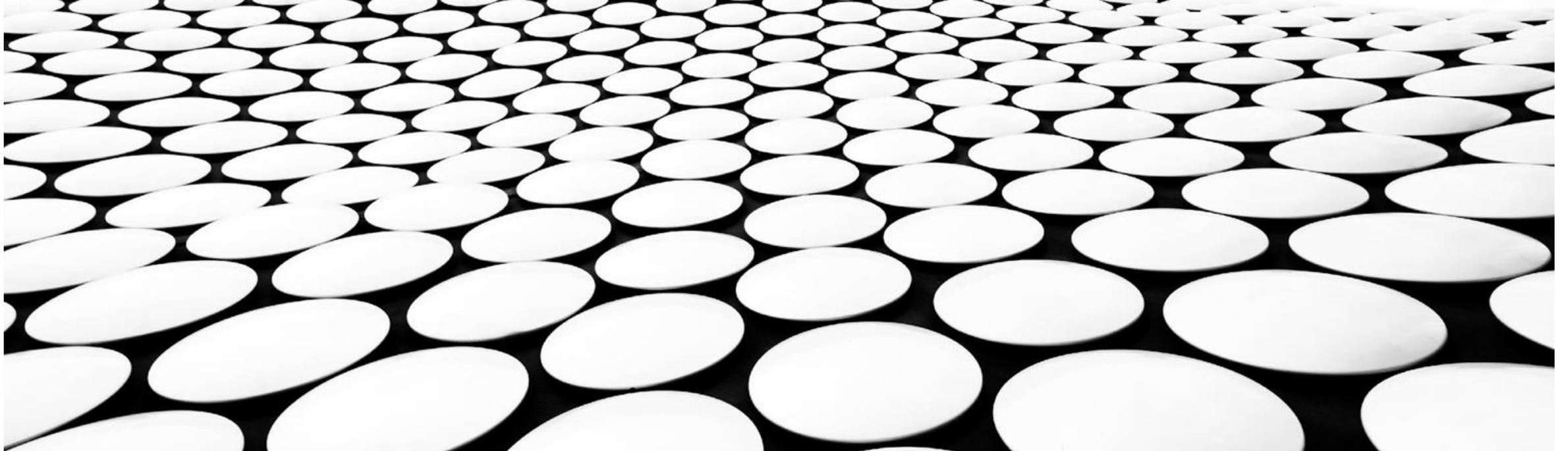

NORDeHEALTH

Nordic eHealth for Patients: Benchmarking and Developing for the Future
(NORDeHEALTH), NordForsk call „*Digitalisation of the Public Sector*“

Peeter Ross, MD, PhD
Tallinn University of Technology
East Tallinn Central Hospital

Building Impactful Partnerships: Nordic-Estonian Research Day on 27 May in Tartu





CONTENT

- Preparation for application
- Project content and execution
- Scientific value
- Summary

PREPARATION FOR APPLICATION

- Research is always based on research topics and should be without state borders.
- This principle applies exceptionally well to Estonia, because to be at an international level, we need to cooperate.
 - The Nordic countries are close to Estonia in many ways
 - Very advanced in the world of science
 - Scientific cooperation with the Nordic countries is natural and vitally necessary for us.
- Personal contacts

Patient access to electronic health records: differences across ten countries

Authors Anna Essén, Isabella Scandurra, Reinie Gerrits, Gayl Humphrey, Monika Alise Johansen, Patrick Kierkegaard, Jani Koskinen, Siaw-Teng Liaw, Souad Odeh, Peeter Ross, Jessica S Ancker

Publication date 2018/3/1

Journal Health policy and technology

FOCUS OF THE PROGRAMME

The Digitalisation Programme focuses on three interrelated areas that enable and shape the digital transformation of the public sector:

- (1) the enabling factors of digitalisation;
- (2) digital innovation; and**
- (3) society and the end-user perspective.**

The overarching aim of the call is to combine and integrate

knowledge-based, digital innovation efforts related to the public sector

with

research on the related drivers, effects and impact on society and end-users.

eHEALTH IN THE WORLD



- Reducing risks and improving patient health outcomes are requirements currently faced by healthcare systems all over the world



- Increasing healthcare costs and cuts in health funds demand enhanced efficacy and efficiency of healthcare services provision



- eHealth interventions are acknowledged to have great potential to improve efficacy and efficiency of healthcare provision and strengthen opportunities for patient self-care, self-management and participation



- The Nordic countries are recognized as being at the forefront of eHealth development and use.



