2021

Troubling Care – A critical look at the systemic shift toward healthcare digitization

Prakash, Shivani, Nilsson, Felicia and Vink, Josina

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A critical look at the systemic shift toward healthcare digitization

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RSD10

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Arkitektur- og designhøgskolen i Oslo
The Oslo School of Architecture and Design

C3 Centre for Connected Care

Introduction

Shivani Prakash

Felicia Nilsson

Josina Vink

Our project partners

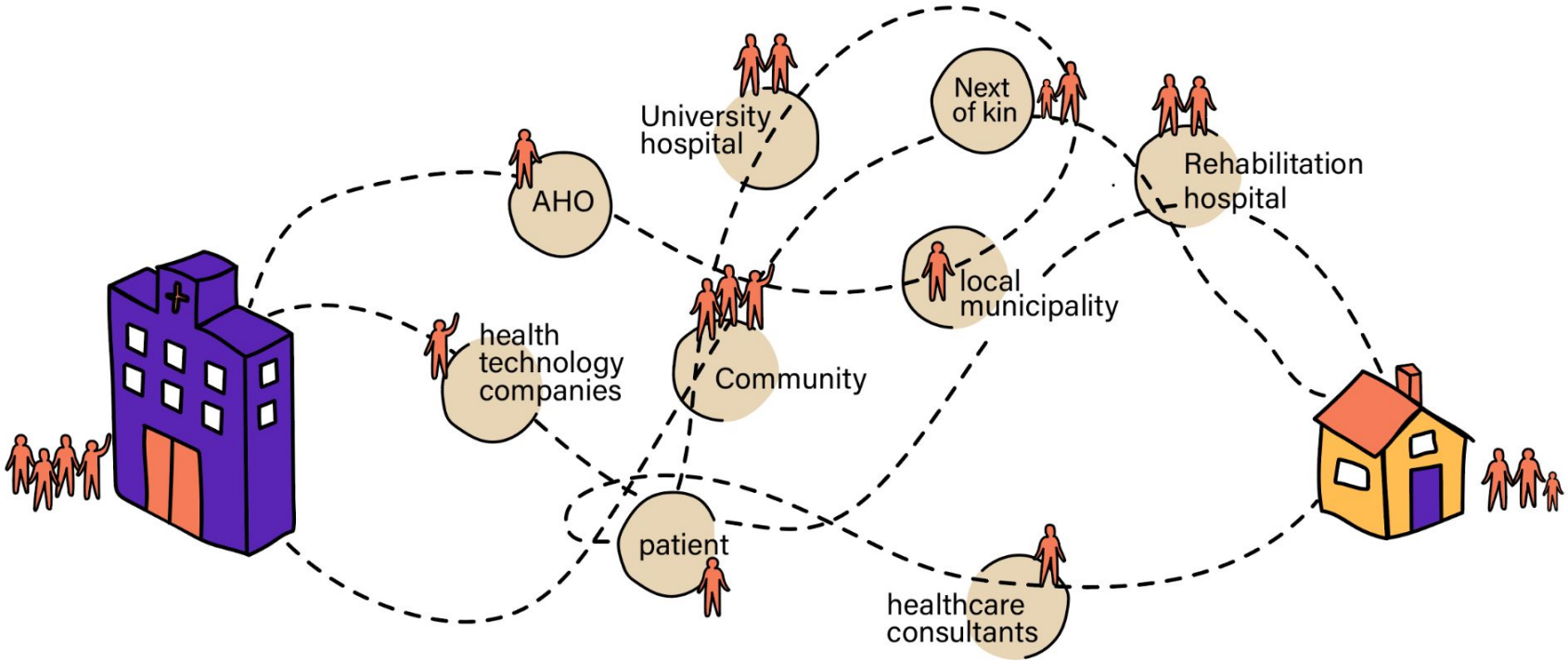


Illustration: Shivani Prakash

The dominant view of the systemic transition

