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# Register data with clinical value

INVITERT KOMMENTAR

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**Register data are used for quality improvement, research and decision-making. This requires the quality of data to be demonstrated – not assumed.**

National medical quality registers have been given a central role in Norway's health service. They are intended to facilitate quality improvement, ensure equal access to healthcare services and strengthen the evidence base for research and priority-setting. This, in turn, places greater demands on the underlying data, which must not only be accessible but also reliable.

In this issue of the Journal of the Norwegian Medical Association, Hagen et al. examine inter-rater agreement between healthcare personnel's registering of variables in the Norwegian quality register for severe headaches (1). The study addresses a fundamental question: to what extent can we trust the data in quality registers?

> *«A well-functioning register can therefore have a major impact on diagnosis, treatment and follow-up»*

The register covers rare but severely debilitating conditions such as cluster headache, hemicrania continua, paroxysmal hemicrania and SUNCT/SUNA. These conditions are associated with substantial functional impairment and, in many cases, a prolonged delay in diagnosis (2, 3). A well-functioning register can therefore have a major impact on diagnosis, treatment and follow-up.

The study design is well suited to the research question. Using anonymised case reports based on unstructured clinical notes enables the authors to examine information as it is recorded in clinical practice, i.e. often with incomplete details and the need for interpretation. This makes the findings more relevant than if idealised datasets had been used. The participation of 11 of 18 neurology departments reflects strong engagement within the medical community and support for national cooperation (1). Nevertheless, broad participation from all neurology departments and headache clinics is essential if register data are to be representative and suitable for comparison and quality improvement at a national level.

> ***«The more clinically meaningful a variable is, the harder it is to standardise»***

The main findings are reassuring. Inter-rater agreement is high for many key variables, particularly where the information is clearly defined and complete (1), such as diagnosis, smoking status and medication use. These results indicate that key parts of the register are reliable. The weaker results are, however, the most informative. Variables requiring clinical discretion or retrospective assessment, such as efficacy of treatment and number of headache days, showed lower inter-rater agreement (1). This illustrates a fundamental dilemma in quality registers: the more clinically meaningful a variable is, the harder it is to standardise.

This is particularly relevant in headache medicine, where key assessments are often based on the patient's own account and a comprehensive clinical understanding. When such factors are converted into standard register categories, the risk of variation in how information is registered increases. This highlights the need for well-defined variables and clear guidance for registering data.

> ***«The quality of data in a register is closely linked to the quality of the clinical documentation on which it is based»***

In the study, low inter-rater agreement was often associated with missing information in the case reports. In clinical practice, such information can often be clarified directly with the patient. However, this points to a more general issue: the quality of data in a register is closely linked to the quality of the clinical documentation on which it is based.

> ***«Data quality efforts should not take place in disciplinary silos; they should draw on experience gained elsewhere»***

It is therefore particularly encouraging that this work has already led to a revision of the register's initial registration form (1). Clearer definitions, more precise information registration procedures and the inclusion of an 'Unknown' response option for missing information are not merely technical details but prerequisites for more robust data. Other national quality registers have had similar experiences, and this underlines the importance of register holders learning from one another. Data quality efforts should not take place in disciplinary silos; they should draw on experience gained elsewhere. Thus, the study illustrates how systematic evaluation of register variables must be a continuous process rather than a one-off exercise.

As register data are increasingly used for research, comparison and decision-making, trust in the figures must be built rather than assumed. Hagen et al. clearly demonstrate why this work is necessary. Quality registers only have clinical value when their data are robust enough to be used.

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