ABOUT THE PROJECT

- **NORDeHEALTH** aims to give patients online access to their electronic health records (PAEHR) and increase self-management and transparency in healthcare.
- The goal is to enable further digitalisation of the public health sector by providing
 - concrete feedback to the national authorities in their respective countries,
 - guidelines and frameworks for design, implementation and evaluation of personal eHealth services (PeHS)



PROJECT GOALS IN DETAIL

- **Study** the current implementation and adoption of PAEHR in the Nordic countries to create new knowledge and an in-depth understanding of challenges and opportunities.
- **Develop evidence-based valuation** frameworks and guidelines to help researchers and practitioners within and beyond the Nordic countries evaluate personal eHealth services (PeHS) and their acceptability, and support the successful implementation and adoption of PeHS.
- **Explore Factors around the co-design of PAEHR through innovation projects focusing** on patient-generated data and tools for patients' co-creation of the medical record, as well as providing best practice guidelines.



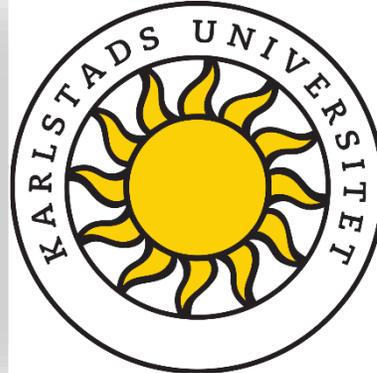
TIME FRAME AND PROJECT PARTNERS

Project time frame: 01.01.2021-31.12.2023

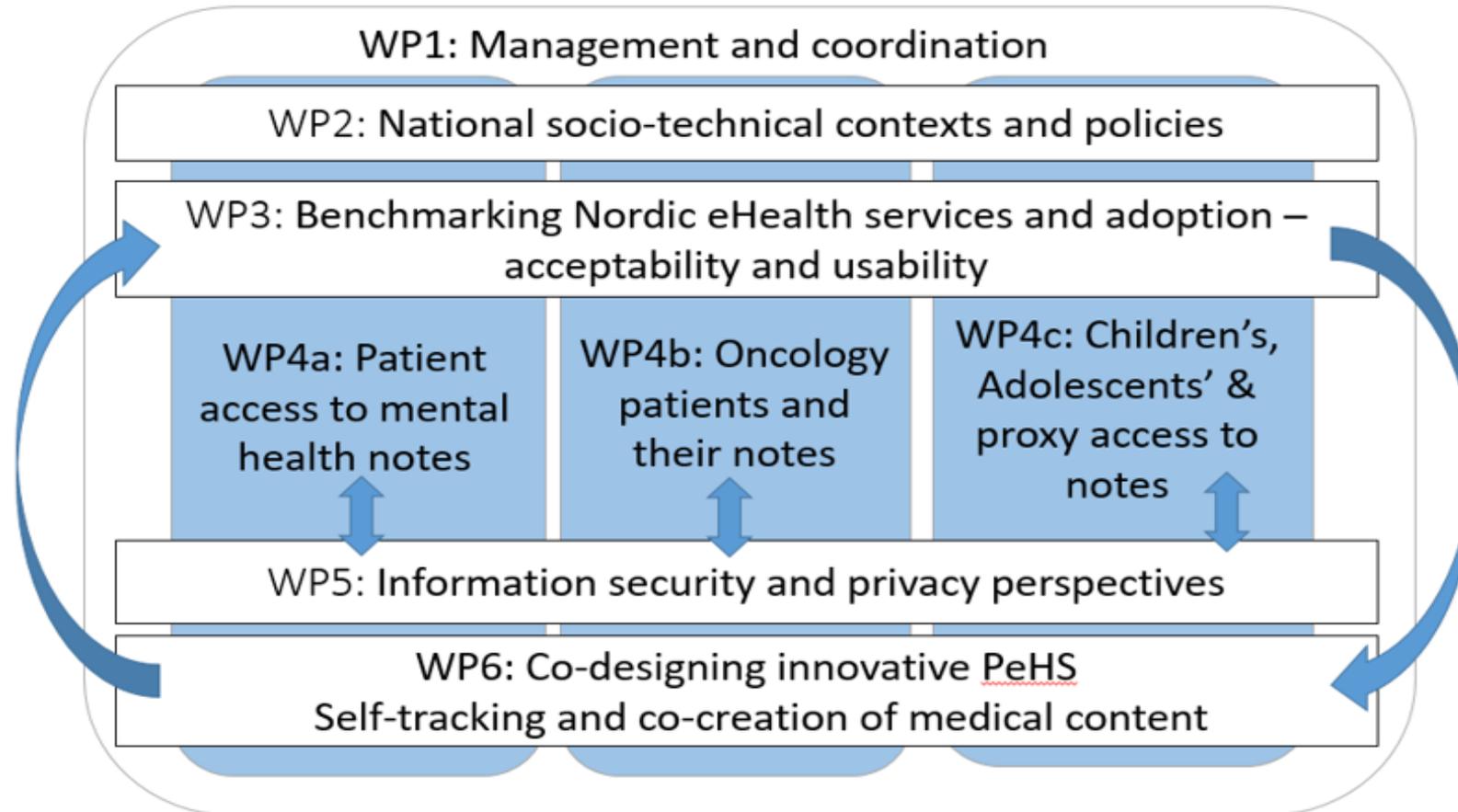
Project partners: Uppsala University (Sweden); Örebro University (Rootsi); Skövde University (Sweden); TalTech (Estonia); Aalto University (Finland); Karlstad University (Sweden); Norwegian Centre for E-health Research (Norway); OpenNotes (USA).



