

# Preconference: Patient generated data



Norwegian Centre for  
E-health Research



WELCOME TO

EHIN/SHI Workshop on Patient Generated Data (PGD)  
- Opportunities and Challenges

Arranged as part of the FullFlow project and  
The EHIN/SHI conference

by

The University of Tromsø - UiT,

The University of Agder - UiA,

The Aalborg University - AAU,

The Norwegian Centre for e-health Research - NSE.

Time	Min.	Theme	Presenter/Org.
11:30		LUNCH, Baguettes / mingling	
12:00	20	Introduction. Background and objectives for the workshop	Astrid, Eirik, Gunnar /NSE/UiT
12:20	20	The patient's perspective - Status and future trends	Eirik Årsand / NSE
12:40	20	Physical Inactivity is killing us. Can PAI help the collaboration between patients and doctors in understanding the importance of physical activity?	Stian Ellingsen Lobben / GP at Nytorget Legesenter
13:00	10	Live Demo: Fitness Age test	Alf Egil Edvardsen / PAI Health Norway
13:10	15	Pause (or time for more discussions?)	
13:25	20	Examples and experience from municipality services	Santiago Gil Martinez / UiA
13:45	20	DIY and Patient generated data in Danish diabetes treatment	Ole Hejlesen /AAU
14:05	20	How can we ensure that digital tools are accessible, effective and trusted?	Øystein Tveite / Health directorate Norway, Project manager for digital tools
14:25	20	From successful research to national health care implementation. Helsenorge as infrastructure for patient generated data	Ole Kristian Losvik, Direktoratet for e-helse
14:45	20	Digital medicine and emergent technologies	Gunnar Hartvigsen / UiT
15:05	15	Pause (or time for more discussions?)	
15:20	20	Case from Finland: Bringing Diabetes Data into PHR's and EHR's	Mikael Rinnetmäki / Sensotrend (by Eirik Årsand)
15:40	20	International perspective, experience from Be Healthy-Be Mobile	Per Hasvold / NSE
16:00	20	Reflections from the diabetes patient organization, as an introduction to plenary discussion	Sverre Ur / Diabetesforbundet
16:20	40 min	Discuss: How to plan for this trend (authorities, regulations, research, etc)	All
17:00		End	



# Who is here?

- The patient, and their organization
- Health care personnel
- Researchers from different countries
- Health authorities (Norwegian Health directorate, and eHealth directorate)
- The industry, big and small companies
- International – WHO project (Be Healthy be Mobile)

**a very comprehensive pool of actors who all see the Opportunities and Challenges of this development**



No. 1 February 2016

# diabetesforum

Informasjon og kommunikasjon må i langt større grad samles i et nasjonalt system. Den nasjonale helseportalen, helsenorge.no, har en slik ambisjon. Dette krever kobling til helseforetakenes nettportaler, og etter hvert også til primærhelsetjenesten. I tillegg til dagens konsultasjonspraksis vil det måtte tilrettelegges for langt bedre digital dialog mellom pasient/bruker og sykehus/leger/helsepersonell. Bruk av telemedisin og videokommunikasjon vil øke kraftig.

**Den nye pasientrollen**



# 18 years with R&D on patients' data

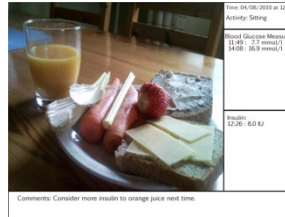
BG Bluetooth adapter



Smart step counter



T1D, Photo Diary, Child



Diabetes Diary Android version

Diabetes Diary iPhone version



Social media



Data to the cloud



Sensors



BG Bluetooth prototype



T1D, SMS Child → parents



T2D app ver.1



T2D app ver.2



T2D, RCT



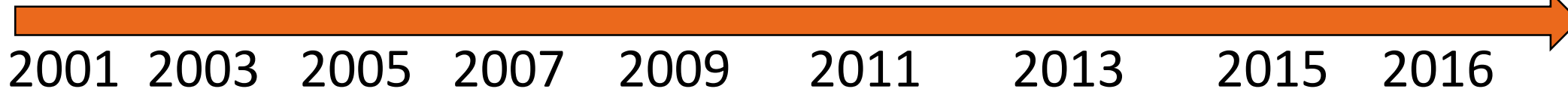
RunKeeper

Pebble app



Data sharing

Patient engagement!



