

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

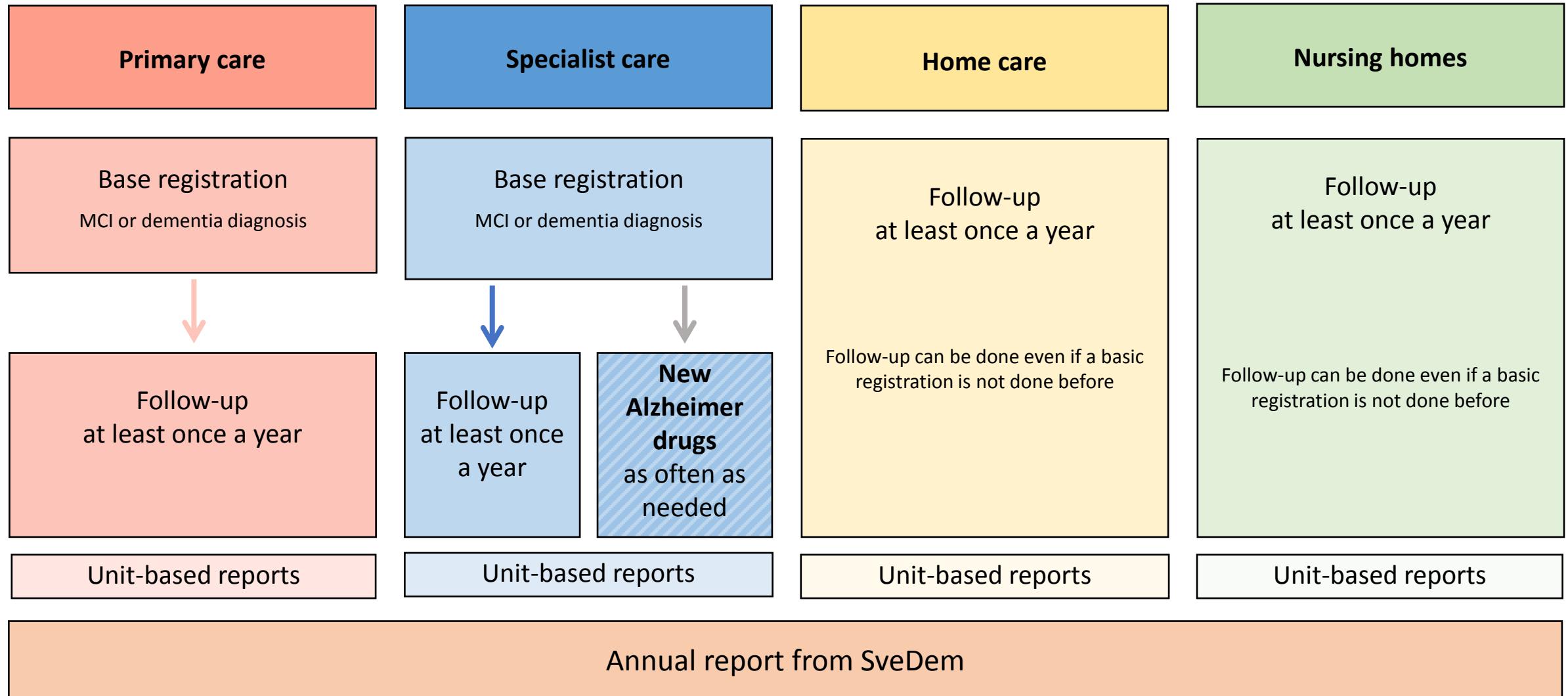


In December 2025

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/ejhf.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}

Diabetes Care

ACCESS TO 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 Sečník,¹ Pavla Cermakova,^{1,2}
Seyed-Mohammad Fereshtehnejad,^{3,4}
Pontus Dannberg,¹ Kristina Johnell,⁵
Johan Fastbom,⁵ Bengt Winblad,^{1,6}
Maria Eriksdotter,^{3,6} and Dorota Religa^{1,6}

PHARMACO-EPI



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 58 (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 Sečník^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.

