

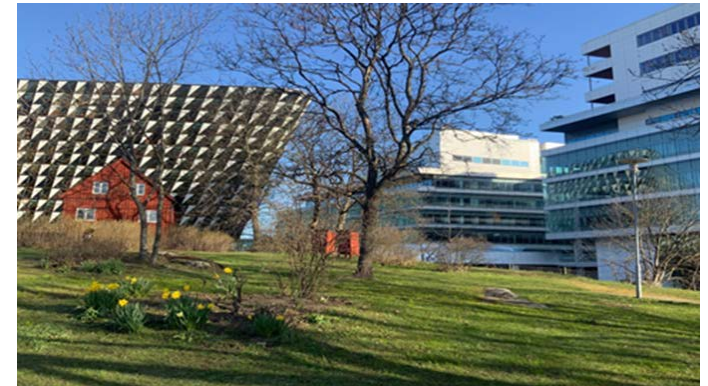
Registry holders' perspectives on real-world evidence generation



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SveDem, the Swedish registry for cognitive/dementia disorders, www.svedem.se

**National quality registry to improve
diagnostics, treatment and care of people
with dementia in Sweden**

- ✓ Includes patients at the time of the dementia diagnosis or MCI and follow-ups
- ✓ Main purpose: to improve health care and care based on national guidelines
- ✓ Cover 35-40% of the estimated incident dementia cases/year—but ca 50% of expected cases are undetected
- ✓ Financed through the Swedish Association of Local Authorities and Regions



In December 2025

144 000

Individuals with dementia or MCI

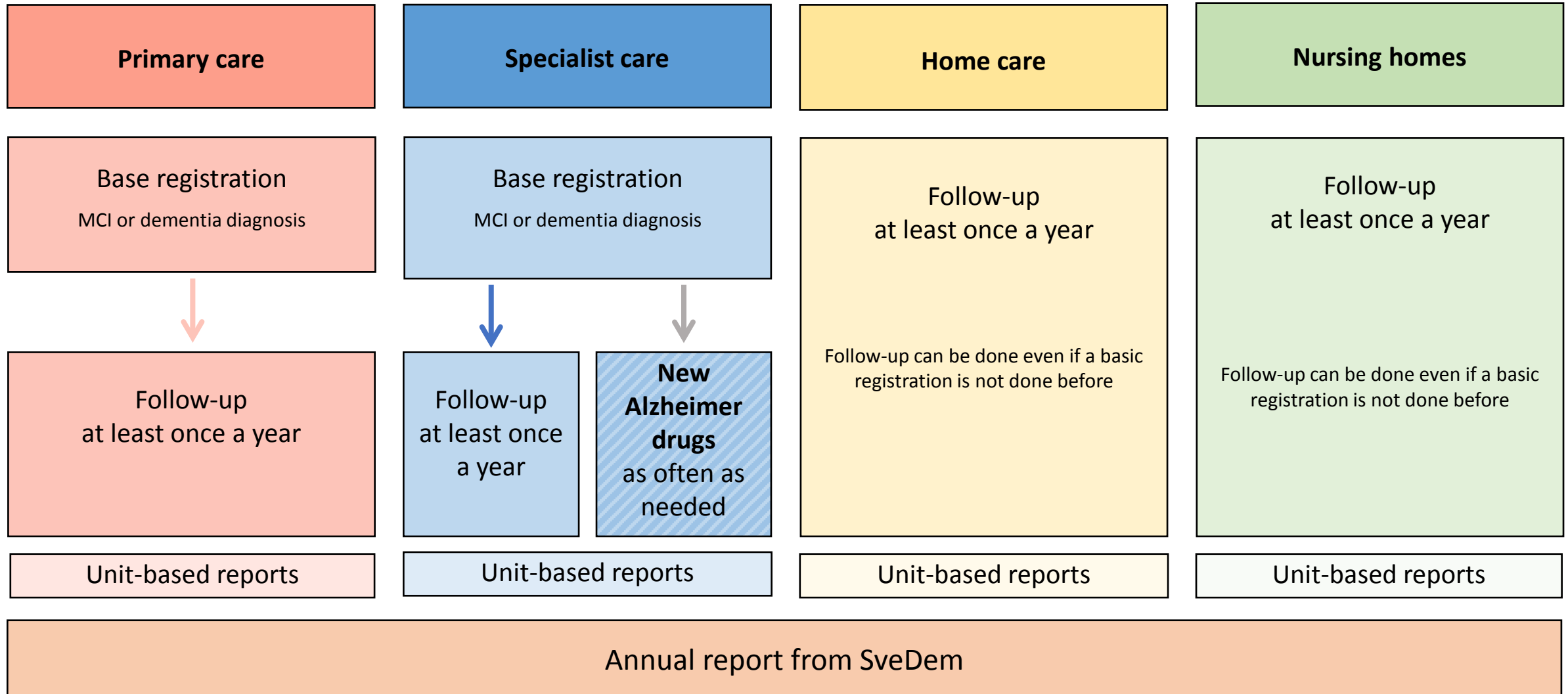
58 memory clinics (100%)