2001

2003

2005

2007

2009

2011

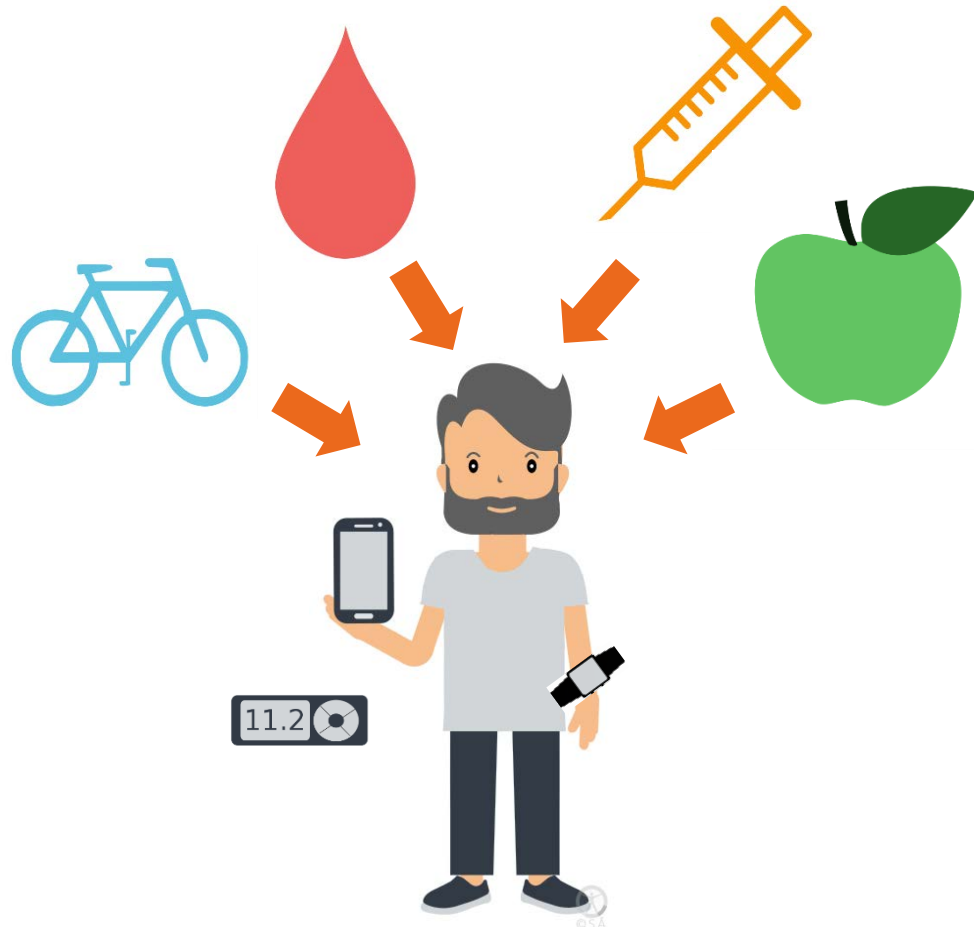
2013

2015

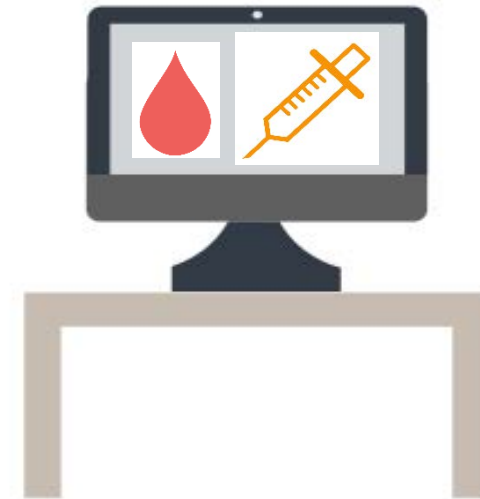
2016

# Mobile health technologies

Trend: Patients gather more and more data, - BUT....



Best case:  
Clinicians will see only a fraction  
of these





# Current situation

I have some data too...



What would you like me to do with that?

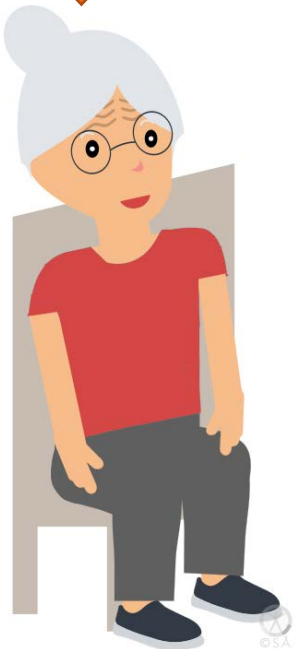






# Wanted situation

Yes – I have.



