Nasjonalt senter for e-helseforskning

SAK TIL STYRINGSGRUPPEN

Videreføring av Praksisnett

Saksnummer	25-2023
Avsender	Senterleder
Møtedato	16.06.2023

Bakgrunn for saken

Praksisnett er et nettverk for klinisk forskning i primærhelsetjenesten, der NSE er ansvarlig for IT-løsningen av prosjektet. Styringsgruppen har flere ganger blitt orientert om og diskutert prosjektet (se saker 44-2022, 34-2022 og 21-2021).

Praksisnett har så langt vært tilgjengelig for fastlegekontor, men ønsker å utvide til andre deler av primærhelsetjenesten, i første omgang til legevakt. Sammen med Nasjonalt kompetansesenter for legevaktsmedisin i Norce og Praksisnett har NSE skrevet en skisse for infrastrukturutlysningen i Norges forskningsråd[1]. I tillegg er det planlagt en skisse på utvidelse til kommunale helse- og omsorgstjenester. Frist for innsending av skisse er 21.06.2023.

Praksisnett er en svært tiltrengt løsning for forskning i primærhelsetjenesten, og IT-infrastrukturen gjør løsningen unik. Regjeringen har også vist vilje til å satse på prosjektet gjennom bevilgning i statsbudsjettet for 2023. En utvidelse av løsningen vil tilrettelegge for forskning i flere deler av tjenesten, og på pasientflyt mellom flere aktører i tjenesten. Løsningen er personvernbevarende, og åpner derfor for enklere tilgang til forskningsdata for pasientgrupper som i dag er krevende å forske på. Praksisnett passer inn i senterets strategi som en forskningsbasert innovasjon som bidrar til forskning og bærekraft i tjenesten.

Samtidig har det vært krevende for NSE å gjennomføre og drifte prosjektet, som vist til i de tidligere sakene i styringsgruppen. Kort oppsummert dreier utfordringene seg om blant annet:

- Finansiering; Det har vært for lite midler i prosjektet til å gjennomføre alle ønskede aktiviteter. NSE har etter styringsgruppens vedtak gått inn med noe egenfinansiering.
- Rekruttering; Det er krevende å rekruttere utviklere med relevant kompetanse. NSE har et stabilt kjerneteam, men det har vist seg krevende å rekruttere til nye stillinger som har vært utlyst.
- Infrastruktur; NSE er en forskningsinstitusjon, og er ikke organisert for drift. Det har vært flere initiativ for å finne løsninger for drift og tilhørende infrastruktur, både fra NSEs og Praksisnetts side, men ingen av disse har lykkes. NSE drifter derfor løsningen per i dag.

På denne bakgrunnen ønsker senterleder at styringsgruppen diskuterer hvilken rolle NSE bør har når det gjelder videre utvikling av Praksisnett.

[1] https://www.forskningsradet.no/utlysninger/2023/skisse-infrastruktur/

Nasjonalt senter for e-helseforskning

SAK TIL STYRINGSGRUPPEN

Forslag til vedtak

Styringsgruppen støtter/støtter ikke at NSE sender skisse til utlysningen forskningsinfrastruktur i Norges forskningsråd.

Vedlegg

Foreløpig skisse til utlysning om forskningsinfrastruktur.

Template for mandatory outlines in connection with grant applications to the National Financing Initiative for Research Infrastructure

INFRASTRUKTUR outline no.: (To be completed by the Research Council)

1. Title and contact information

INFRASTRUKTUR working title	The Norwegian Emergency Primary Care Research Network
Host institution	National Centre for Emergency Primary Health Care, NORCE Norwegian Research Centre AS
Contact person at the host institution (name, tel., email)	Jesper Blinkenberg, +47 93435481, jebl@norceresearch.no
Partner institutions	University of Bergen University of Oslo The Norwegian University of Science and Technology in Trondheim University of Tromsø – The Arctic University of Norway The Norwegian Centre for E-health Research at the University hospital of Northern Norway

1. Category (more than one may be selected)

☐ Pre-project (Up to 2 mill. kroner)

☒ Establish/upgrade of research infrastructure of national importance:

- ☐ Advanced scientific equipment and facilities (NOK 2–200 mill. kroner)
- ☒ E-infrastructure/datainfrastructure/ Scientific databases and collections (2–200 mill. kroner)

☐ Participation in international infrastructures

☐ Basic funding of operational costs

☐ Research infrastructures that require external investment of more than NOK 200 million kroner in public funding allocated by the Research Council of Norway. The assessment will form the basis for a recommendation to the ministries.