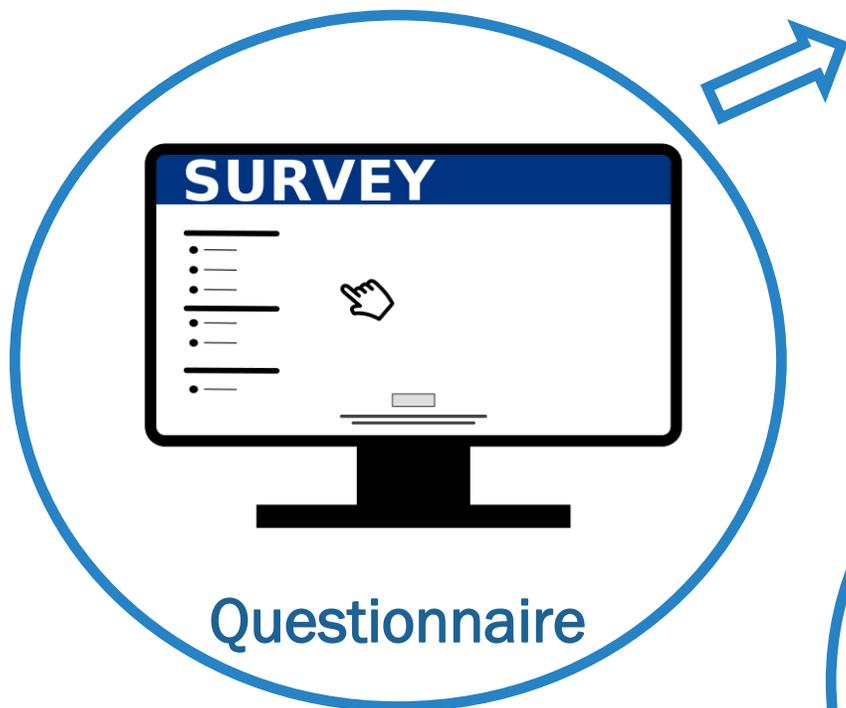
**TAL
TECH**



PROJECT ACTIVITIES

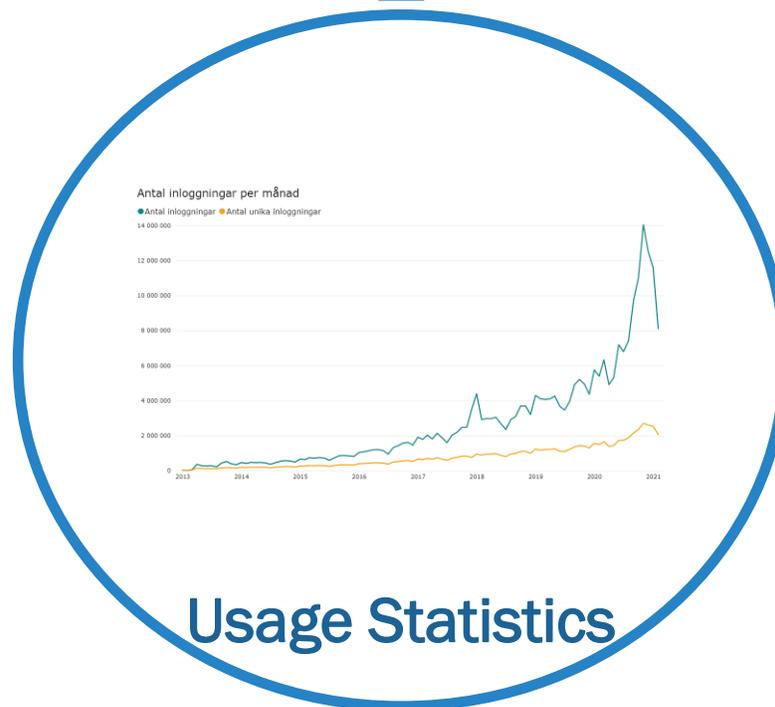


DATA COLLECTION



- National patient portals will be used to distribute the questionnaires & as source for usage statistics

Cross-country analysis
of both quantitative and
qualitative data



- Qualitative data will be collected in each country, analyzed separately

WP ENGAGEMENTS

| Work Package Overview | | | | | | | | |
|-----------------------|-----|-----|-----|------|------|------|-----|-----|
| | WP1 | WP2 | WP3 | WP4a | WP4b | WP4c | WP5 | WP6 |
| Uppsala | X | X | | X | | X | X | X |
| Örebro | X | X | X | | X | | | X |
| Skövde | X | X | | | X | | X | |
| Karlstad | X | | | | X | | X | |
| TalTech | X | X | | X | | | X | PR |
| Aalto | X | X | X | X | X | | | X |
| eHealthNO | X | X | X | X | X | X | | X |
| OpenNotes | X | | | X | | X | X | X |

THE USE OF HEALTH RECORD ON DIGILUGU.EE PATIENT PORTAL

- The survey was part of the Nordic research project NORDeHEALTH, where data from Norway, Sweden, Finland and Estonia were analysed and compared.
- The aim of the study was to map the experiences of Estonian residents with electronic health record on the Digilugu.ee patient portal. The main topics of this study were:
 - Incentives to access health record;
 - Positive aspects and user experience;
 - Challenges and areas for improvement;
 - Perspectives of the security and privacy of the patient portal.
- The study was conducted as an online survey from January 24 to March 28, 2022, participation was possible on the Digilugu.ee website.
- **2104** users of Digilugu.ee aged 15 and older responded to the survey.