Data available during consultation



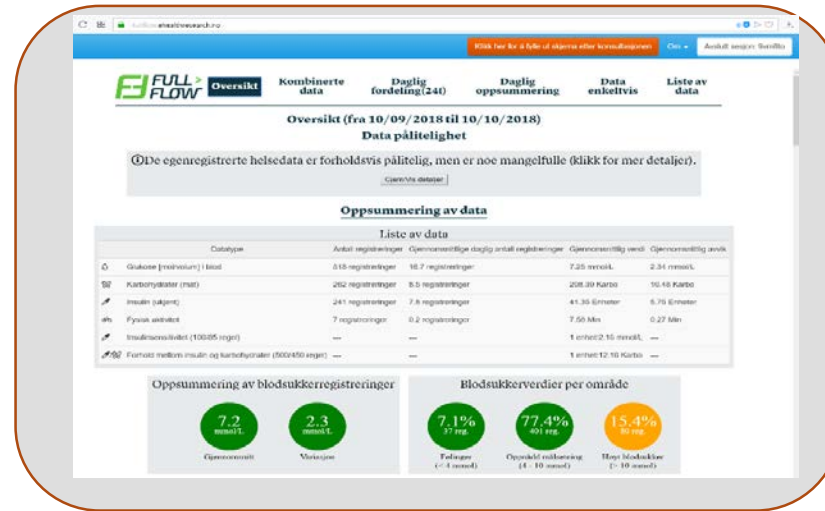
I see you have shared your data with me, Mrs. Hansen!





# Wanted situation

Data available during consultation



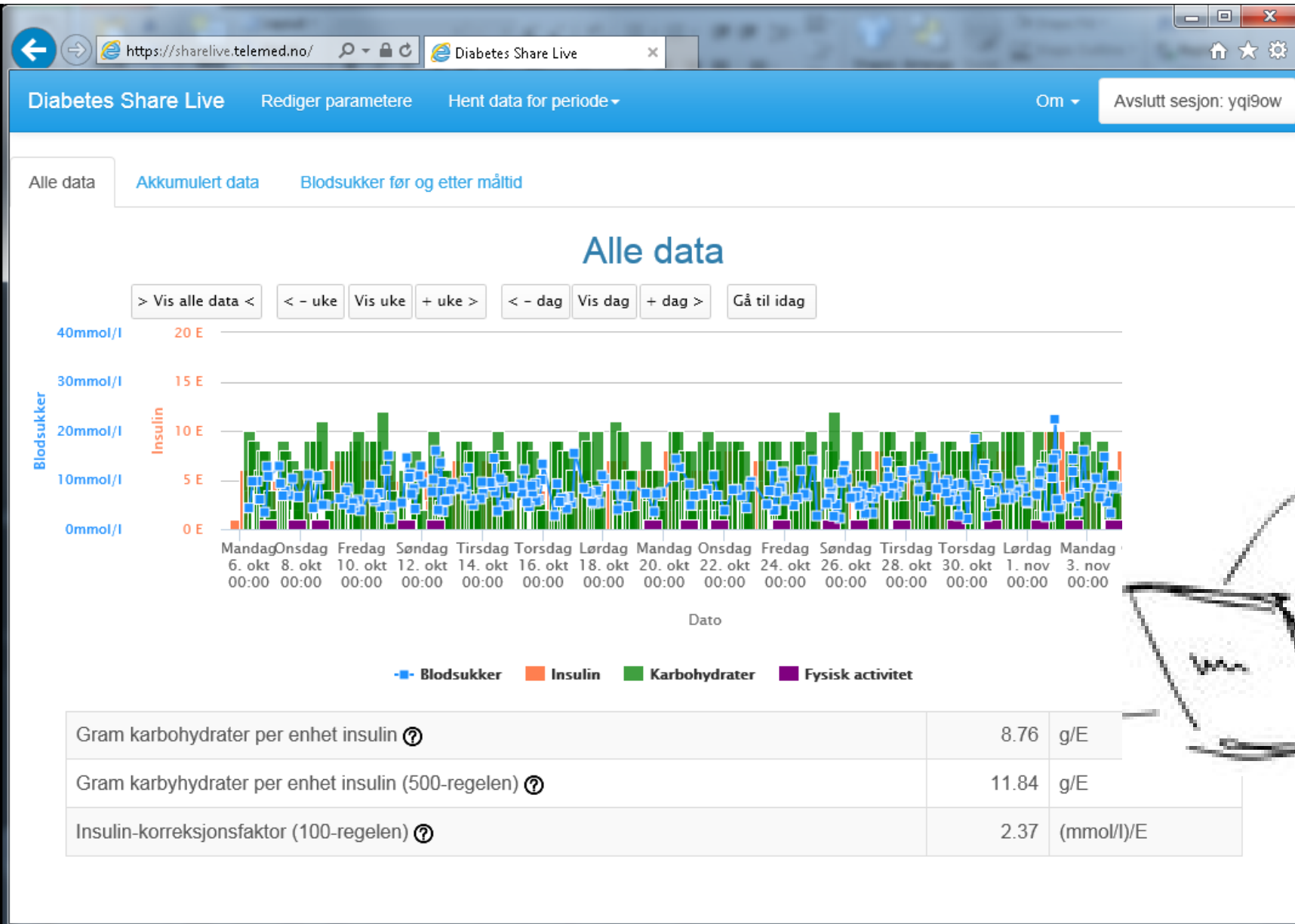
Let us look at your data together!