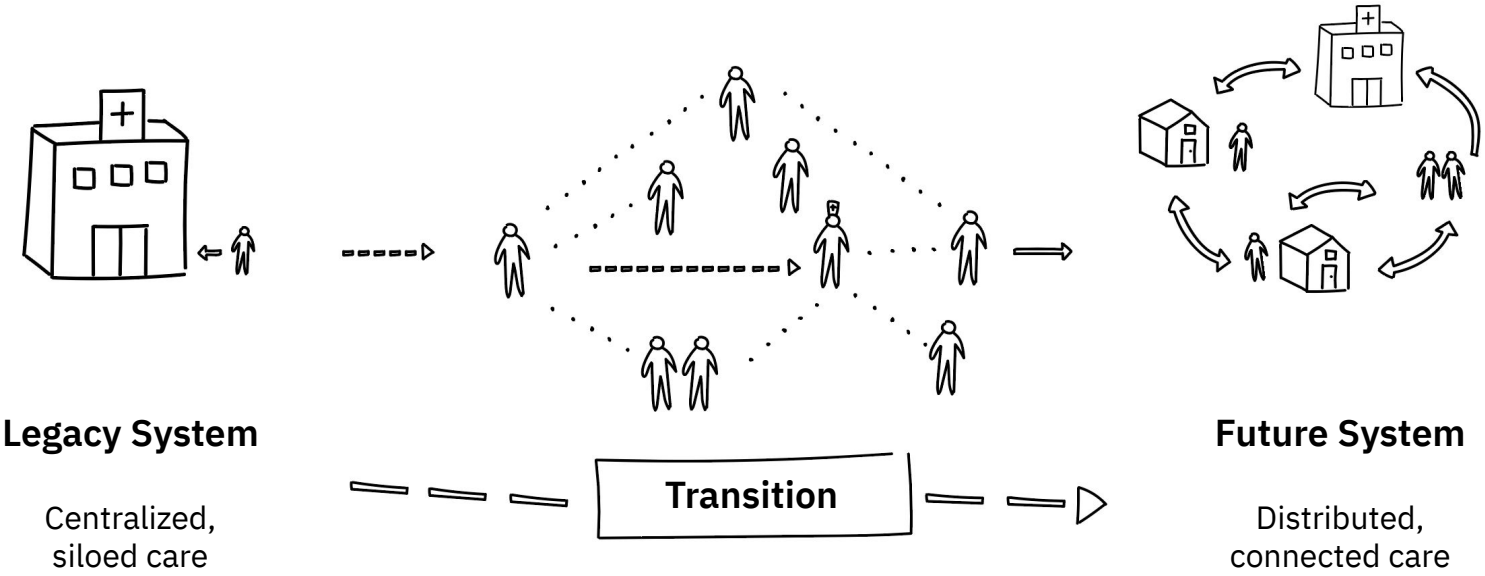


Illustration: Thiago Freitas

Scaling-up remote care

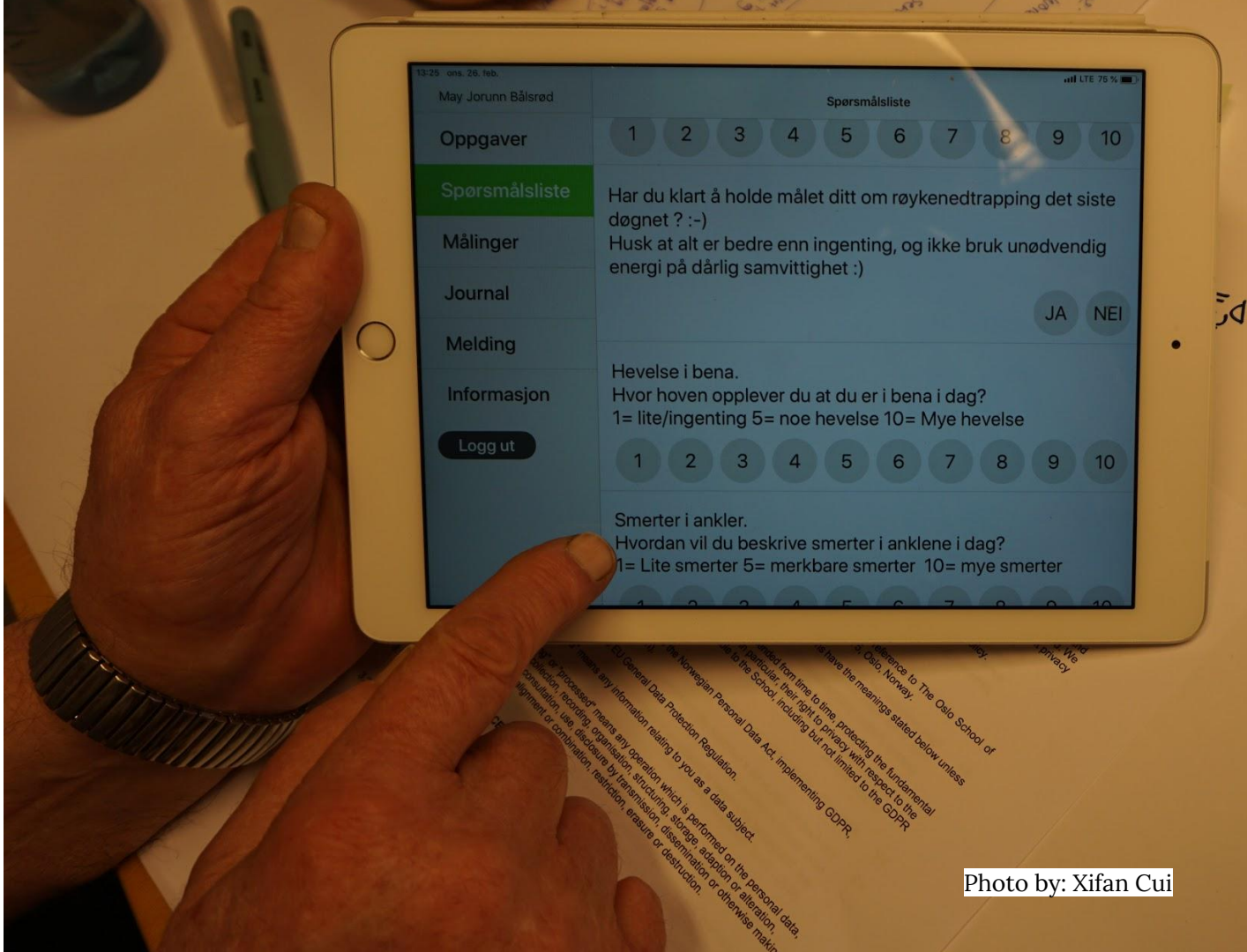


Photo by: Xifan Cui

The context of remote care

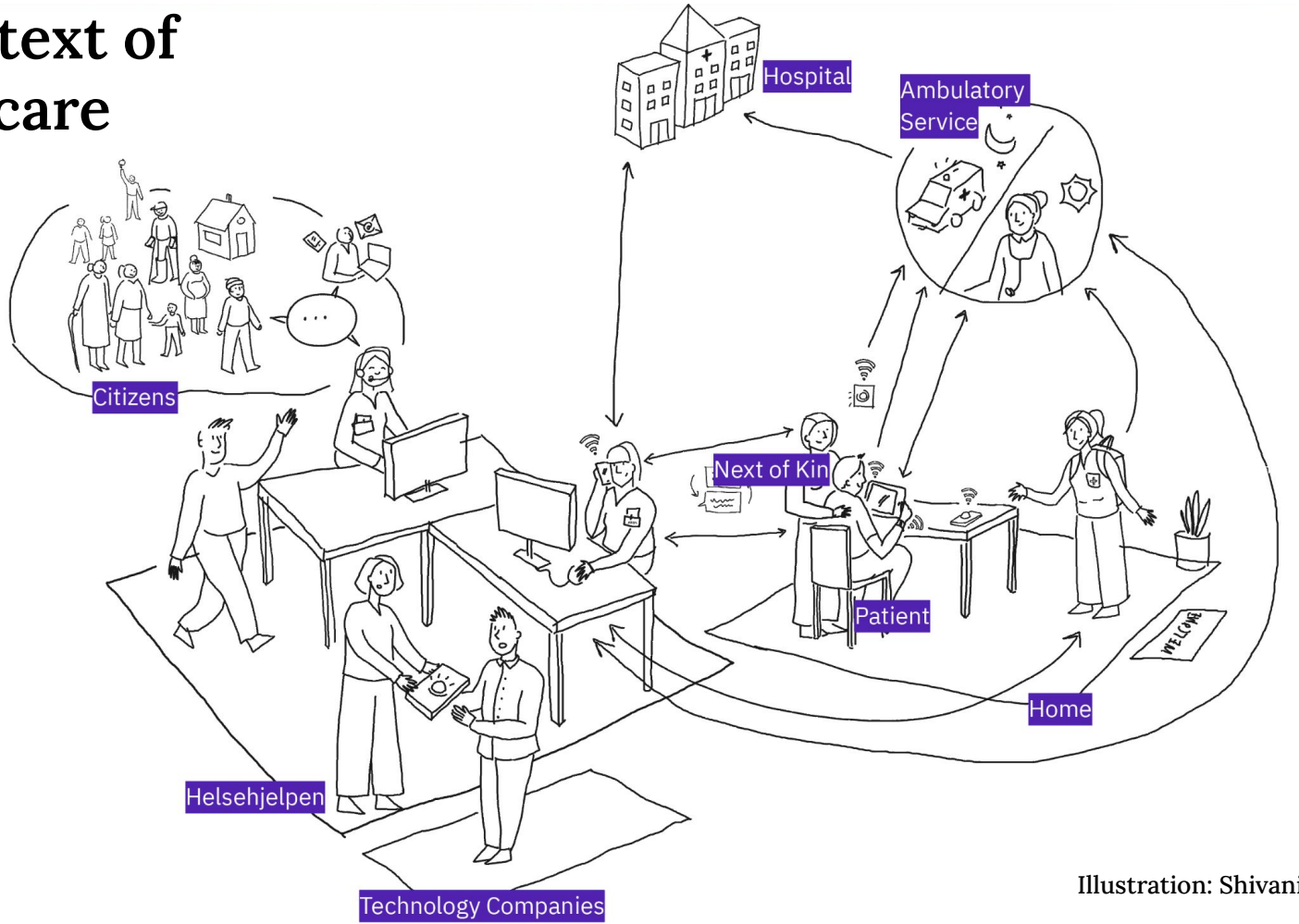


Illustration: Shivani Prakash

Troubling care

Move away from ‘technofixes’

We see the need for design to move away from an emphasis on