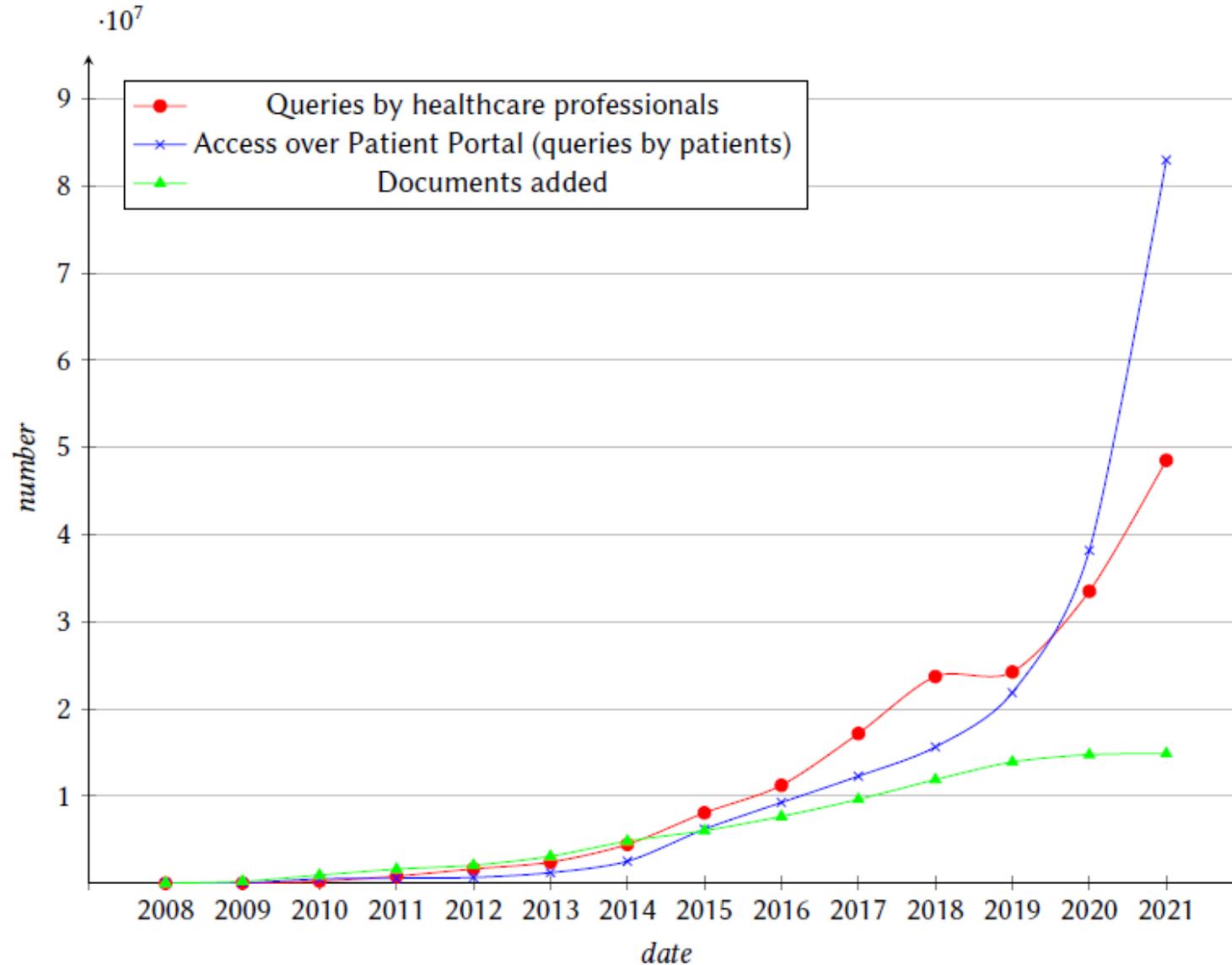
PATIENT PORTAL USER EXPERIENCE



- Digilugu.ee is **widely and frequently** visited and used.
- Mostly **meets the needs** of users and is **easy to use**.
- **Helps to trust** healthcare provider and **supports better communication** between the patient and healthcare professionals.
- **Two thirds of the respondents have had a very positive experience** using the Digilugu.ee patient portal.
 - Convenience of using the environment and the possibility to see the results of analysis and treatment information.
 - The quick results of the covid test and the ease of creating a certificate were also mentioned as positive experiences.
 - Receiving and checking prescriptions is also valued.
- **Belief in the security and privacy of patient portal is high** – three-quarters of respondents are confident. The privacy issue is only seen when copying your health information to other applications.
- There is very little experience that anyone else has requested access or has seen health information that a person has not wanted to share.
- Quite a number of possible new features in Digilugu.ee are considered useful.
Most of all, being able to read all the information about their health and contact their healthcare provider via the Internet.

- **Discovering mistakes and missing information** in health records is **rare**.
 - The most serious mistake was the error in writing the diagnosis. The main shortcoming was the incomplete description of the condition or visit and also the lack of entry to health record.