FullFlow study

Forskningsrådet



# EU-project 2014-2017

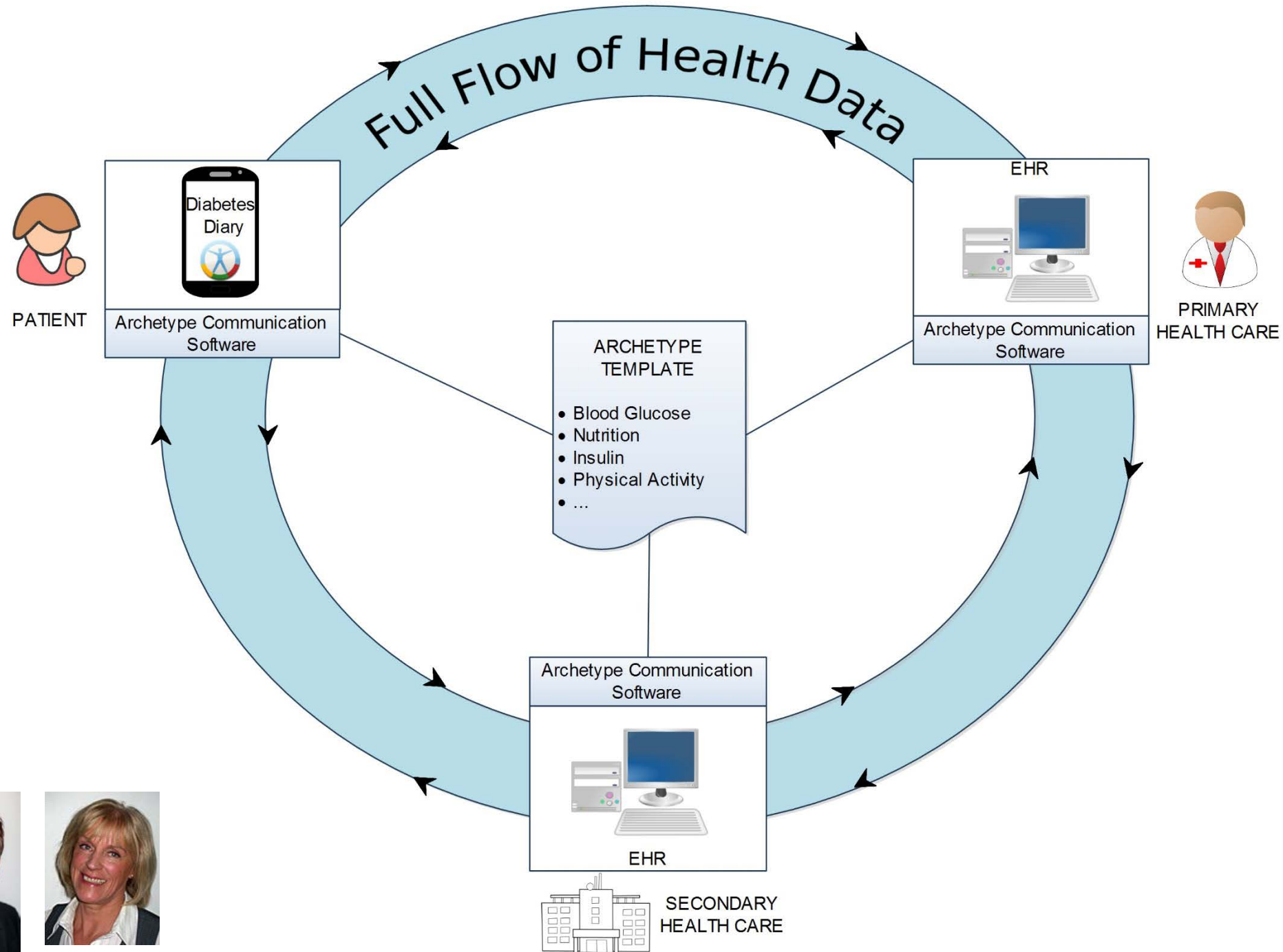




# Full Flow of Health Data