technofixes under the banner of working toward “good care” and instead create room for making trouble in care.

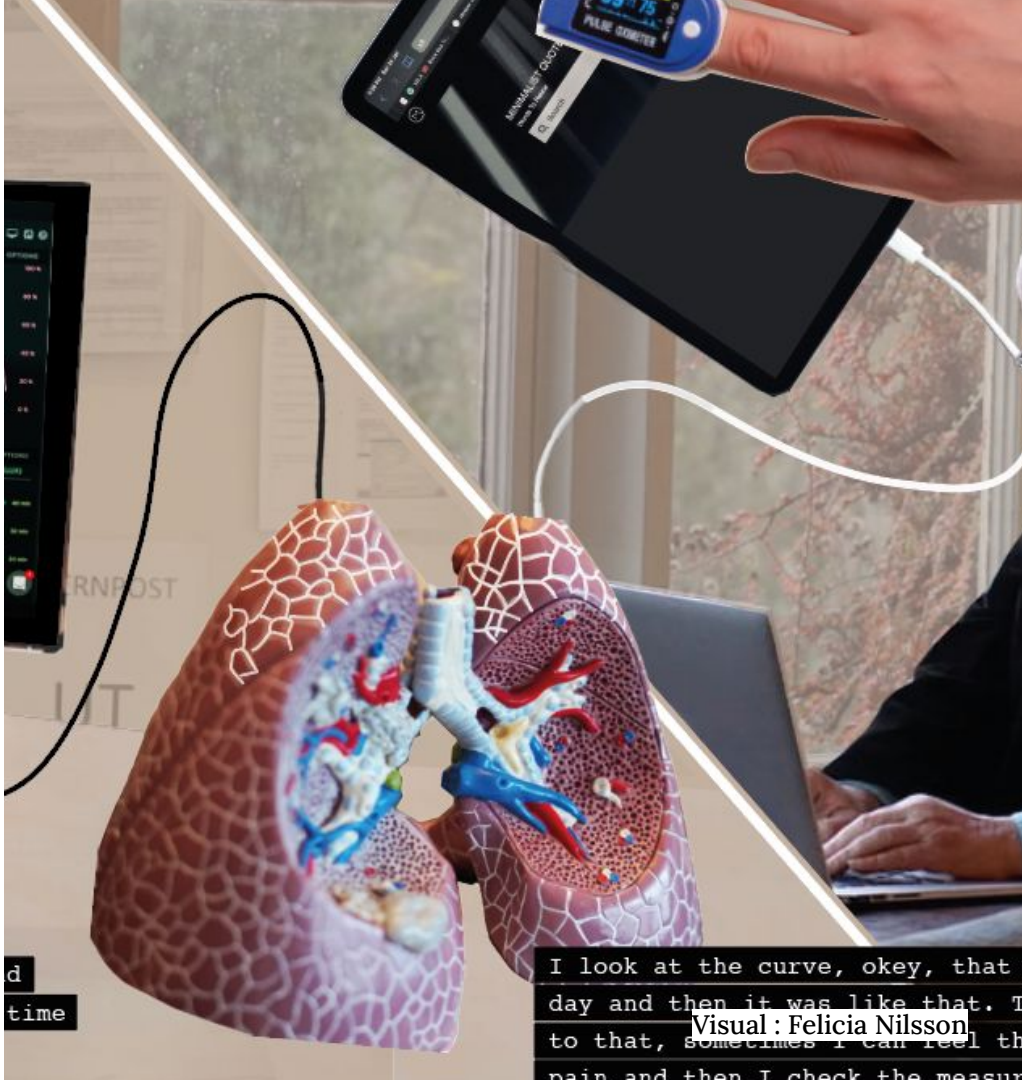
Visual: Shivani Prakash

Staying with the trouble

Drawing on Haraway, we use the term trouble to denote entangled contradictions, multiplicities of meanings and a plurality of ways of being in the world.

