

Strategic goal 4: Epidemiology and research

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Vision

Care of patients with dementia is routinely monitored at the national level. The most important indicators of the care are regularly reported and clearly presented.

Research on dementia addresses the national priorities, is multidisciplinary, coordinated and has secured long-term funding. Rich databases are available in order to conduct research of high quality, relying on population-based studies, clinical cohorts as well as routinely collected data.

Content

Specific goal 1: Systematic assessment of data about dementia

Specific goal 2: Development of research on dementia

Content

Specific goal 1: Systematic assessment of data about dementia

Rationale

necessary for planning and evaluation of services for patients with dementia

achievable utilizing already existing data sources – registers of routinely collected data

collaboration between the health and social care is necessary

Specific goal 1: Systematic assessment of data about dementia

Measure 1: Reporting of indicators of care about individuals with dementia

Measure 2: Merging of health-related data with data about social services

Measure 1: Reporting of indicators of care about individuals with dementia

Yearly reported data on patients diagnosed with dementia, medical examinations, prescriptions of drugs and care delivery in each medical specialty.

The source of data is the National Register of Paid Health Care Services.

Data is presented as a part of the information system „Mental disorders of people older than 65 years“ and is compatible with the rest of this system.

Measure 1: Reporting of indicators of care about individuals with dementia

A) Number of individuals diagnosed with dementia in the specific year

- G30, F00 *Alzheimer's disease*
- F01 *Vascular dementia*
- F02 *Dementia is other diseases classified elsewhere*
- F03 *Unspecified dementia*
- F067 *Mild cognitive disorder*

Measure 1: Reporting of indicators of care about individuals with dementia

B) Share of diagnosed individuals who underwent the following examination in the specific year

- CT
- *MRI*
- *LP*
- *PET*
- *SPECT*
- *Complex psychological examination*
- *Laboratory examination*

Measure 1: Reporting of indicators of care about individuals with dementia

C) Share of diagnosed individuals who were prescribed the following drugs in the specific year

- *Acetylcholinesterase inhibitors* (ATC N06DA)
- *Memantin* (ATC N06DX01)
- *Antipsychotics* (ATC N05)
- *Antidepressants* (ATC N06A), separately tricyclic / SSRI / other
- *Anxiolytics* (ATC N05B), separately BZD / other
- *Analgesics* (ATC N02), separately opioids / other
- *Cardiovascular drugs + blood thinners* (ATC B01, C01, C02, C03, C04, C05, C07, C08, C09, C10)
- *Urologic drugs* (ATC G04BD)
- *Total number of drugs*

Measure 1: Reporting of indicators of care about individuals with dementia

D) Share of diagnosed individuals who utilized the following services in the specific year

- GP visit (code 001)
- Outpatient neurologist visit (code 209)
- Outpatient geriatrician visit (code 106)
- Outpatient psychiatrist visit (codes 305, 307, 308)
- Clinical psychologist visit (code 901)
- All three specialists (neurologist AND geriatrician AND psychiatrist)
- All four physicians (neurologist AND geriatrician AND psychiatrist AND GP)
- All five clinicians (neurologist AND geriatrician AND psychiatrist AND GP AND psychologist)
- Number of hospitalizations
- Number of hospitalization days

Measure 1: Reporting of indicators of care about individuals with dementia

Gestor: National Institute of Mental Health

Cooperating subject: Institute of Health Information and Statistics

Deadline: 3.1.2020

Funding: not required

Indicator: The data is presented as a part of the information system „Mental disorders of people older than 65 years“

Note: Evaluation after the first implementation period. If not sufficient, a dementia register should be considered

Specific goal 1: Systematic assessment of data about dementia

Measure 1: Reporting of indicators of care about individuals with dementia

Measure 2: Merging of health-related data with data about social services

Measure 2: Merging of health-related data with data about social services

Yearly reported data concern only health care services. This is insufficient for a complex picture necessary for planning services.

The Ministry of Labour and Social Affairs provides data about requested and utilized social services to the Institute of Health Information and Statistics. Using a unique birth number, the data is merged with the National Register of Paid Health Care Services.

Measure 2: Merging of health-related data with data about social services

Gestor: Ministry of Health (dementia coordinator)

Cooperating subject: Ministry of Labour and Social Affairs and

Institute of Health Information and Statistics

Deadline: ?

Funding: ?

Content

Specific goal 1: Systematic assessment of data about dementia

Specific goal 2: Development of research on dementia

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Necessary to address the gaps in knowledge about effective strategies to decrease the incidence of dementia and improve the care of the patients.

Requires stable funding and appropriate infrastructure (population-based studies, clinical cohorts and routinely collected data).

Research activities need to address national priorities.

Priorities

- 1) Long-term research of the ageing population (using a population-based longitudinal cohort study) in order to determine
 - prevalence and incidence of dementia
 - risk and protective factors for dementia
- norms for cognitive functions of the ageing population and long-term trends in cognitive ageing

Priorities

- 2) Research on care of patients with dementia in order to determine
- accessibility, continuity, quality and effectiveness of services in different stages of the disease (early detection by GP, specialized health care, community care, relief services, social institutions)
 - burden, needs and quality of life of informal caregivers
 - management of behavioural and psychological symptoms of dementia

Priorities

- 3) Multicentric clinical cohort of patients with dementia in order to
 - facilitate collaboration of different clinical centers
 - standardize diagnostic protocols
 - share clinical data between researchers

Priorities

4) Basic research in order to enhance understanding of biological mechanisms in the development of dementia

Specific goal 2: Development of research on dementia

Measure 1: Specific funding for dementia research

Measure 2: Population-based longitudinal study

Measure 3: Multicentric clinical study of patients with mild cognitive impairment or dementia

Measure 4: Utilization of routinely collected data for dementia research

Measure 1: Specific funding for dementia research

- Emphasis on dementia research as a part of the priority „population ageing“ (Ministry of Health)
- Division of the panel „age-specific diseases“ into two (Czech Health Research Council)
- Minimal budget of funding allocated to dementia research
- Other funding sources search and dissemination (coordinator)

Measure 1: Specific funding for dementia research

Gestor: Ministry of Health (Czech Health Research Council)

Cooperating subject: dementia coordinator

Deadline: 3.1.2020

Funding: Ministry of Health

Measure 2: Population-based longitudinal study

Prospective population-based cohort study aiming at fulfilling the Priority 1

Based on three already established cohorts: HAPIEE, SHARE and post-MONICA

Establishing of the study follows a pilot phase

Measure 2: Population-based longitudinal study

Gestor: ?

Cooperating subject: ?

Deadline: Pilot phase initiated in 2020

Funding: ?

Measure 3: Multicentric clinical cohort study of patients with mild cognitive impairment or dementia

Role of biomarkers in the progression of dementia

Burden and needs of caregivers

Merging of several small patient cohorts in individual clinics

Sharing of imaging, neuropsychological and clinical data

Standardization of diagnostic protocols

Large dataset

Measure 3: Multicentric clinical cohort study of patients with mild cognitive impairment or dementia

Specific call by the Ministry of Health
Minimum number of clinics
Minimum number of patients

Measure 4: Utilization of routinely collected data

National Register of Paid Health Services

Transparent rules how the data can be used for academic research

Legal, ethical issues

Measure 4: Utilization of routinely collected data

Gestor: Dementia coordinator

Cooperating subject: Institute of Health Information and Statistics