Between Patients and Health Care Systems

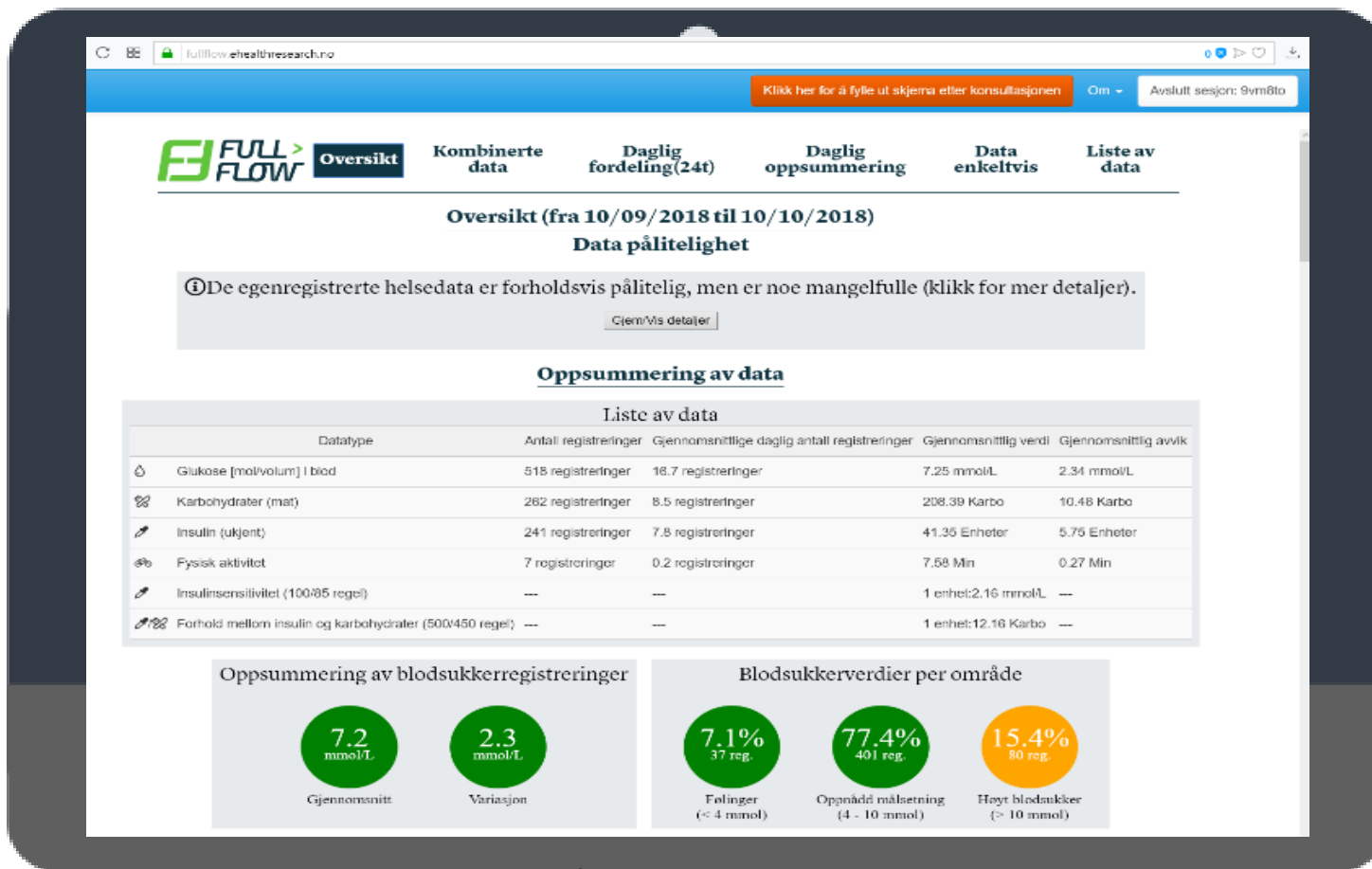
(NFR, IKT Pluss, 2016-2020)

Management team:

