

# New infrastructure for research in general practice

#### **PERSPECTIVES**

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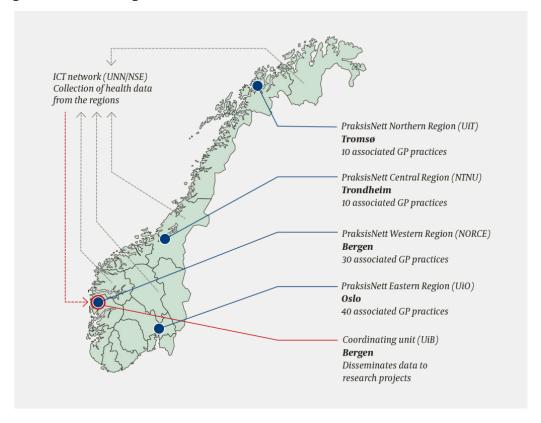
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There is an acute need for practice-oriented research in general practice in Norway. A new infrastructure for such research has now been established, and we encourage all GP practices to report their interest.



**Figure 1** PraksisNett is led by general practice researchers at the universities in Bergen, Oslo, Trondheim and Tromsø, and NORCE (Research Unit for General Practice in Bergen). The ICT infrastructure in the project, Snow, is managed by the Norwegian Centre for E-health Research (NSE).

The research network in primary health care (PraksisNett) is now recruiting GP practices all over the country. This will enable research on issues in general practice in a completely new fashion. Clinical medical research is characterised by studies undertaken on selected groups of patients in highly specialised centres. PraksisNett is a new national network for research in primary care (1), in which GPs are linked to general practice research communities www.praksisnett.no). The plan is to conduct a high number of practice-oriented, clinical studies with a far higher number of participants and better predictability than today. Experience from other countries indicates that such networks produce relevant research of high quality ((2–5).

We have established close cooperation with many of these networks, and annual meetings of an international advisory board are foreseen, with participants from Scotland, England, the Netherlands and Ireland. In Norway, we tend to think that we ought to protect the patients from research, while other countries emphasise that patients are *entitled* to participate in research. We can see that patients increasingly want and demand to be included in research – they want the newest and best options, and the patients wish to play a role in developing them. We therefore believe that many patients will take a positive view of participating in studies, and that GP practices that participate in PraksisNett will be attractive to the patients.

# Why is this important?

Approximately 70 % of the population see their GP on an annual basis, and in 2016 each inhabitant had 2.7 consultations with their GP on average (6). General practice constitutes the single healthcare services' largest arena for diagnostics, treatment, follow-up and prioritisation. This notwithstanding, little clinical research is undertaken in this sector of the healthcare services, partly because both patients and doctors are dispersed around the country, making research both labour-intensive and costly. Today, such research is mainly undertaken in the health enterprises, most often in the university hospitals. Because both illness and treatment of patients admitted to the university hospitals often differ considerably from the clinical realities in general practice, results from hospital-based research may have limited applicability in primary care.

Practice-oriented, clinical investigation of the health problems that cause the patient to see their GP and for which the GP provides the treatment is crucial, however, for building an evidence base for general practice and improving the quality of the treatment provided to patients. PraksisNett will open completely new opportunities to undertake clinical research of high quality and relevance

to the field of general practice. It will also be useful for other research areas, such as health economics and studies of patient pathways, and to strengthen the evidence base for decision-making in health administration and policy.

# Recruitment

Recruitment of GP practices started recently, and our goal is to have 90 GP practices associated with PraksisNett within the next two years. We are confident that Norwegian GPs will see the benefit of the project and be willing to participate. PraksisNett is seeking GP practices from around the country. The more doctors in the GP practice, the more patients will be able to participate in studies, and it is therefore especially desirable to also include large GP practices. Not all doctors in the practice need to contribute to all studies, but they all need to consent to participation by their practice in PraksisNett.

GP practices that join PraksisNett will receive an annual compensation of NOK 20 000, which is intended to cover the time needed for administrative work linked to their participation. In addition, GPs who join specific studies will receive a compensation calculated on the basis of the time and resources that each GP practice needs to contribute to the research project in question. The compensation will be equal to the hourly rate defined by the salary regulations.

# A small box

The GP practices are supplied with a small computer, a Snow box. The box, which is approximately the size of a hand, is linked to the practice's server and stores data from the server every night. The data retrieved are pre-defined and restricted to provide background information on the network's practices and a basis for planning of studies. By themselves, such data provide opportunities for research and new knowledge, but this is not the primary purpose of the network. The box comes already configured at the time of set-up and is under remote administration by a team at the Norwegian Centre for E-health Research. All health data are stored in the box, not on the local server, but remain within the GP practice's responsibility as data processor. No personally identifiable data are retrieved before the patient has provided consent. The technology is integrated with the Medrave software, thus providing the GP practice with an opportunity to undertake quality assurance of their own practices. Pilot studies of the Snow system have been undertaken in a number of GP practices, and the feedback has been positive.

# Prior approval for everything

As a result of PraksisNett, research on the GP practice's patients will be more predictable. To be included in the network, the GP practices must allocate time to participate in at least one research project per year, but the research institutions will continue to be responsible for the research. The GPs' effort will be an integrated part of their working day, and this is reflected in the financial compensation. In addition, the GP practices will be updated with new medical knowledge, in terms of the research activities as well as various forms of feedback that the network helps provide. Clinicians who participate in research projects will be better and more broadly updated (7).

Today, GPs spend a lot of time assessing the relevance and predicting time use when they receive a request to participate in research. They may also feel uncertain as to whether the necessary permissions from the ethics committee or the data protection officer are in place. PraksisNett will have made all these assessments before a request is sent to the GP practice. For the researchers and the research, an appropriate infrastructure and sophisticated information technology mean that they can plan larger and better projects and expect effective help from PraksisNett in recruiting both GPs and patients.

# Who can use the network?

All researchers with an interest in studying patients in general practice can apply for permission to use the infrastructure. A number of different research project may be relevant – from data extraction studies to sophisticated randomised controlled studies (1) (Box 1).

## Box 1 Examples of research projects through PraksisNett

## Data extraction studies:

- How many patients receive treatment x for disease y
- How many patients are certified for illness absence because of disease x
- Laboratory reports, drug use and symptoms observed in patients with a specific condition

## Clinical studies:

- Patients with diagnosis x are recruited to a qualitative study (focus-group study)
- Patients with diagnosis x are recruited to a study where they answer questions about their health, drug use, etc.

## Randomised controlled study:

• Patients with disorder x are recruited to a randomised controlled study in which treatment y is compared to treatment z. Patients are identified through computer-generated lists of names or as a popup when the diagnosis in question is made during the consultation.

We anticipate that general practice research institutions will make extensive use of PraksisNett. Other parties could be researchers in health enterprises, university colleges, other disciplines (e.g. social scientists and economists), organisations, businesses, authorities and the pharmaceutical industry. An application for access should be sent to the coordinating unit, and the management group of PraksisNett will subsequently decide whether or not the research project will be granted access to the infrastructure. The decision will depend on the research project having the necessary quality, relevance and feasibility, and that sufficient funding is in place.

More information about the network can be found on www.praksisnett.no. GP practices can report their interest in participating here or via e-mail, praksisnett@helsam.uio.no.

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