Staying with the trouble

The aim of this paper is to share a half-baked exploration of how design might start to unsettle care by exploring the patterns of tensions in emerging worlds within the evolving landscape of the Norwegian healthcare system.



Visual : Felicia Nilsson

Troubling the shift to healthcare digitization

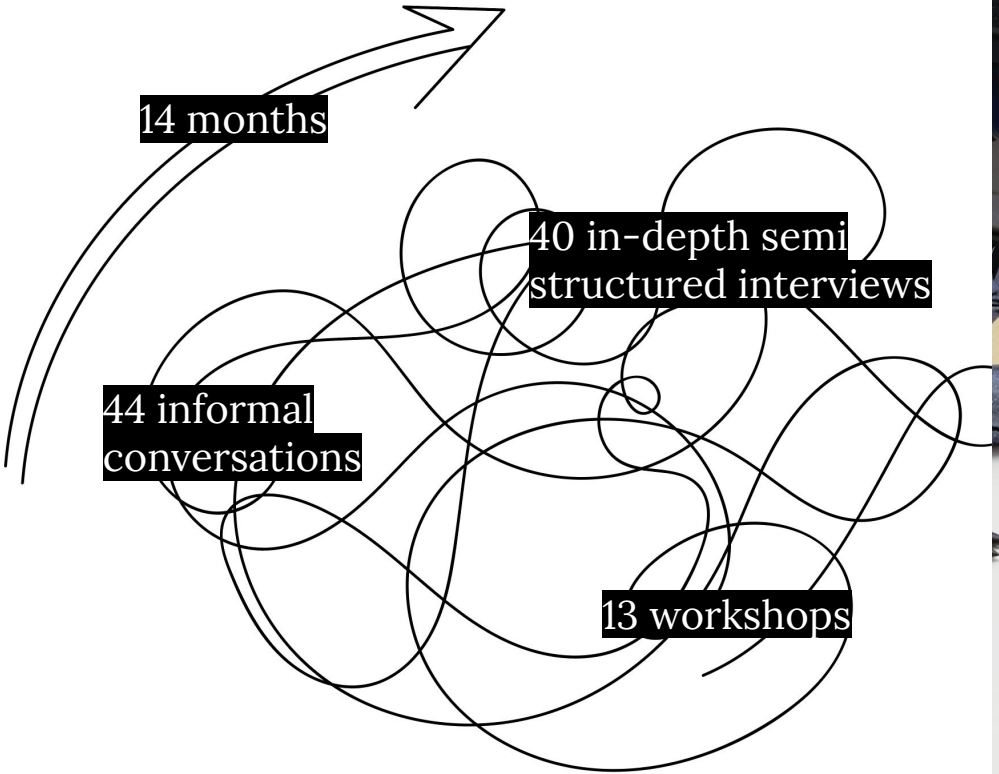
We zoom in on the troubles amid experiences of using remote care plans, where healthcare providers offer in-home support, guidance and monitoring to patients in their homes.

P/C: Dignio

How can we understand care systems in a way that holds the contradictions and portrays the plurality of lived experiences amid systemic transitions?

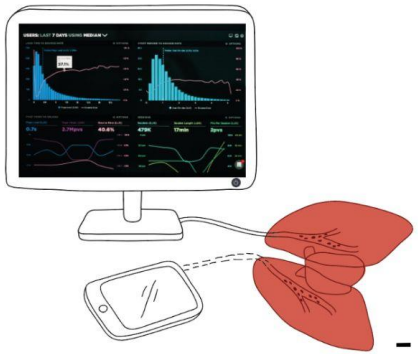
Messy-dology

The study


14 months
40 in-depth semi structured interviews
44 informal conversations
13 workshops


P/C: Josina Vink

Our process



What care looks like from a technological perspective

The values of care that are negotiated

The dilemma of technology - we are connected but physically apart/isolated

P1-R5: The plan is great, I use it almost every day so that I can see if "I'm in the green zone" and then it's great. It does something for the mental part too, because I feel safe, and that doesn't strengthen the COPD.

P1-R5: It's the safety. My safety, I don't get insecure, because I have a tendency to wait a bit to long, but then HH is there straight away, so I don't have time to get to that stage myself because then health care is on right away.