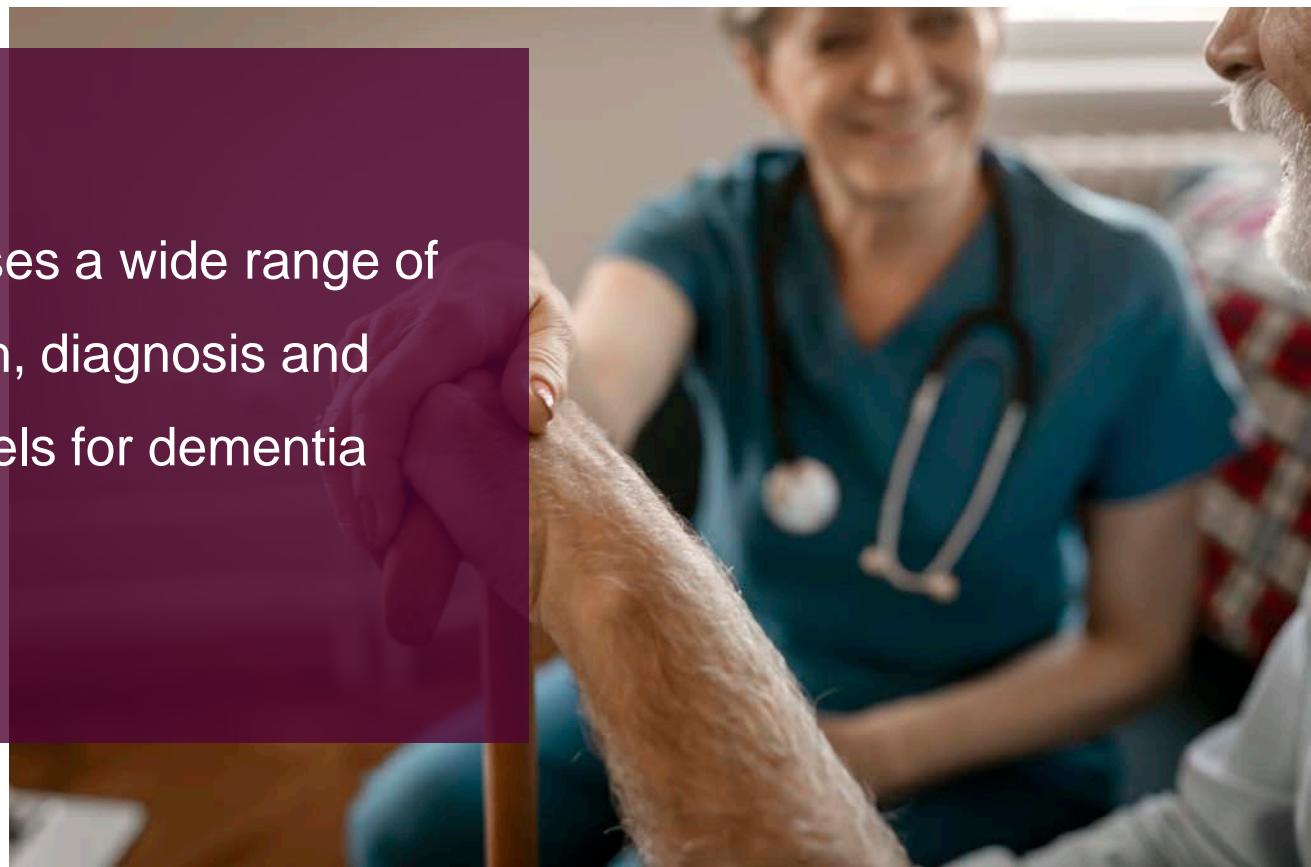


Photo: Getty Images



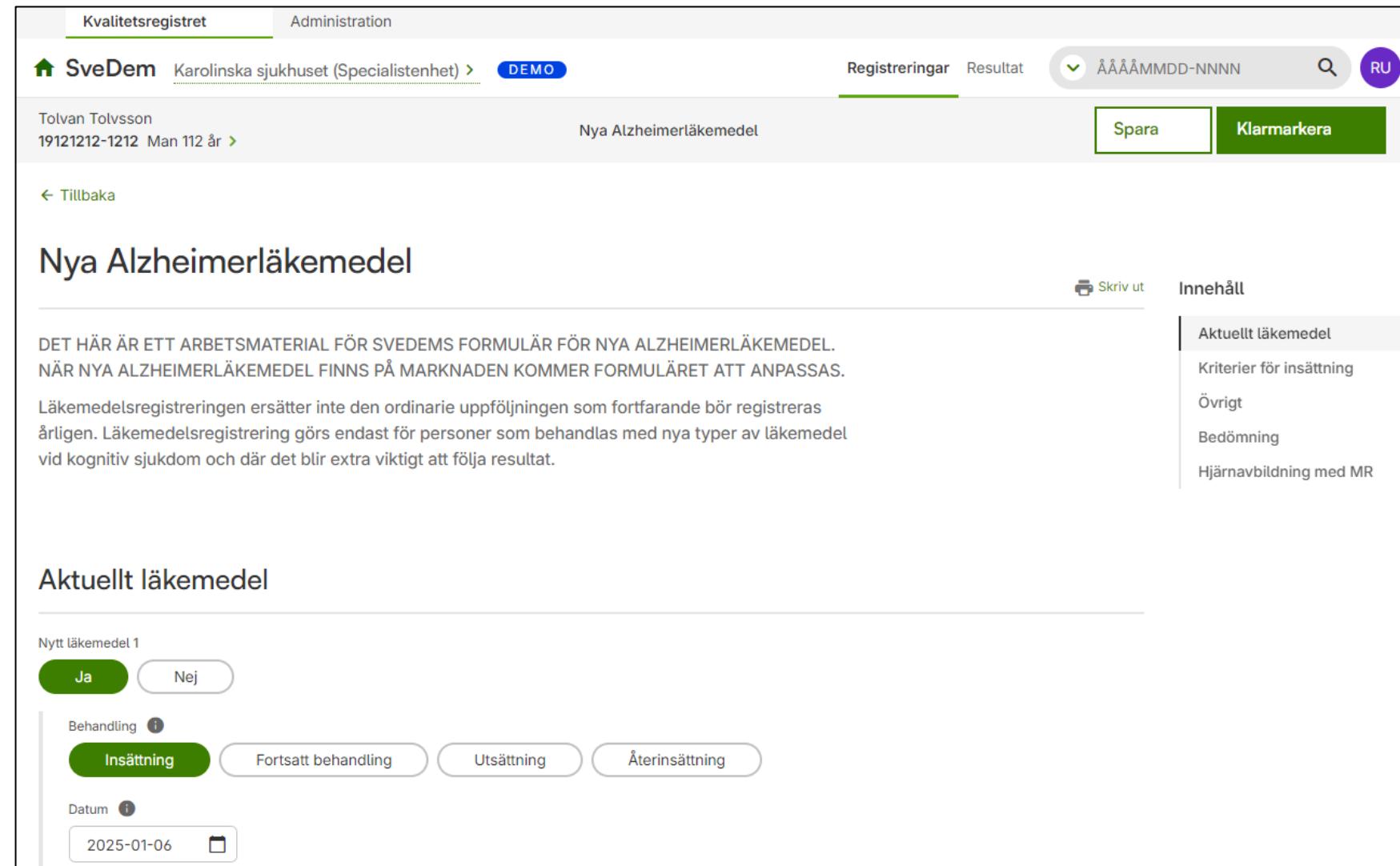
ki.se/epe/dementia

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



Kvalitetsregistret Administration

SveDem Karolinska sjukhuset (Specialistenhet) > DEMO Registreringar Resultat

ÅÅÅÅMMDD-NNNN

Tolvan Tolvsson
19121212-1212 Man 112 år > Nya Alzheimerläkemedel

[Tillbaka](#)

Nya Alzheimerläkemedel

DET HÄR ÄR ETT ARBETSMATERIAL FÖR SVEDEMS FORMULÄR FÖR NYA ALZHEIMERLÄKEMEDEL. NÄR NYA ALZHEIMERLÄKEMEDEL FINNS PÅ MARKNADEN KOMMER FORMULÄRET ATT ANPASSAS.

Läkemedelsregistreringen ersätter inte den ordinarie uppföljningen som fortfarande bör registreras årligen. Läkemedelsregistrering görs endast för personer som behandlas med nya typer av läkemedel vid kognitiv sjukdom och där det blir extra viktigt att följa resultat.

Aktuellt läkemedel

Nytt läkemedel 1

Behandling i

Datum i

2025-01-06

Innehåll

- Aktuellt läkemedel
- Kriterier för insättning
- Övrigt
- Bedömning
- Hjärnavbildning med MR



A close-up photograph of a young boy with light brown hair, wearing an orange baseball cap and a red t-shirt with a graphic on it. He is smiling and looking down at a bicycle he is working on. He is wearing a dark blue long-sleeved shirt under his t-shirt. He is wearing a black glove on his left hand and a red and black glove on his right hand. He is holding a black multi-tool with several tools attached to it. The bicycle has a teal frame and a black seat. The background is dark and out of focus.

From healthy aging
to complex needs

Thank you