How dementia quality registries can contribute to better dementia care

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The Austrian Institute for Health Technology Assessment (AIHTA) has investigated which key factors are essential in the planning, design, implementation and operation of so-called dementia quality registries.

The AIHTA report also formulates "good practice strategies" for handling these registries by decision-makers in the health sector.

Key findings concern data management, governance and reporting structures, data protection and the nature of quality indicators. An important conclusion of the study is that various interdisciplinary aspects from organizational, evaluation and outcome research must be taken into account when setting up and operating a dementia quality registry.

It is estimated that up to 150,000 people in Austria live with a dementia-related impairment. According to current forecasts, this number will even double by 2050. The syndrome manifests itself in everyday life primarily through chronic or progressive loss of function of nerve cells (neurodegeneration), which gradually makes everyday life more and more difficult for those affected—for example, through problems with memory, language or spatial orientation. The complexity and incurability require a careful and, above all, evidence-based approach with patients and all other actors involved.

The AIHTA has now analyzed various dementia quality registries in a study and derived related quality indicators that are helpful in developing optimal care pathways concerning dementia. In total, six national quality registries from Australia, Denmark, Ireland, Norway and Sweden were analyzed, which cover a wide range of dementia types and, in addition to the common goal of improved dementia care, also strive for improved networking with research. Although the governance structures were heterogeneous, they also shared commonalities. For example, a multi-professional steering group was one of the core elements of all the dementia quality registries studied.

"These expert groups are made up of dementia care practitioners and researchers, as well as affected patients and caregivers, and are responsible for the administrative, legal, ethical and scientific decisions,"

explains Christoph Strohmaier, head of the study and health economist at AIHTA.

Differences and similarities

In addition to governance structures, commonalities emerged across registries regarding data management. All the dementia quality registries studied used a so-called minimum data set, i.e. a minimum set of common data elements that all facilities should use for standardized data collection in secondary and primary care. The number of data items collected could be divided into several categories but varied greatly between registries: for example, the Irish registry collected 56 data items, while the Swedish registry (BPSDR) had only 10 data items.

In addition to differences in quality assurance measures, data entry and validation methods, there were similarities in data protection (for EU registries based on the DGSVO) and data use for research purposes. In addition, all identified quality registries were publicly financed because national dementia action plans or strategies in all five countries form the basis for the goal of quality improvements based on registry data, emphasizes study author Christoph Strohmeier from AIHTA.

Based on the minimum data set, so-called quality indicators are formed in each quality registry. In most cases, these are proportion indicators that are intended to depict the desired quality standard in three dimensions (process, structure, outcome quality).

In most cases, these indicators are based on a consensus-based decision by the respective steering groups. Only the two Swedish registries explicitly based their selection of quality indicators on the Swedish National Guideline for Dementia Care. In total, the analysis identified 46 individual quality indicators from the categories of pre-diagnosis, diagnosis and diagnostic clarification, treatment and support measures,

outcome-related—and meta-indicators.

Framework and recommendations for practical implementation

Finally, the concluding part of the AIHTA report focuses on specific aspects of dementia quality registries that healthcare decision-makers need to consider. These aspects include, for example, the clarification of responsibilities and questions of funding right from the planning phase or strategies for the recruitment of patients and providers, as well as the selection of quality indicators.

"The use of large sets of quality indicators is not recommended. The focus should be on evidence- and consensus-based quality rather than quantity. Carefully validated scales should be used to measure patient-related outcomes and quality indicators based on them," says Christoph Strohmaier. In addition, aspects of interoperability must be considered, i.e., a linkage of the dementia quality registry data with other health databases must be ensured.

Ultimately, efficient functioning requires the cooperation of all actors involved across all levels of care—this is the only way to bring about quality improvements in dementia care.

  More information: Quality Registries in Dementia Care: Mapping of Registries to improve Quality and Service Delivery. HTA-Project Report 150. eprints.aihta.at/1419/

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