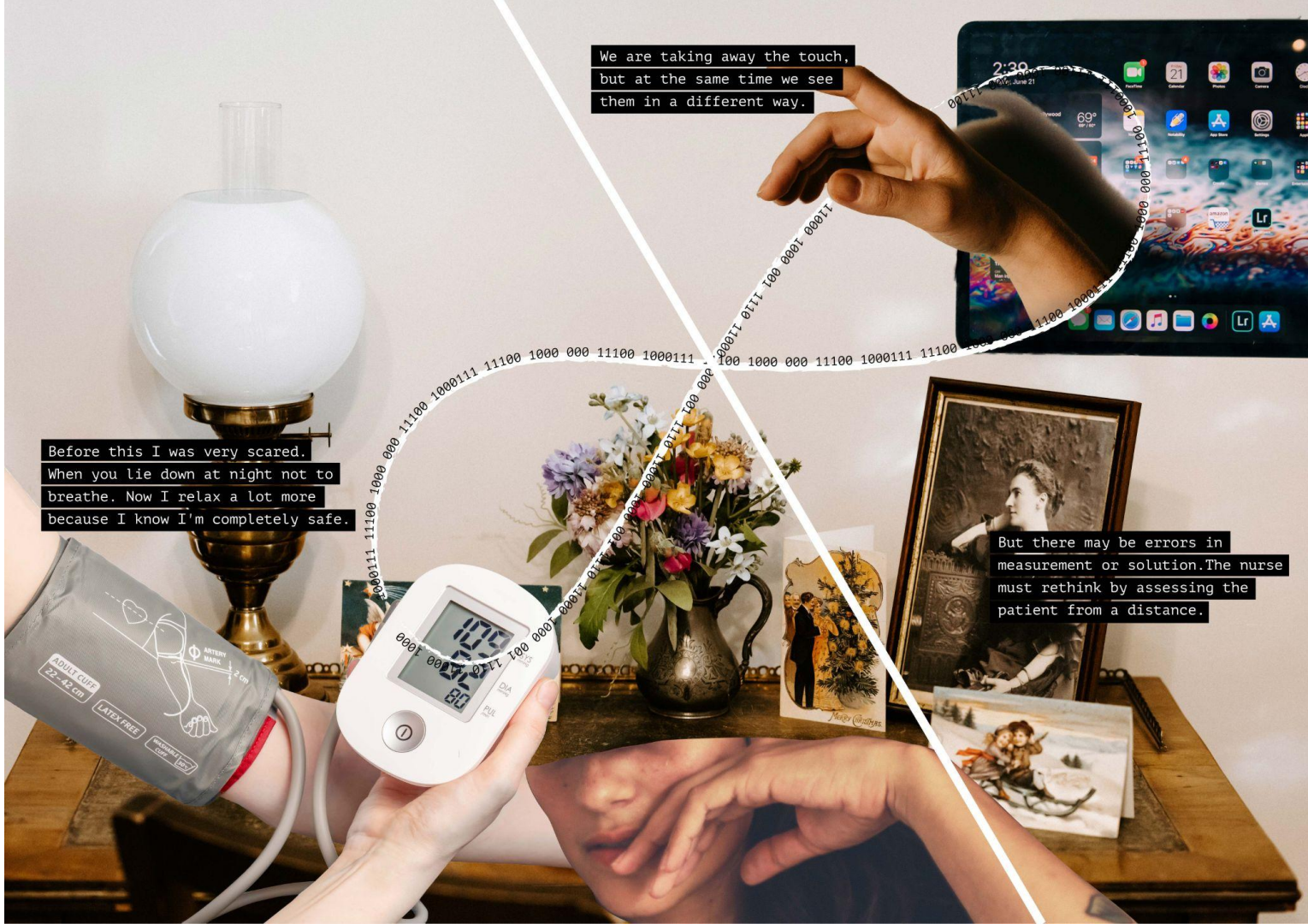
P1-R5: (What is great with the digital:) the family gets safer too. Then they know that I'm under surveillance, I almost said, that I'm seen all the time. They also feel more safe when they know that I'm being followed up.

Post-it notes used to pen down our thoughts and reflections

Example of visual explorations done to analyse connections

Pulled out excerpts from interviews and highlighted interesting parts

Visual collage



Visual collage

Textual collage

Patients need to take responsibility for their own health. The remote care plans are designed in a way to shift some of the responsibility of care onto the patient.

Some patients begin to see the value of remote care in a few months. Overtime, my team is able to create a sense of safety for the patient and their family. They need to see that we will be there for them when a measurement goes wrong. The patient needs to know themselves and their chronic disease. My team also gains an understanding of the patient through the monitoring. We begin to understand if such-and-such symptoms are normal or far from normal. I see some of my patients have become very well acquainted with themselves and have gained more responsibility for their disease. We are taking away the touch, but at the same time we see our patients in a different way. I think that they feel the same way, that we are listening more to them than we would have if we were home care and visited them every day.