2. Main area(s) the infrastructure will serve (no more than two may be selected)

Teknologi og naturvitenskap

☐ Computer science and digital technologies

☐ Technology and natural sciences

☐ Energy and future energy systems

☐ Geoscience, climate and environment

Livsvitenskap og helse

☐ Bioresources

☐ Biotechnology

☒ Medicine and health

Humaniora og samfunnsvitenskap

☐ Humanities

☐ Social sciences

3. Short summary

In Norway, primary care provides health care for the population 24/7/365 and acts as gatekeepers to more specialized health care. Within a year, approximately 80% of the population are in contact with primary care, and most of these patients are cared for only within primary care. Changes in quality of care, service provision and gatekeeping abilities of primary care have a huge impact on the whole health care system. Two thirds of all acute admissions to hospitals are referred from primary care, and even small changes in routines and clinical practice can result in large changes of the influx to emergency wards at hospitals. Primary care is provided by general practitioners working in GP offices and at emergency primary care clinics (Norwegian: legevakt). Despite that the largest part of medical treatment takes place in primary care, clinical research in this domain is lacking, in particular on acute care.

The Norwegian Primary Care Research Network (PraksisNett) is an established research infrastructure for general practice that has improved the possibilities for performing high quality research in primary care. The aim of this project is to extend the existing PraksisNett to the emergency primary care services and establish the research infrastructure ***PraksisNett legevakt***. There is a huge scope for expanding the IT infrastructure developed in PraksisNett to include emergency primary care clinics, as the software used for medical records at these clinics corresponds to the software used at GP offices. Furthermore, there is an existing research network of emergency primary care clinics and corresponding local emergency communication centres, the Watchtower project, in which aggregated data has been collected for years. This existing network will be incorporated into ***PraksisNett legevakt*** and will constitute the core of the new research network. Additional emergency primary care clinics will be recruited to increase the strength and usefulness of the network.

The IT part of ***PraksisNett legevakt*** will be a distributed network of emergency primary care clinics where research data can be extracted for research purposes. A centralized web portal will be used for communication, recruitment, and definition of research projects. The research servers and infrastructure will be identical to the servers in the existing PraksisNett, and the data will be saved in a safe haven.

The extension of the PraksisNett to emergency primary care clinics will make it possible to perform important clinical research on emergency primary care and to investigate acute care trajectories. Above all, it will allow research on the overlapping services of GP offices and emergency primary care clinics, providing a complete picture of the clinical activity in primary care.

Description of the infrastructure

The proposed Norwegian Emergency Primary Care Research Network (***PraksisNett legevakt***) is an expansion of and a supplement to the existing research infrastructure The Norwegian Primary Care Research Network (PraksisNett). The establishment of PraksisNett in 2018 was funded by the NFR-program INFRASTRUKTUR and aimed at facilitating clinical research in Norwegian general practice. PraksisNett has been a success. More than 20 research projects have used the infrastructure. Currently the infrastructure includes more than 490 general practitioners (GP) working at more than 90 GP offices.

However, the activity at GP offices during normal working hours is only part of primary care. The municipalities have legal responsibility for providing urgent and emergency primary care for their inhabitants 24/7/365. Out-of-hours - and sometimes also in-hours - urgent and emergency care is provided from emergency primary care clinics and local emergency medical communication centres (LEMCs). The inclusion of these parts of the municipal services into PraksisNett will allow for clinical research on acute medical conditions and a broader understanding of primary care.

The current human infrastructure in PraksisNett consists of one coordinating node and four regional nodes serving GP offices in different parts of Norway. In this project we want to develop and establish an additional thematic node, the emergency primary care node. This node will be the central research coordinating node for emergency primary care and will be located at the National Centre for Emergency Primary Health Care, NORCE Norwegian Research Centre AS in Bergen. In addition to the central research coordinating node, there will be 15-20 nodes at emergency primary care clinics and local emergency medical communication centres located in municipalities across Norway.

