Ageing with intellectual disability – a study based on six national registers

GERD AHLSTRÖM, PROFESSOR & MAGNUS SANDBERG, PHD

The need of the project came from the practice of disability service

- Questions about what happens in the ageing with intellectual disability (ID) was expressed by staff working in disability services already for 15 years ago.

- More recently for example have the managers wondering how they best can support the staff to manage the everyday care and service with the steadily growing number of older people with ID living in group homes.

- The leaders expressed that they wanted the research to help them understand how they could help their staff in the everyday care and service.

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Scientific rationale for this project

- Increased life expectancy, both in the general population and in people with intellectual disabilities (ID)
- Little is known about ageing in this group
- Few comprehensive studies, usually small sample sizes, cross-sectional, including all/low ages, and/or without control group
- Few studies looking at the ‘big picture’, i.e. just investigating one outcome, for example use of one type of healthcare

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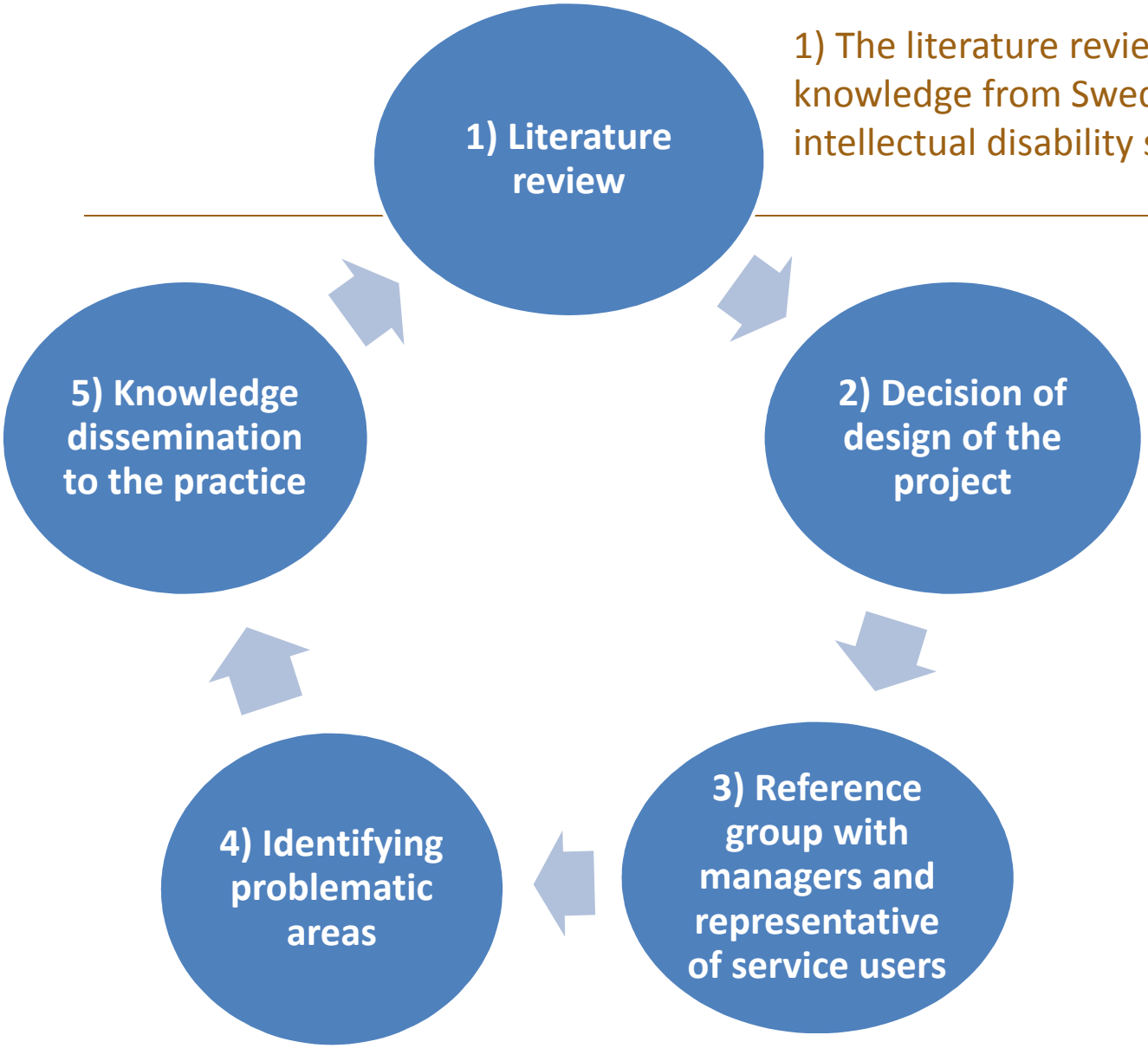

1) The literature review revealed that epidemiological knowledge from Sweden about ageing among people with intellectual disability since childhood is missing

2) Design: 6 national register including ID and reference group from population register

3) Reference group with managers and representative of FUB (user participation) from year 2012

4) The studies investigate different research questions.