But some patients are not really pleased that we don't work during the weekend. They feel unsafe that we are not sitting in the control room and monitoring them. Patients feel that they won't get a phone call if something went wrong. But that's the part of responsibility and knowing yourself. But, keep in mind, that every patient is not able to take responsibility for their chronic disease through these remote care plans. Some patients lose interest in monitoring and tracking their symptoms. In such cases, we are not able to extend any support. I need to spend my time on the patients who are interested in using the technology. You see, motivation is a key factor.

The nurses wanted to sign me up for a remote care plan. They are still testing the technology. It's all wireless, so it seemed less messy when I said yes to using their remote care plan. All I needed to do was measure two aspects daily. The measuring included recording my oxygen levels and blood pressure once in the morning. I reflected back on my daily routine. There can be space for two measurements.

After a few weeks, it felt great. A nurse called me every time a measurement shifted and checked-in on me. They weren't there during the weekends. But I'm healthy enough to be left alone. If I'm having a bad day, I know I can have two bad days before I need to get nervous. The plan is great, I use it almost every day to see if "I'm in the green zone" and it does something for the mental part. I feel safe, and that doesn't strengthen the COPD.

And then it's about how I feel. I wrote to them when I felt dizzy, and bang they were at home with a blood pressure monitor for me. Then they contacted the general practitioner and got me an appointment. I think it is very reassuring because I feel in control. If something happens to my body that I have no control over, I become very insecure. But now I can go into the plan and see my symptoms and which measurements I can take. I'm very fond of the remote care plan and I use it a lot.

There may be errors in measurement or solution. But the nurse can take a video call and check-in with the patient. If the patient looks fine then there may be a fault in the equipment. The nurse must rethink by assessing the patient from a distance. My experience is that they fix it well, but have to think and work differently.

But we need to proceed cautiously as somethings may go wrong sometimes. A patient may not really be in the yellow zone, and they may have consequences if they then do 'yellow' activities. There are human failures on equipment or assessments made by the health personnel. For now we chose to move away from automation for that security. But when things start to get more secure with the current system, then we can start thinking about it again.

Discussions & findings

1. Knowing by measuring /
experiencing through sensing

2. The situated view /
the isolated view of the patient

3. Helping the dependent /
coaching the independent

1. Knowing by measuring / experiencing through sensing

“We begin to understand if such-and-such symptoms are normal or far from normal” Nurse

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"Sometimes I can feel that I have pain and then I check the measurement and it says it is fine and then I can calm down." Patient

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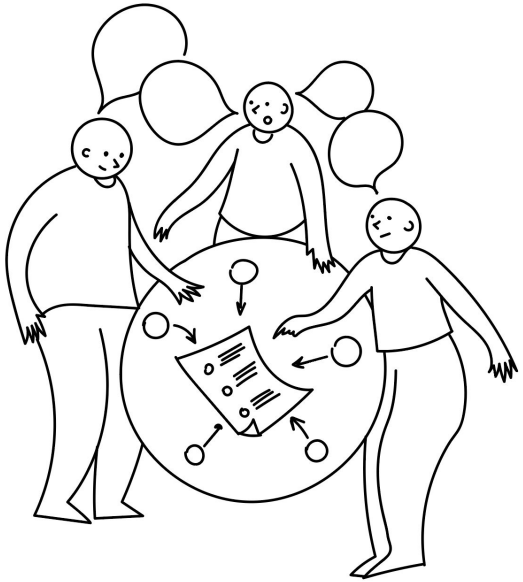
“We begin to understand if such-and-such symptoms are normal or far from normal” Nurse

“Sometimes I can feel that I have pain and then I check the measurement and it says it is fine and then I can calm down.” Patient

“A patient may not really be in the yellow zone, and they may have consequences if they then do ‘yellow’ activities.” Nurse & designer

Messy learning process



We see this tension-based understanding offering our partners approaches to move away from a one-sided perspective of this systemic transition and begin embracing the multiple realities that exist with their care contexts.