- **One-fifth of the respondents have had a very negative experience** of using the patient portal.
 - The most common negative examples (free answers) were the general complexity, inconvenience and slowness of using the patient portal, also the difficulty of finding the necessary information or performing an activity.

USE OF DIGITAL DATA IN ESTONIAN PATIENT PORTAL BY DIFFERENT USERS



SCIENTIFIC WORK

- 48 publications so far
 - 41 scientific publications
- Tight scientific cooperation between partners
- Master's thesis
- Doctoral thesis

| | | |
|---|----|------|
| The NORDeHEALTH 2022 patient survey: cross-sectional study of national patient portal users in Norway, Sweden, Finland, and Estonia | 21 | 2023 |
| M Hägglund, A Kharko, J Hagström, A Bärkås, C Blease, Å Cajander, ... Journal of Medical Internet Research 25, e47573 | | |
| A nordic perspective on patient online record access and the european health data space | 6 | 2024 |
| M Hägglund, A Kharko, A Bärkås, C Blease, Å Cajander, C DesRoches, ... Journal of Medical Internet Research 26, e49084 | | |

SCIENTIFIC WORK IN WP6 BY OUR UNIVERSITY

- Design thinking framework
- Adaptation of relevant standardized data models for patient self-reporting,
- Finding proper evaluation and approval mechanisms for data entered by the patient,
- Prototype development through user-centred design processes, including close collaboration with patients and other relevant stakeholders.