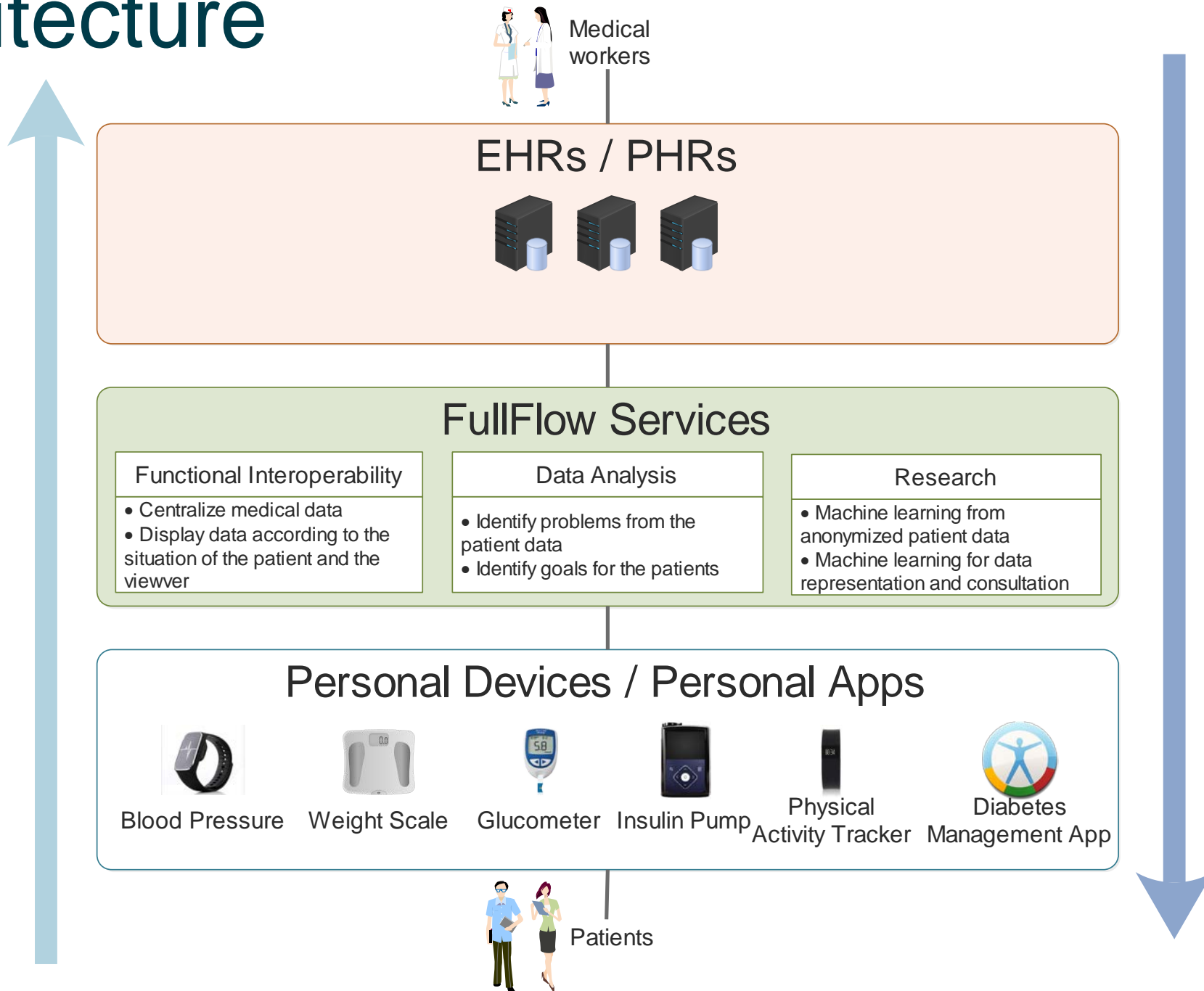




# Focus on solutions for user interfaces (patients and clinicians)



# Architecture





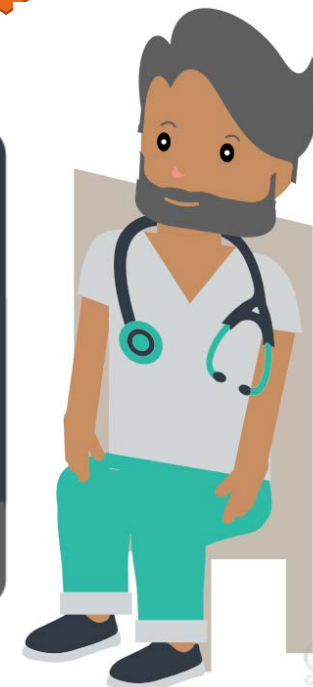
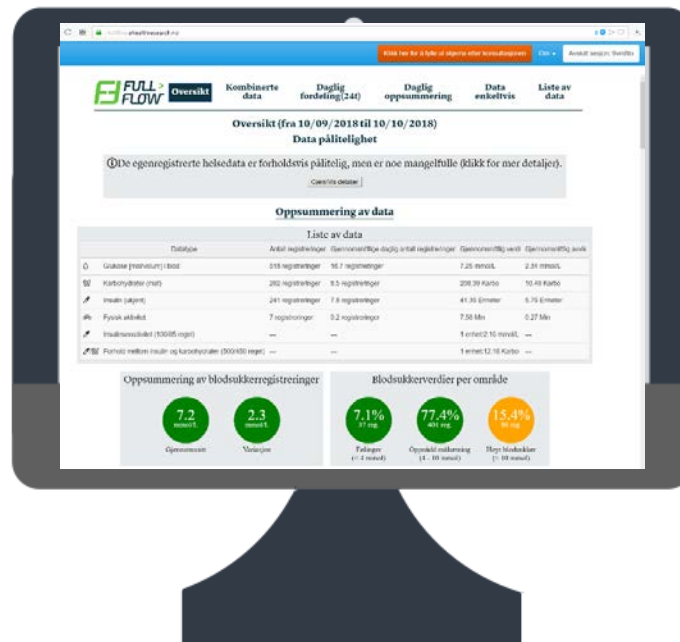
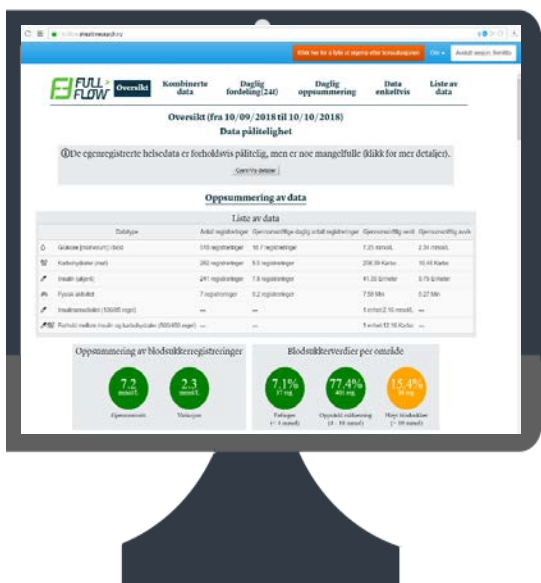
# “Medisinsk avstandsoppfølging”

