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Dementia assessment – mandatory registration with clinical benefit

FROM THE SPECIALTIES

MARIT NÅVIK

Marit Nåvik is an occupational therapist with a master's degree in public health. She contributed to the establishment and is the coordinator of the NorCog register, is employed at the National Centre for Ageing and Health, and is project manager of the Old Age Psychiatry Research Network Telemark–Vestfold (TeVe).
The author has completed the ICMJE form and declares no conflicts of interest.

ANNE-RITA ØKSENGÅRD

Anne-Rita Øksengård is a specialist in geriatrics and Head of Research at the Norwegian National Association for Public Health and head of the NorCog advisory board.
The author has completed the ICMJE form and declares no conflicts of interest.

INGRID TØNDEL MEDBØEN

Ingrid Tøndel Medbøen is a PhD candidate with a master's degree in neuroscience and a professional advisor at the National Centre for Ageing and Health.
The author has completed the ICMJE form and declares no conflicts of interest.

GEIR SELBÆK

Geir Selbæk is Professor of Geriatrics at the University of Oslo and Head of Research at the National Centre for Ageing and Health. He is also a member of the Lancet Commission on Dementia Prevention, Intervention and Care.

The author has completed the ICMJE form and declares the following conflicts of interest: he has attended Advisory Board meetings for Roche, Eli-Lilly and Eisai concerning disease-modifying medications for Alzheimer's disease, and has received speaker fees from Eisai and Eli-Lilly.

KARIN PERSSON

karin.persson@aldringoghelse.no
Karin Persson is the register manager of NorCog, employed at the National Centre for Ageing and Health. She holds a PhD in dementia and also works as a senior consultant at the Department of Geriatrics, Oslo University Hospital, including at the Memory Clinic.
The author has completed the ICMJE form and declares the following conflicts of interest: she has participated in clinical trials for Roche and Novo Nordisk.

An important goal of the Norwegian Registry of Persons Assessed for Cognitive Symptoms (NorCog) is to serve as a resource with direct practical value for clinicians.

Since 2013, the register has had the status of a national quality register. The purpose is to ensure that assessment, treatment and follow-up are of high quality, nationally harmonised and in accordance with the national clinical guidelines for dementia.

Need for increased coverage

According to the Health Register Act (1) and the Regulation on Medical Quality Registers (2), it is mandatory to register patients in national quality registers. This means that all outpatient clinics in the specialist health service that assess cognitive impairment and dementia are required to register patients in NorCog. Currently, patients from 46 geriatric, old-age psychiatry and memory clinics are included (3).

For data to be representative and results to be generalisable, the coverage rate of a register should be at least 80 %, whereas the coverage rate of NorCog was 70 % in 2024. Several measures have been implemented to increase coverage. In 2024, the register transitioned from a consent-based to an opt-out model, and from 2025 a data-sharing function was developed to enable the sharing of data with the Quality Register in Old Age Psychiatry (KVALAP).

Our goal is for centres that currently submit data to include all eligible patients, for non-participating centres to join, and for neurological outpatient clinics to start including patients in the register.

Simple and useful registration

Clinicians continuously register data digitally via the registration solution. This involves some additional work but enables real-time registration, allowing updated data to be presented at any time. The variables cover demographics, informant-reported information on everyday functioning and neuropsychiatric symptoms, somatic health information, patient-reported outcome measures (PROMs), cognitive test results, supplementary diagnostic procedures performed, and information on further follow-up. Registration takes 3–5 minutes. A questionnaire on patient-reported experience measures (PREMs) is automatically sent after the assessment. Follow-up data are registered during clinical follow-up visits.

In recent years, NorCog has focused on making registration simpler, faster and useful in clinical practice. The number of mandatory variables has been reduced. Automatic calculation of z-scores supports the evaluation of cognitive test results, and the generation of text that can be copied directly into the medical record results in time savings.

What lies ahead?

Within the medical community, there is considerable anticipation regarding new disease-modifying medications for Alzheimer's disease. The register has developed a medication module that can be rapidly implemented if new drugs requiring careful monitoring of effects and adverse events become available in Norway.

Patient experience data indicate that patients are generally satisfied with the assessment but less satisfied with the information provided about the diagnosis and treatment options. A solution for automatic extraction of data for patient information letters is under development.

In addition to contributing to improved quality and services for patients, the register provides access to large volumes of data from clinical practice that can be used for research. To date, this has resulted in 152 scientific articles.

Further development of the register as a useful tool for clinicians, and ensuring inclusion of eligible patients, requires close dialogue with medical communities. However, support from local management is essential; without this, there is a risk of incomplete or random registration, which weakens coverage, data quality and the overall usefulness of the register.

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