5) There is a large need of education and preventative intervention to reduce ill-health and unplanned health utilization

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Definitions

- *Intellectual disability* (ID) is a disability characterized by significant limitations in both **intellectual functioning** and in **adaptive behavior**, which covers many everyday social and practical skills. This disability originates **before the age of 18**

- The LSS: the Swedish Act concerning Support and Service for Persons with Certain Functional Impairments [Lagen om stöd och service till vissa funktionshindrade]. LSS describes which persons are covered by the law. They are divided into three groups based on different assessment bases, so-called personal circles.
  - Personal circles 1 (Personkrets 1): With developmental disorder, autism or autism-like condition.

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Support and services according to LSS

- Counselling and other personal support
- Personal assistance
- Companion service
- Contact person
- Relief service in the home
- Short stay away from home
- Daily activities
- Residence with special services for adults or other specially adapted housing
- Short period of supervision for schoolchildren over the age of 12
- Living arrangements in a family home or in a residence with special services for children and adolescents

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Three different acts for people with ID

- the **LSS-Act** for support and service for certain disability (for all ages, municipalities' responsibility)

- the **Social Services Act** (for persons 65 years old or above, municipalities' responsibility)

- the **Health and Medical Services Act** (for all ages, county councils' responsibility)

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Ethical considerations before project start

- Ethical approval from The Regional Ethical Review Board in Lund
- Ads in a newspapers about the study and how to withdraw
- Additional ethical reviews by Statistics Sweden and Swedish National Board of Health and Welfare
- Anonymized dataset
- Encrypted data files stored on external hard drives
- Analyzed on computers without internet access

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Research group

Gerd Ahlström
Project leader

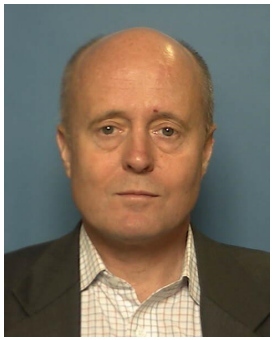
Magnus
Sandberg

Anna
Axmon

Nawi
Ng

Peter
Höglund

Eva
Flygare-Wallén



Jonas
Eberhard

Hans
Westergren

Magnus
Tideman

Jimmie
Kristensson

Patrik
Midlöv

Barry
Karlsson

Lena
Nylander

Petra
Björne

Naida
El Mrayyan

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To use registers as proxy

- To be ’creative’ in using the registers
- Diagnoses – also a measure of the prevalence of a disease?
- Prescribed medications – a measure of consumed medications?
- Clinically relevant question vs. available data

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Validity of the registers

- Poor validity for some of the registries for some of the years (i.e. Social Services)
- Lacking information for certain registers (i.e. primary care)
- Registers connected to reimbursement system -> higher validity
- Administrative registers (of which municipalities are responsible for) are less fitted for research purposes.

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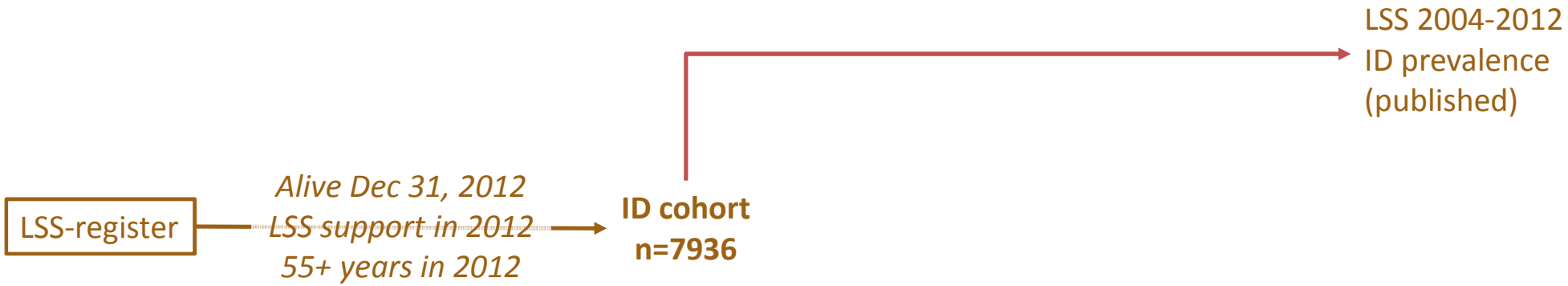

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JIDR Journal of Intellectual Disability Research
Published on behalf of mencap and in association with IASSID

Journal of Intellectual Disability Research doi: 10.1111/jir.12219

Prevalence of older people with intellectual disability in Sweden: a spatial epidemiological analysis, 2015 Dec;59(12):1155-67. doi: 10.1111/jir.12219. Epub 2015 Aug 26.