933 primary care units (78%)

754 nursing homes

200 home care units

SveDem - structure



Dementia work-up according to National guidelines

Basic dementia work-up

Primary care

- Patient history
- Physical examination
- Routine blood work
- MMSE and clock test
- Evaluation of functional ability
- CT brain scan



Extended work-up

Memory clinic

- Extensive cognitive testing
- MRI scan
- Lumbar puncture-CSF analyses
- PET
- Genetic testing
- Evaluation by speech, physio-therapist

Registrations

- Patient flow efficacy in health system
- Living conditions
- Dementia investigations performed
- Cognitive Assessment – MMSE, MOCA, RUDAS
- Date of MCI or dementia diagnosis
- Type of dementia disorder diagnosed
- Treatment
- Support from community
- Annual follow-up
- Specific care variables for nursing homes, home care

Brief summary of the variables

- A basic registration is made when the dementia diagnosis is established and then a follow-up at least once a year
- We do not have direct transfer from medical record to SveDem
 - all registration is done manually
- Answer options for most variables
 - Yes, No and Do not know
- MMSE-SR, MoCA, RUDAS-S and Qualid – if yes; the value is filled in
- For some variables, it is voluntary to fill in results
 - Cerebrospinal fluid – biomarkers
 - MRI and CT - atrophy degree

Current pharmacological treatment in Alzheimer's disease

- Guidelines by the Swedish national Board of Health and Welfare recommend for persons with Alzheimer's disease (AD):
 - ✓ treatment with Cholinesterase-inhibitors (ChEIs) in mild to moderate AD
 - ✓ treatment with Memantine in moderate AD
- The ChEIs currently in use: donepezil, galantamine and rivastigmine

Current Drug treatment in AD patients – target % ?

Current Drug treatment in AD patients – **target 80%** in specialist setting

What is unique with SveDem and research?

- Cognitive ability assessed (MMSE, MOCA, RUDAS)
- Access to data from specialist, primary care, nursing home, home care, ie follows person through whole chain of care
- Annual follow-up
- Registered by personal number
- Possibility to merge with multiple national registers such as
 - Swedish National Patient Registry
 - Prescribed Drug Registry
 - Total Population and Causes of death registry
 - CSF-registry in Gothenburg

Religa D, et al. PLoS One, 2015

Long-term follow-up of new drugs is extremely important

- Follow-up over a long period – several years
- Track all individuals treated in real-world clinical practice
 - Are there effects on cognition after treatment for 1? 2? 3–5 years?
 - Has functional ability changed after 1? 2? 3–5 years?
 - Are there different outcomes among subgroups regarding age? Gender? Comorbidities?
 - Effects on biomarkers?
- Compare with previous unique **long-term follow-up data** from SveDem of individuals with Alzheimer's disease (AD) regarding cognition, mortality, etc.