2. The situated view / the isolated view of the patient

“My team also gains an understanding of the patient through the monitoring” Nurse

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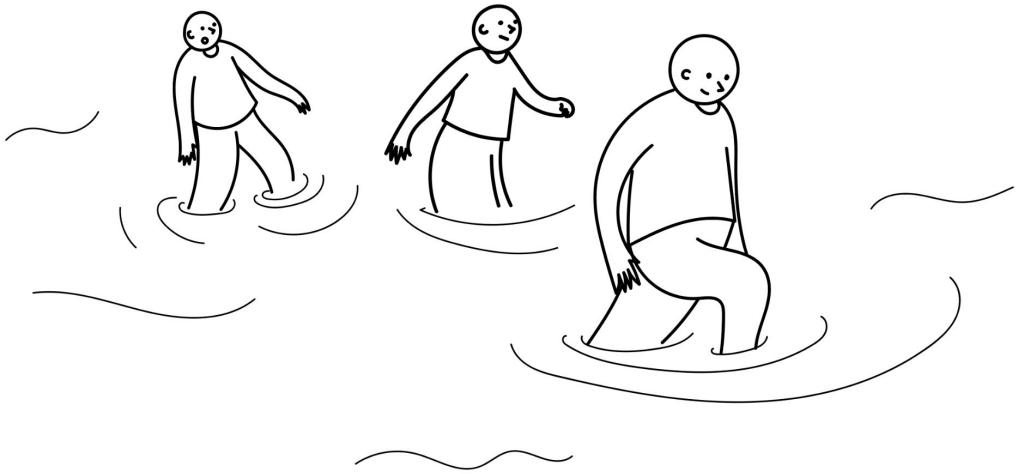
“some are not really pleased that we don't work during the weekend because they feel unsafe ... They don't get a phone call if they get something wrong. But that's the part of responsibility.” Nurse

“It is very reassuring. Measured and 2 minutes after Helsehjelpen was on the phone with me. My saturation was low”. Patient

Wading in tensions



We were immersed in the present to the extent that we saw tensions dissolve, but then again, we saw contradictions emerging.

3. Helping the dependent / coaching the independent

“So, by using this [remote care] plan, that also raises the responsibility and awareness for the patient.” Nurse

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"I'm like, why didn't you tell us that you had a sore throat? You know that's a symptom. But he doesn't see it that way. He is a man, and he's stubborn, and it will go over, it's just a sore throat." Nurse

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"If I have a bad day, I know I can have two bad days before I need to get nervous. Then the [municipal remote care service] staff are on it straight away." Patient

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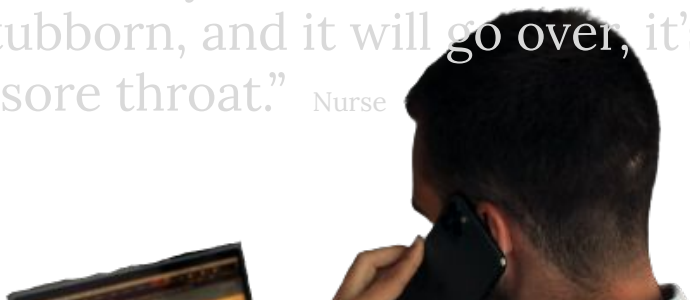
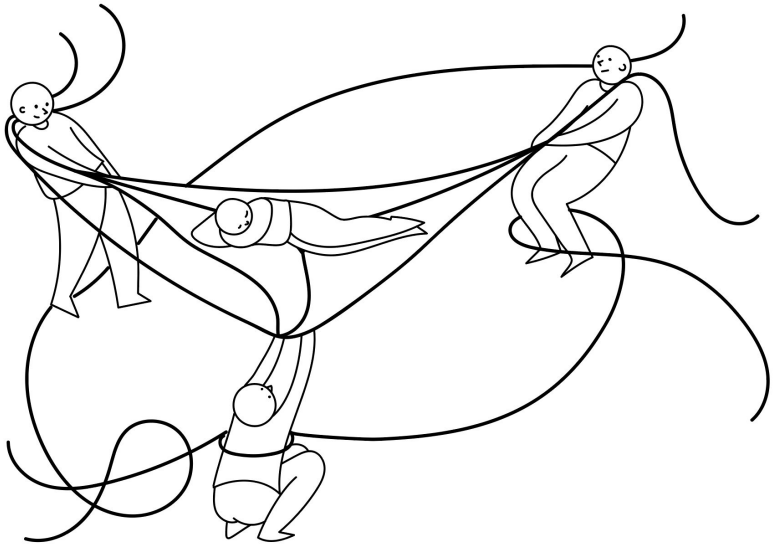


"in the end the only person that can affect their own life is the patient themselves, it's difficult for us to force the patient into doing something.” Healthcare technologist

Caring by keeping the friction



If care holds values contradictions, then designing in care needs recognition of these different tensions. By staying with the trouble, we question what value of care designers are enacting or should enact within this systemic transition.

‘it matters with what care we
care for our systems of care’

Thank you!