N. Ng, (1,2), M. Sandberg (3) & G. Ahlström (3)

1. Unit of Epidemiology and Global Health, Department of Public Health
2. Clinical Medicine, Faculty of Medicine, Umeå University, SE-901 87 Umeå, Sweden.
3. Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden

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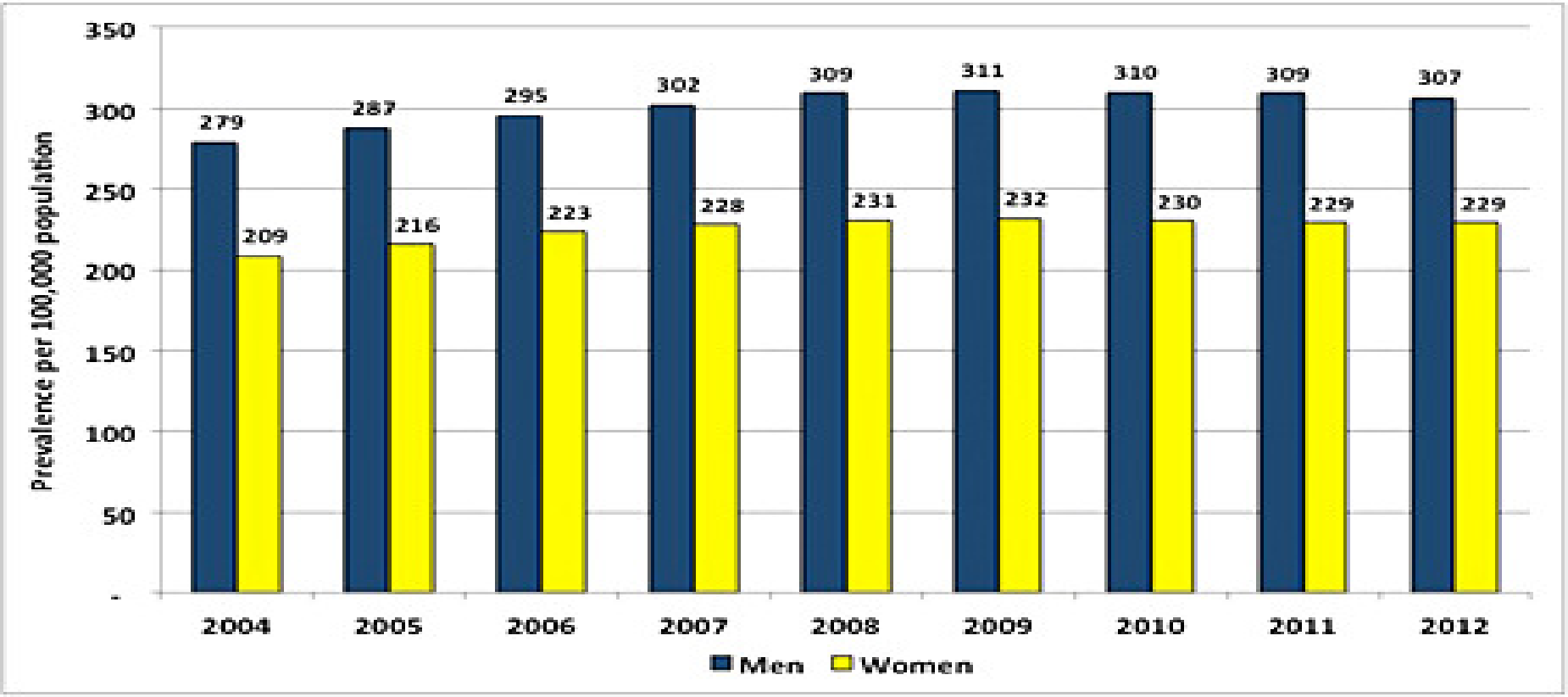
Prevalence of ID among men and women



Prevalence of older people with intellectual disability in Sweden: a spatial epidemiological analysis. Ng N, Sandberg M, Ahlström G. J Intellect Disabil Res. 2015 Dec;59(12):1155-67