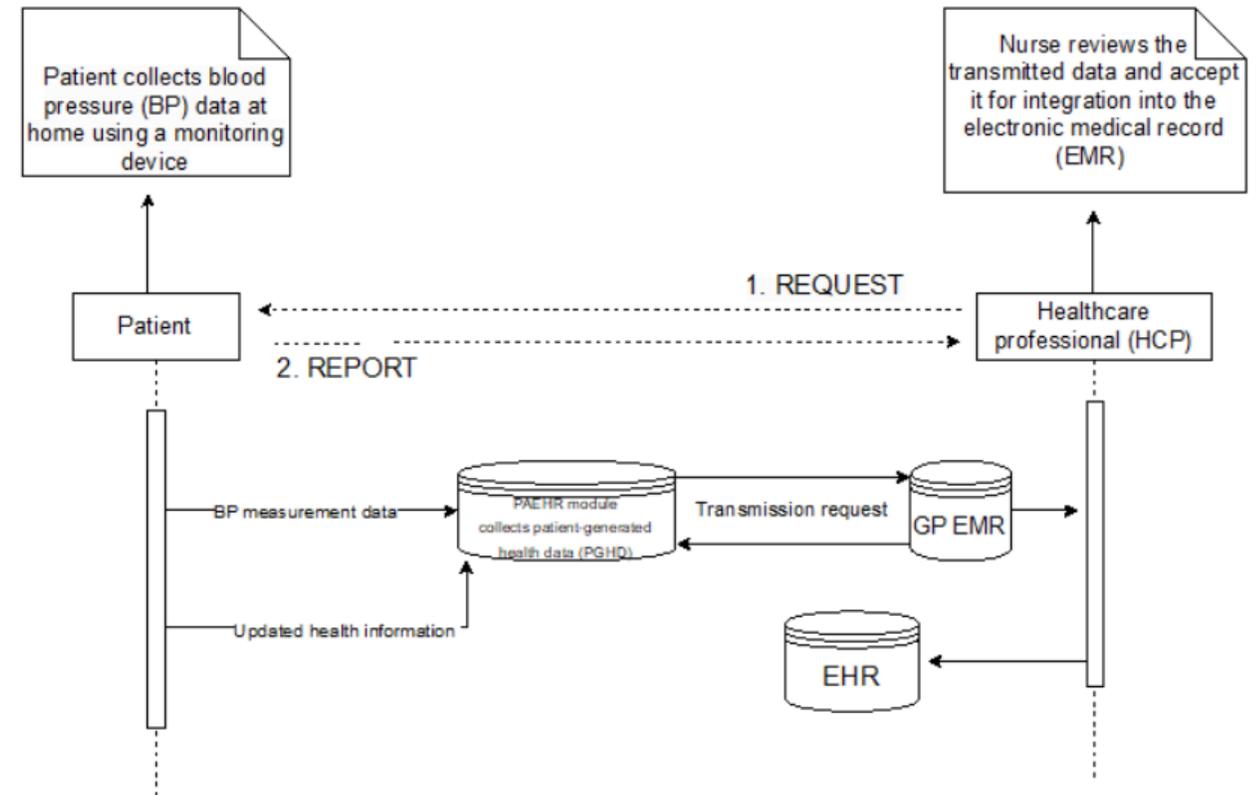


Figure 1. Continuous data flow chart of HCPs workflow with PGHD for high blood pressure patients. The data flow in the Estonian example shows that the process should seamlessly fit into the patients' and HCPs' data capture process. The upper part represents two actors, and the lower part is the technical data flow solution. The figure does not address devices or other technical capabilities at this initial stage.

ROLE OF THE ESTONIAN RESEARCH COUNCIL

- Clear rules
- Research-oriented
- Supportive staff
- Reporting is reasonable and with little bureaucracy

Thank you!
Peeter.Ross@taltech.ee