MULTIMORBIDITY



European Journal of Heart Failure (2015) 17, 612–619
doi:10.1002/ehf.222

Heart failure and dementia: survival in relation to types of heart failure and different dementia disorders

Pavla Cermakova^{1,2*}, Lars H. Lund^{3,4}, Seyed-Mohammad Fereshtehnejad⁵, Kristina Johnell⁶, Bengt Winblad^{1,7}, Ulf Dahlström⁸, Maria Eriksdotter^{5,7}, and Dorota Religa^{1,7}

ACCESS TO CARE

Diabetes Care

1



Diabetes in a Large Dementia Cohort: Clinical Characteristics and Treatment From the Swedish Dementia Registry

<https://doi.org/10.2337/dc16-2516>

Juraj Secnik,¹ Pavla Cermakova,^{1,2}
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Pontus Dannberg,¹ Kristina Johnell,⁵
Johan Fastbom,⁵ Bengt Winblad,^{1,6}
Maria Eriksdotter,^{3,6} and Dorota Religa^{1,6}



PHARMACO-EPI



ELSEVIER

Alzheimer's & Dementia ■ (2018) 1-8

Alzheimer's
&
Dementia

Featured Article

Acetylcholinesterase inhibitors and risk of stroke and death in people with dementia

Edwin C. K. Tan^{a,b,*}, Kristina Johnell^b, Sara Garcia-Ptacek^{c,d}, Miriam L. Haaksma^{b,e},
Johan Fastbom^b, J. Simon Bell^a, Maria Eriksdotter^{c,f}

SOCIO-DEMOGRAPHY

Journal of Alzheimer's Disease 38 (2017) 1265–1272
DOI 10.3233/JAD-170102
IOS Press

1265

Living Alone with Alzheimer's Disease: Data from SveDem, the Swedish Dementia Registry

Pavla Cermakova^{a,b}, Maja Nelson^a, Juraj Secnik^a, Sara Garcia-Ptacek^{c,d,e}, Kristina Johnell^f,
Johan Fastbom^f, Lena Kilander^g, Bengt Winblad^{a,d}, Maria Eriksdotter^{c,d} and Dorota Religa^{a,d,*}

Master's Courses in Dementia Care for Physicians

A unique education that addresses a wide range of aspects, from the latest research, diagnosis and treatment to organisational models for dementia care.



Photo: Getty Images



ki.se/epe/dementia

The new drug-module

- The new Alzheimer's medication module will be adapted to the recommendations for the current drug
- User-friendly
- Implemented first at specialist clinics

SveDem's module for follow-up of new dementia drugs

- ✓ Adapted to the recommendations for new drug in question
- ✓ User-friendly
- ✓ For specialist settings

The screenshot shows the SveDem web application interface. At the top, there are tabs for 'Kvalitetsregistret' and 'Administration'. Below these, the user is logged in as 'Tolvan Tolvsson' (19121212-1212, Man 112 år) under the 'Karolinska sjukhuset (Specialistenhet)' institution. The page title is 'Nya Alzheimerläkemedel'. There are buttons for 'Spara' and 'Klarmarkera'. A search bar shows 'ÅÅÅÅMMDD-NNNN'. The main content area has a heading 'Nya Alzheimerläkemedel' and a subheading 'Aktuellt läkemedel'. The text explains that this is a work material for the SveDem form for new Alzheimer's drugs, which will be adapted when they are on the market. It states that drug registration replaces the ordinary follow-up, which should continue to be registered annually. The registration is only for people treated with new types of drugs for cognitive disorders, and it is important to follow the results. On the right, there is a table of contents with links to 'Aktuellt läkemedel', 'Kriterier för insättning', 'Övrigt', 'Bedömning', and 'Hjärnbildning med MR'. At the bottom, there are buttons for 'Ja' and 'Nej' under 'Nytt läkemedel 1', and buttons for 'Insättning', 'Fortsatt behandling', 'Utsättning', and 'Återinsättning' under 'Behandling'. A date field shows '2025-01-06'.





**From healthy aging
to complex needs**

Thank you