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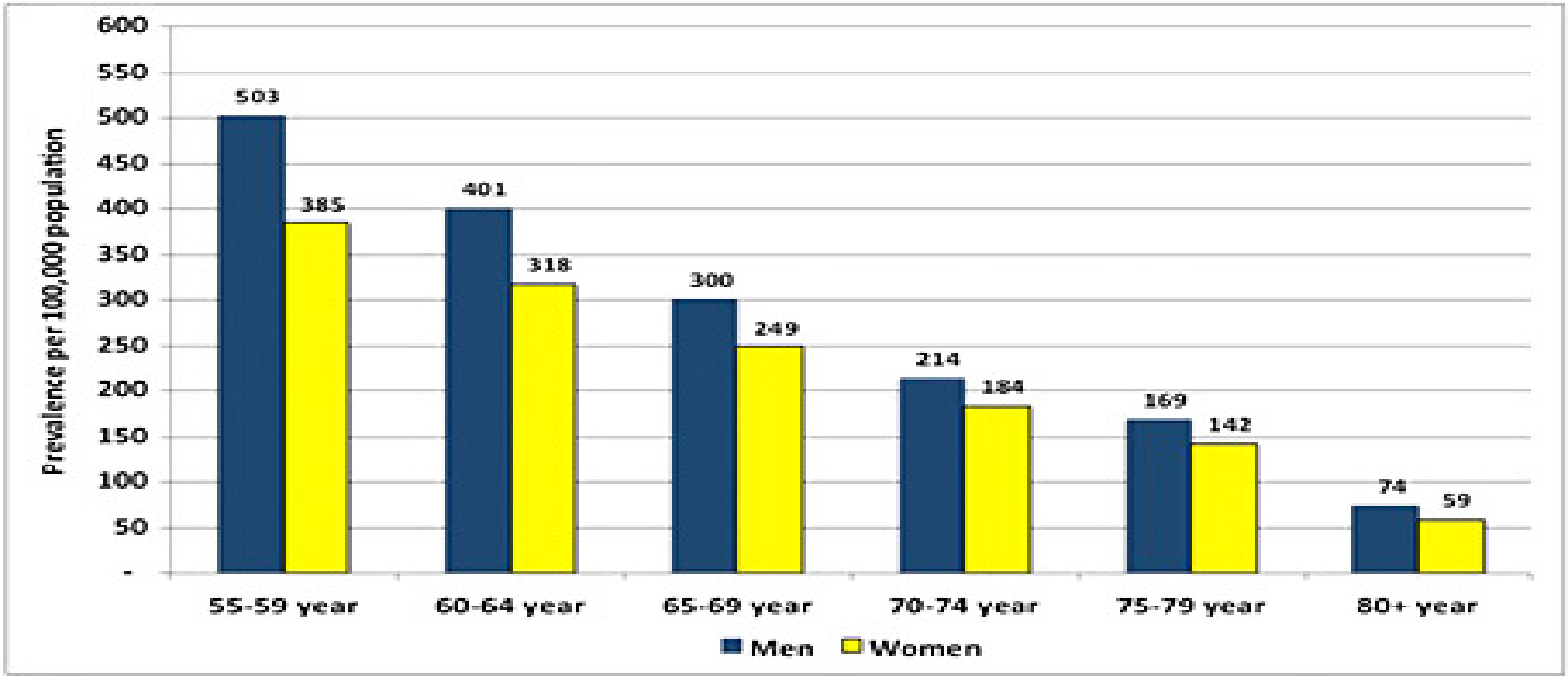
Prevalence of ID for people by age group and sex