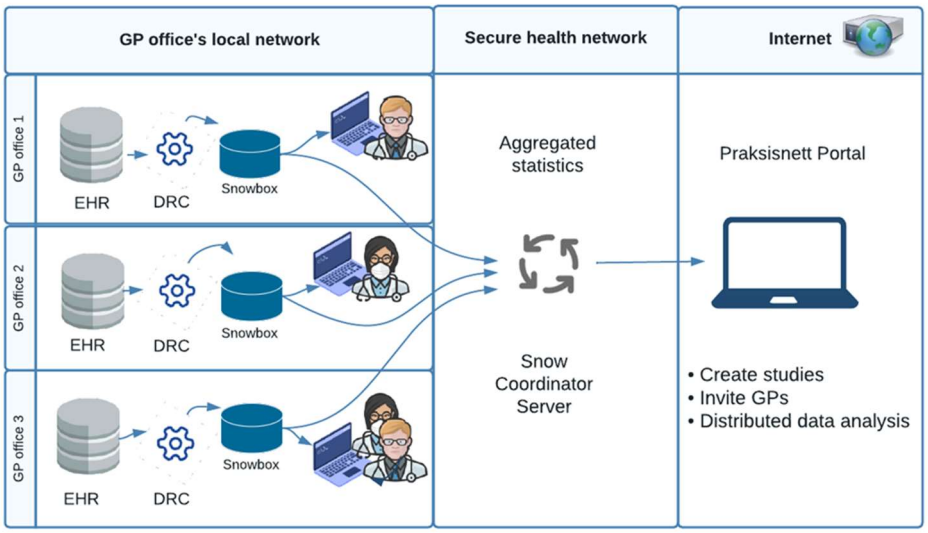

Fig. 1. The current set up of PraksisNett

Figure 1 shows the current set up of PraksisNett. Expanding PraksisNett to emergency primary care clinics and local emergency medical communication centres challenges the current structure and administration of PraksisNett. Whereas the unit of the current network is the inhabitants registered with a specific GP, the unit of the ***PraksisNett legevakt*** will be everybody needing the services of LEMCs and corresponding emergency primary care clinics in a municipality, primarily inhabitants of the given municipality, but also tourists. The expansion of PraksisNett to ***PraksisNett legevakt*** will demand practical, technological and administrative adjustments and development.

Since 2006 the National Centre for Emergency Primary Health Care has had its own research network, called the Watchtowers. Data from this research network has resulted in 14 reports and XX scientific publications. The current infrastructure of the Watchtowers can only provide administrative and basic data on contacts to the services. The infrastructure needs further development to allow for automatized collection of clinical data. The Watchtowers will be included in ***PraksisNett legevakt*** to ensure continuity of data from emergency and urgent primary care, and a continued ability to discover and follow trends and development within these services.

There is a total of 94 LEMCs and 168 emergency primary care clinics covering the whole population of Norway. Initially, we will aim at recruiting a minimum of 15 LEMCs and their corresponding emergency primary care clinics. We will aim at recruiting a diverse sample, representing different organisational aspects of emergency primary care.

The IT part of ***PraksisNett legevakt*** will be a distributed network of LEMCs and emergency primary care clinics, each equipped with a dedicated research server for storage of electronic health record data (EHR data). The research servers will be under the data controller responsibility of each administrative unit, but with a common data processor for operating the research infrastructure. A centralised web portal will be used to define the research projects that will use the research servers.

The research projects utilising the research infrastructure will need to recruit the units, as each unit need to digitally approve participation in the research project and the associated processing, to satisfy the requirements stated in GRDP article 30. With permission to process the data stored in each server, anonymous analysis of the data across the participating research servers will be possible. Statistical analysis of the EHR data will be used for study planning and for research projects that only need access to anonymous data generated for privacy preserving federated statistical analysis of the EHR data stored on the research servers in the units.

As the research servers will be identical to the servers used in the existing PraksisNett research infrastructure it will be possible to serve projects needing access to patients' use of both GP offices and emergency primary care. Research projects that need to extract EHR data from the emergency primary care clinics will need to collect electronic consent through digital study invitation from each patient before the data can be transferred to so-called "safe havens" where complete datasets can be assembled. Patients consenting to use of their medical record data will have the opportunity to withdraw their consent to processing of their data at any time.

The IT part of the research infrastructure will need resources for expanding the software part of the IT solution and deploying and operating the research infrastructure.

4. Preliminary budget and costs (maximum half (1/2) a page)

Sums are given in 1000 NOK

	2024	**2025**	**2026**	**2027**	**2028**	**Sum**
Human infrastructure						
Coordinator of the emergency primary care node (50+%)	1 304	1 363	1 424	1 488	1 555	**7 134**
Facilitators 3x 20%	1 485	1 552	1 621	1 694	1 771	**8 123**
Integrated infrastructure for basic clinical data	450	450	450	450	450	**2 250**
Recruitment, selection processes etc.	500	500	500	500	493	**2 493**
IT infrastructure						
Technical personnel, including CRIO, data scientist, technical support	5 911	3 985	3 855	3 718	3 581	**21 050**
Cost of central servers (portals) per year	-	1700	1700	1700	1700	**6 800**
Cost per node (10 per year)	-	150	150	150	150	**600**
CRM system	100	50	50	50	50	**300**
Cyber security systems	250	250	250	250	250	**1 250**
Total	**10 000**	**10 000**	**10 000**	**10 000**	**10 000**	**50 000**

5. List of contact persons

List a contact person (name, tel., email) for each partner.

University of Bergen
University of Oslo
The Norwegian University of Science and Technology in Trondheim
University of Tromsø – The Arctic University of Norway
The Norwegian Centre for E-health Research at the University hospital of Northern Norway
National Centre for emergency Primary Health Care: Jesper Blinkenberg