

Occupational therapy for brain injury in community-based health services, 20.04.22 English version



REQUEST TO PARTICIPATE IN THE RESEARCH PROJECT 'OCCUPATIONAL THERAPY FOR BRAIN INJURIES IN COMMUNITY-BASED HEALTH SERVICES'

This is a request for you to participate in a research project to evaluate the usefulness of PRPP (Perceive, Recall, Plan and Perform), which is a type of occupational therapy intervention. You are being asked based on your admission to health services in the municipality and because you have had a brain injury.

WHAT DOES THE PROJECT MEAN TO YOU PERSONALLY?

Ordinary practice:

- The occupational therapist observes you in everyday activities using the PRPP System
- You receive intervention from the method belonging to the PRPP System

Out of the ordinary practice as a result of the project:

- A second occupational therapist performs some of the observations. If this is not possible in the rehabilitation department, we will ask you if we can record a video so that Linda Stigen (the project manager) can make the observation. You can decline this.
- Observation of the activities will be repeated during the interventions, before discharge and 4 weeks after discharge from the rehabilitation unit. This is to evaluate changes in the measures that can be caused by the intervention.
- Two additional assessments will be scored, one that measures independence in daily activities and one that evaluates the goals set for the everyday activities observed. This will be the same as regular assessment and rehabilitation, while evaluation before discharge and after 4 weeks will be an extra follow-up, calculated to be 2x1 hours.

General information about you:

The occupational therapist informed the researchers of your age, telephone number, marital status, education, (previous) work, diagnoses and time since the injury, either from the patient record or by direct questions to you.

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BENEFITS AND DISADVANTAGES

The advantage of participating will be that you are followed up in an extra systematic and structured way, that the initiated measures are carefully evaluated and with follow-up visits after 4 weeks. The disadvantage will be that one of the interventions from the occupational therapist can be initiated a few days later than usual and that the examinations will take some extra time beyond normal treatment time. All other follow-ups from the interdisciplinary team and the occupational therapist will be provided as usual.

VOLUNTARY PARTICIPATION AND THE OPPORTUNITY TO WITHDRAW CONSENT

Participation in the project is voluntary. You can withdraw your consent at any time and without giving any reason. This will not have consequences on your further rehabilitation.

If you withdraw from the project, you can demand that the collected information be deleted, unless the information has already been included in analyses or used in scientific publications.

WHAT HAPPENS TO THE INFORMATION ABOUT YOU?

The information registered about you will only be used as described and is planned to be used until 2029. Any extensions of the project and storage time can only take place after approval from REK and other relevant authorities. You have the right to access the information that is registered about you and the right to have any errors in the information corrected. You have the right to access the security procedures when processing the information.

All information will be handled without name and birth date or other directly recognizable information. A code links your name to the information about you. Only project manager Linda Stigen and Marte Ørud Lindstad have access to this code list.

The information about you will be kept for 5 years after the end of the project for control reasons.

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FOLLOW-UP PROJECTS

It may be relevant to contact you later for an interview or if another occupational therapist/student asks for the opportunity to participate in the observations. This is completely voluntary and can be answered with yes or no if it becomes relevant.

For training purposes for occupational therapists/students, we would appreciate permission to record a video of patients with stroke or other types of brain injury when performing everyday activities. If you allow us to record a video, your face will be visible, but no name will be linked to the video. Of course, this is also completely voluntary, and you have the same opportunity to withdraw consent as described above.

APPROVAL

The Regional Committee for Medical and Health Research Ethics has evaluated the project and has given prior approval with reference number 215391.

According to the new Personal Data Act, the Department of Health Sciences Gjøvik and NTNU, under the Head of department Heidi Viflåt and the Project manager Linda Stigen, have an independent responsibility to ensure that the processing of your information has a legal basis. This project has a legal basis in the EU Privacy Regulation Article 6 (1a) and Article 9 (2a) and your consent.

You have the right to complain about the processing of your information to the Norwegian Data Protection Authority.

CONTACT INFORMATION

If you want to withdraw or have questions about the project, you can contact Marte Ørud Lindstad, 99 592 692, marte.lindstad@ntnu.no or Project Manager Linda Stigen, 932 23 019, linda.stingen@ntnu.no.

Data protection manager at NTNU: thomas.helgesen@ntnu.no

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I AGREE TO PARTICIPATE IN THE PROJECT AND THAT MY PERSONAL DATA CAN BE USED AS DESCRIBED

Yes No

☐ ☐ I accept to be contacted for other projects.
I can still decline by a later direct request.

☐ ☐ I accept video recording of some daily activities for educational purposes.
I can still decline by a later direct request.

Place and date

The participants' signature

The participants' name in capitalized letter

I confirm I have given the following information:

Place and date

Signature

Role in the project