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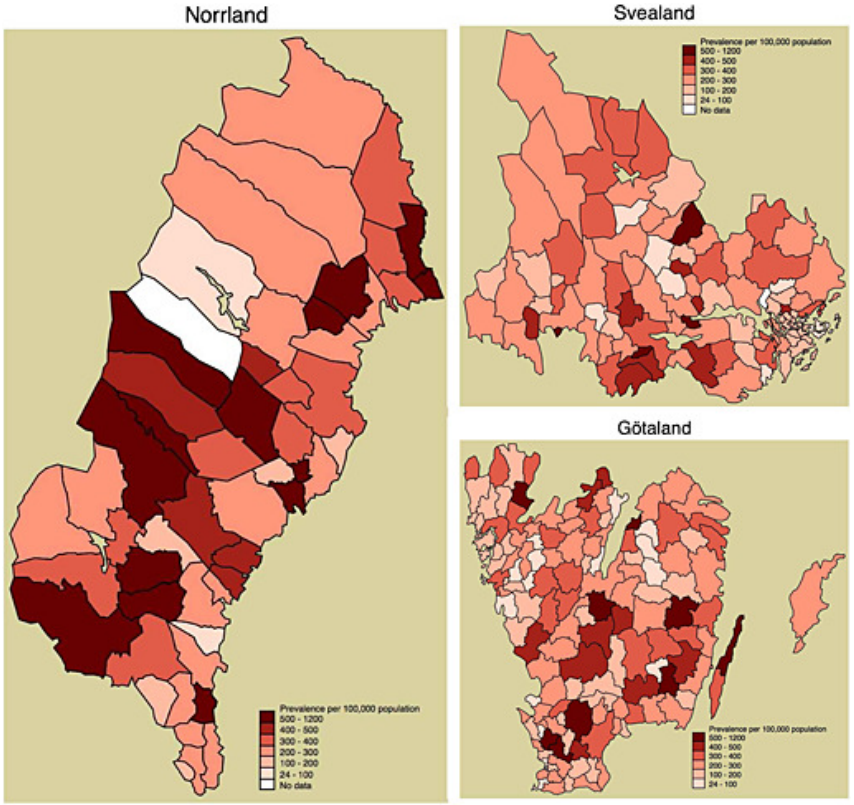
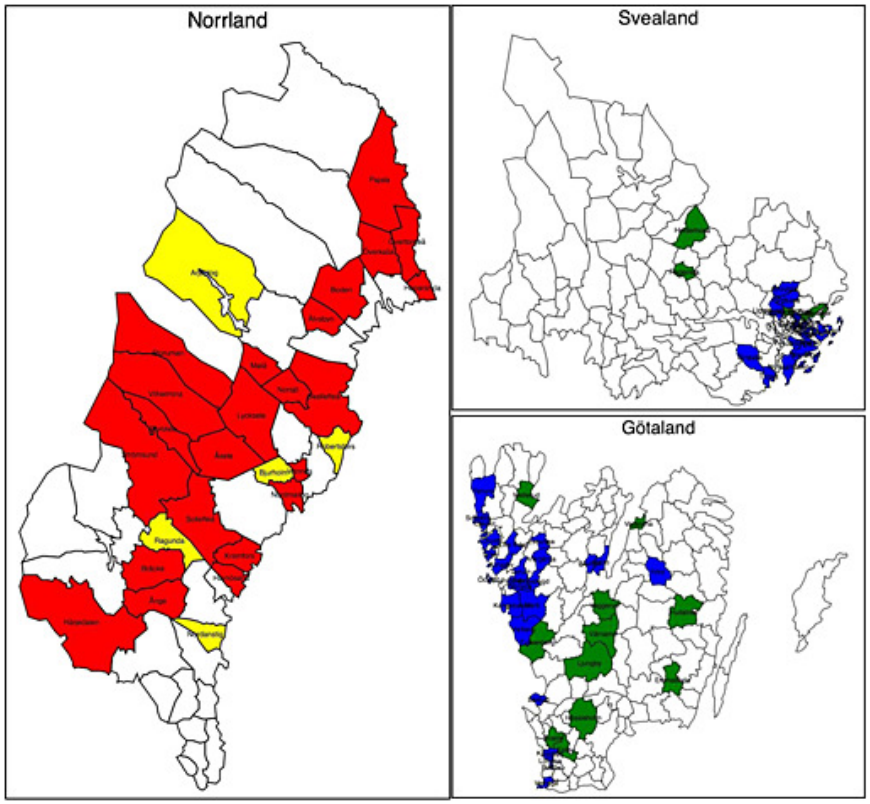
Prevalence of ID





Moran's scatterplot map.

Prevalence of older people with intellectual disability in Sweden: a spatial epidemiological analysis. Ng N, Sandberg M, Ahlström G. J Intellect Disabil Res. 2015 Dec;59(12):1155-67

Main Results - *Prevalence of older people with intellectual disability in Sweden*

- The prevalence of ID among older individuals aged 55+ in Sweden increased from 2004 to 2012.
- The prevalence was consistently higher among men, and the gender gap increased slightly in recent years.
- Age-specific prevalence estimates showed ID to be higher in younger age groups, and the gender gap decreased in older age groups.
- The prevalence was higher in northern counties in Sweden (over 500 individuals per 100 000 population aged 55+).
- Higher prevalence areas were clustered in northern municipalities, whereas municipalities with high prevalence of older individuals with ID in the middle and southern regions of Sweden demonstrated a more widespread distribution.

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The Total Population Register (RTB)

- Statistics Sweden
- Excerpt from the Tax Register
- Vital data on all people in Sweden
  - Personal identification number
  - Age
  - Sex
  - Residence (county, municipality, congregation, house)
  - Civil status
  - Etc

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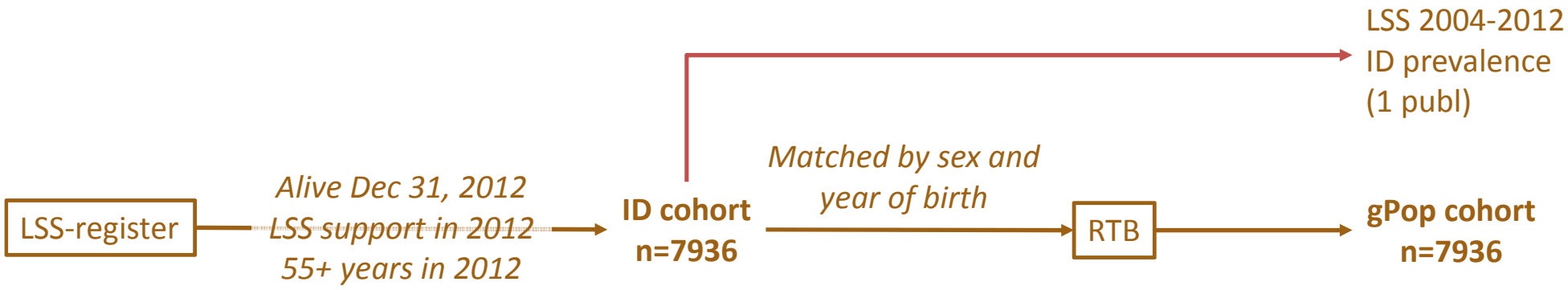