....where PGD may play an important role

Yes!

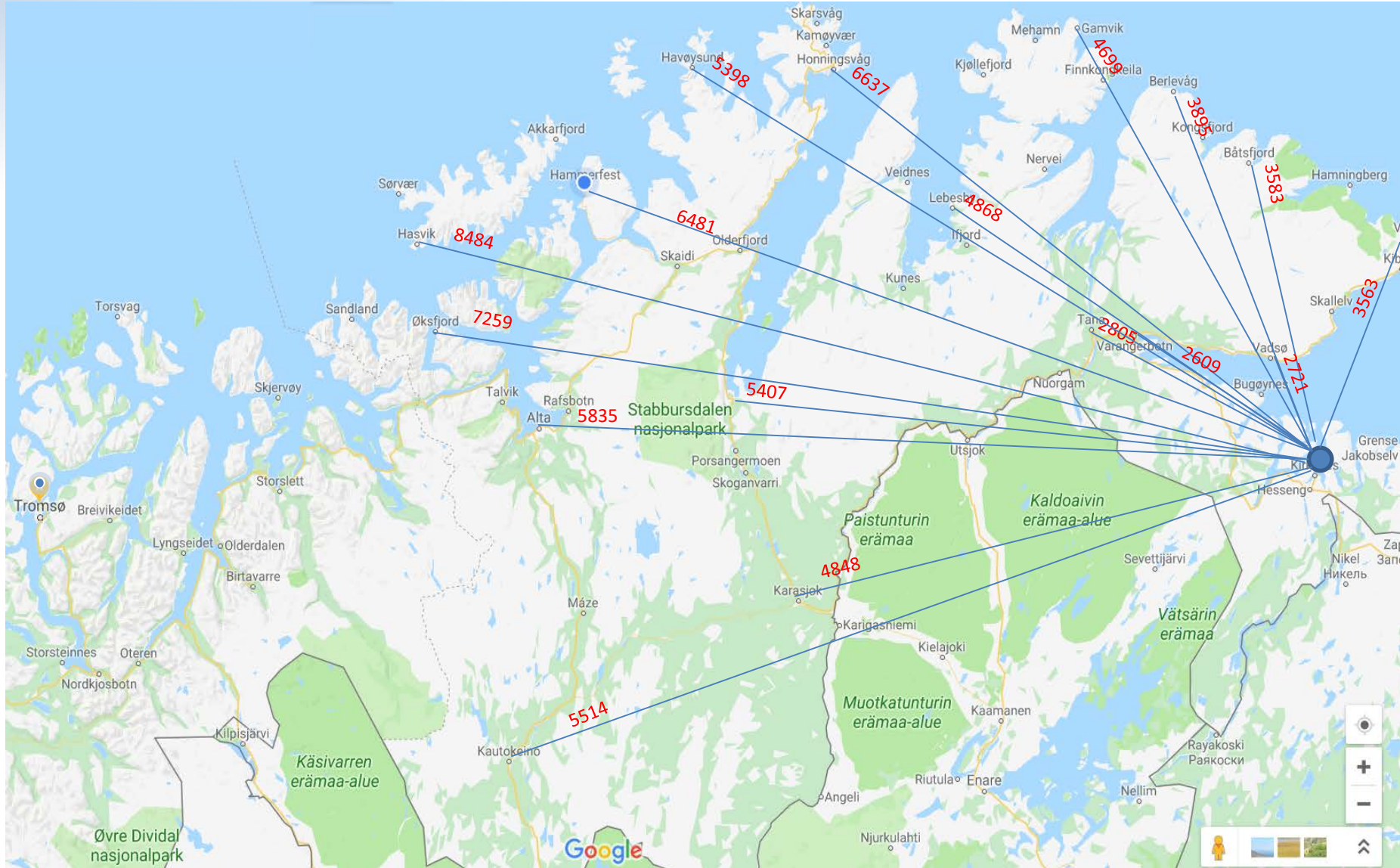


Do you see your data on your screen?



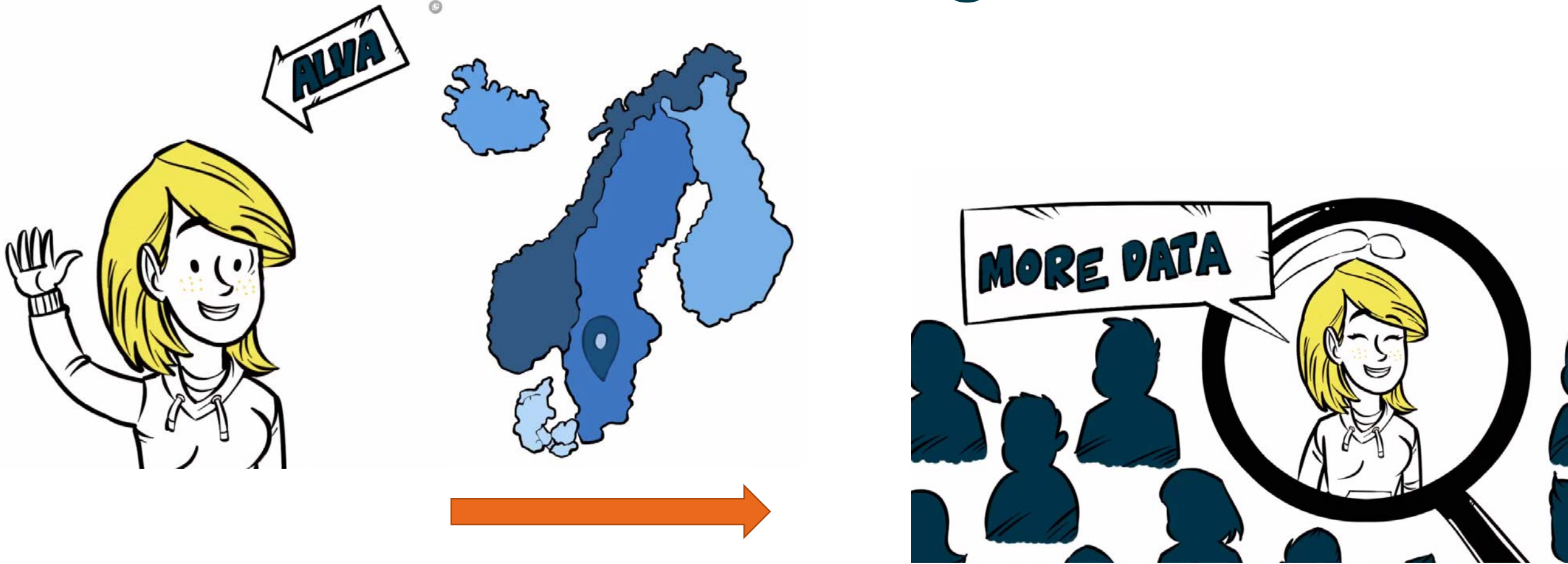
Wanted pilot with Finnmarkssykehuset

# Travel costs to Kirkenes





# Alva travelling



**Knowledge needed!**



# Some opportunities

- The patient becomes more engaged in their own treatment. More «Empowerment».
- Medical follow-up is important in many situations. Useful consultations without physical meetings.
- Clinicians get more data to use in consultations. Can use this data to engage patients.
- Improved EHR-systems if successful in incorporating such data.



# Some challenges

- Patients data can be inaccurate, and data can stress patients. More education needed.
- Clinicians must use reliable data, in QA processes, and admin access to these new data. They also need education.
- EHR-systems need to manage – and restrict – use of new data, where patients are the owners(?)
- Security and privacy (GDPR). Reliability of sensors and patients own recorded data.

# Research – This we already know



1. Patients want systems that automatically gather their health data
2. Patients do not want to share all of their health data (privacy/personal issues across border)
3. Patients do not care about security when their health is at stake
4. Clinicians do not want real-time health from patients



Questions ?  
or  
Comments !