process, not asking "what do you need and want"?
- How can eHealth support the interrelated processes of disease management that are already formed and at the same time generate clinical value?

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# Acknowledgement

## Funding from:

Telemedicinsk Videncenter



&



## Principal

**supervisor:** Head of  
Section, Associate  
professor *Henriette  
Langstrup*

&

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