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The National Patient Register (NPR)

- In-patient care since 1987
  - Recorded at discharge
- Outpatient visits since 2001
  - Including day surgery and psychiatric care
- Patient data
- Geographical data
- Administrative data
- Medical data (ICD-10)

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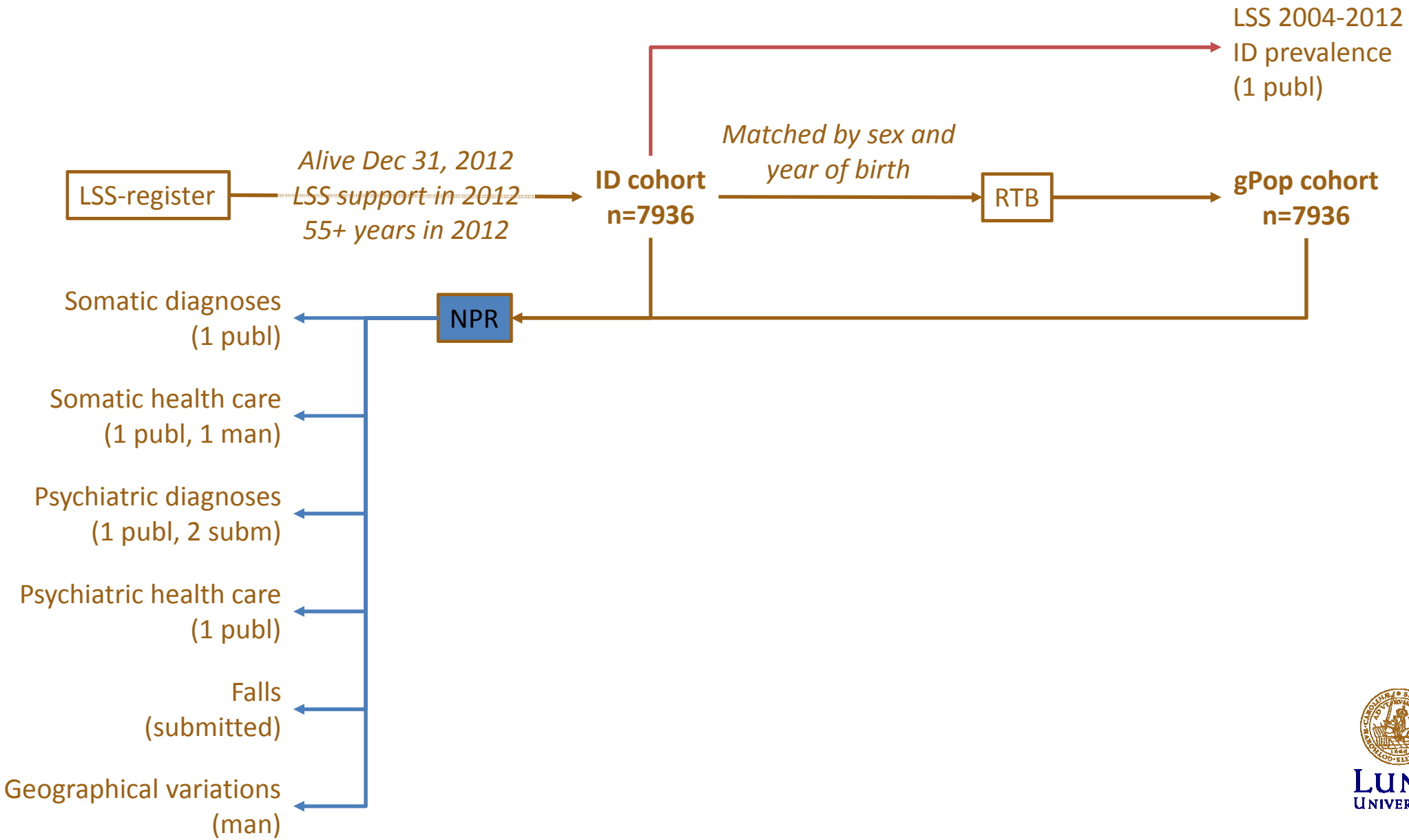

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Sandberg *et al. BMC Health Services Research* (2016) 16:642
DOI 10.1186/s12913-016-1880-x

BMC Health Services Research

RESEARCH ARTICLE Open Access

Somatic healthcare utilisation patterns among older people with intellectual disability: an 11-year register study, 2016 Nov 9;16(1):642. DOI 10.1186/s12913-016-1880-x

Magnus Sandberg (1), Gerd Ahlström (1), Anna Axmon (1,2) Jimmie Kristensson (1,3)

1. Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden
2. Department of Occupational and Environmental Medicine, Lund University, Lund, Sweden
3. Department of Health, Blekinge Institute of Technology, Karlskrona, Sweden

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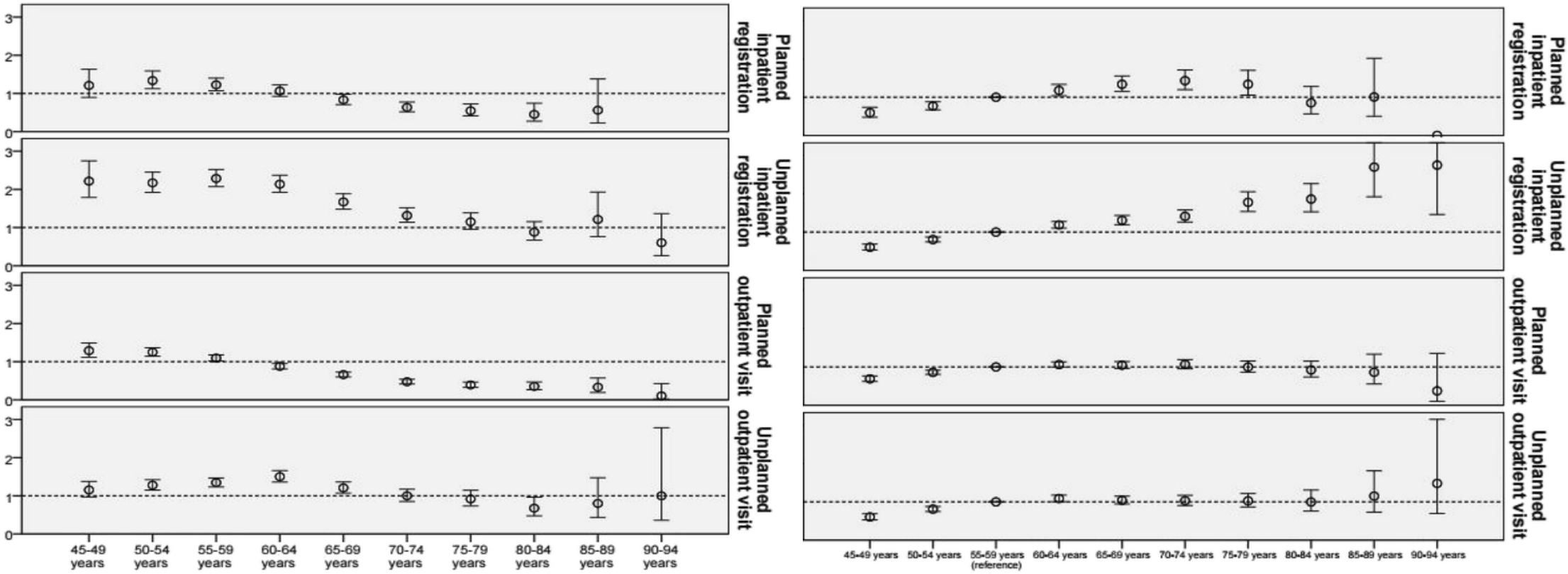
Somatic healthcare utilization



Somatic healthcare utilisation patterns among older people with intellectual disability: an 11-year register study. Sandberg M, Ahlström G, Axmon A, Kristensson J. BMC Health Serv Res. 2016 Nov 9;16(1):642.

Main results *Somatic healthcare utilisation patterns*

- In the younger age groups, the ID group had higher healthcare utilisation compared with the general population sample, with higher risks for planned and unplanned somatic in- and outpatient care, particularly for unplanned inpatient care.

- Decreasing healthcare utilisation were seen with age; with lower risks in the ID group for the oldest age groups.

- In those with at least one health care visit, the ID group had a longer unplanned length of stay in the younger age groups, but fewer planned visits to physicians in somatic outpatient care compared with the control group.

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The Prescribed Drug Register (PDR)

- All dispensed drugs since July 2005
- About 84% of all drug sales
- Patient data
- Geographical data
- Administrative data
- Medical data (ATC)

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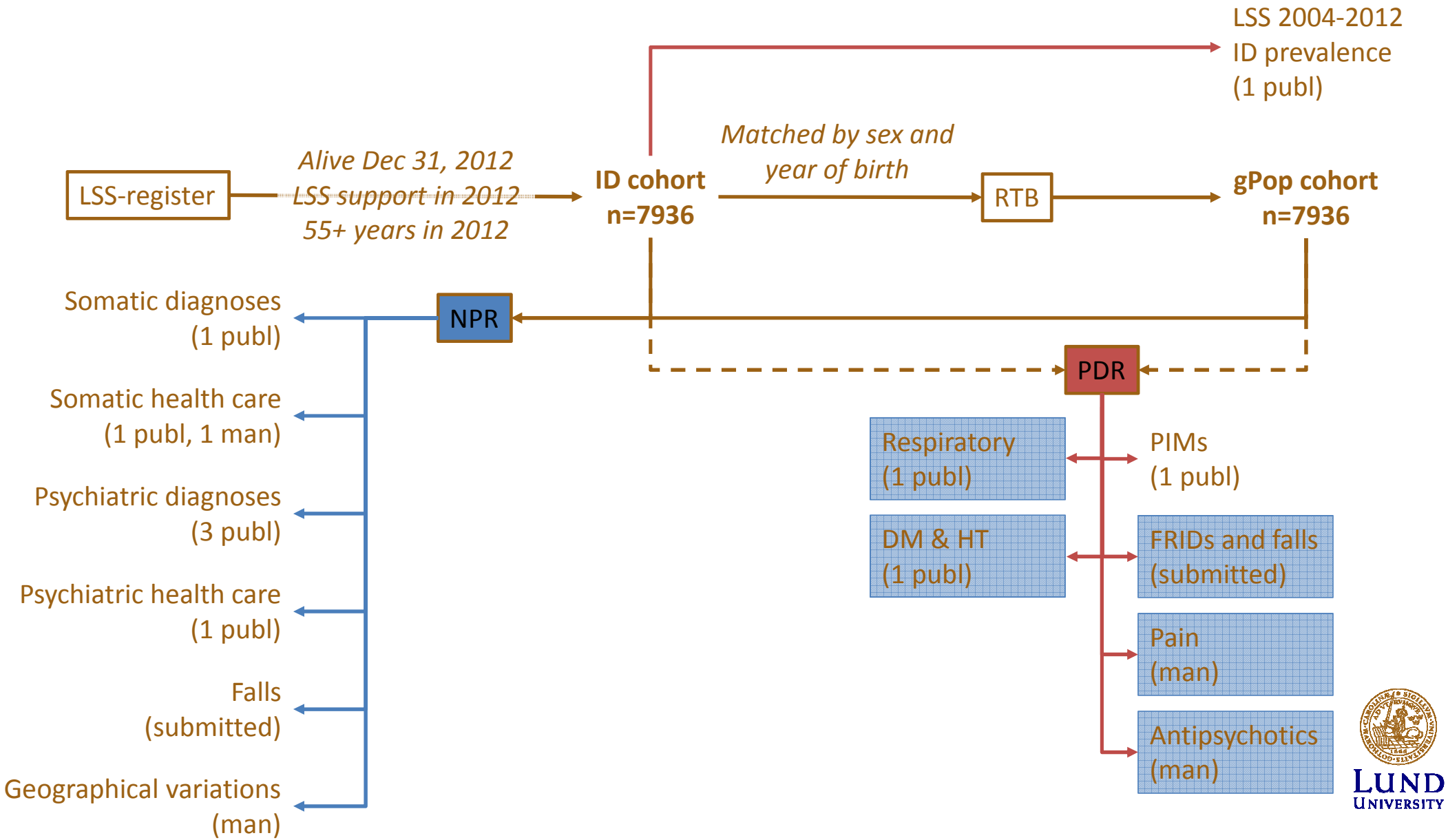
LSS 2004-2012
ID prevalence
(1 publ)
LSS-register
Alive Dec 31, 2012
LSS support in 2012
55+ years in 2012
ID cohort
n=7936
Matched by sex and
year of birth
RTB
gPop cohort
n=7936
NPR
PDR
Somatic diagnoses
(1 publ)
Somatic health care
(1 publ, 1 man)
Psychiatric diagnoses
(3 publ)
Psychiatric health care
(1 publ)
Falls
(submitted)
Geographical variations
(man)
Respiratory
(1 publ)
PIMs
(1 publ)
DM & HT
(1 publ)
FRIDs and falls
(submitted)
Pain
(man)
Antipsychotics
(man)
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Axmon *et al. BMC Geriatrics* (2017) 17:272
DOI 10.1186/s12877-017-0658-2

BMC Geriatrics

RESEARCH ARTICLE Open Access

Prevalence and treatment of diabetes mellitus and hypertension among older adults with intellectual disability in comparison with the general population, (2017) 17:272 DOI 10.1186/s12877-017-0658-2

Anna Axmon (1,2), Gerd Ahlström (2) and Peter Höglund(3)

1. Division of Occupational and Environmental Medicine, Faculty of Medicine, Lund University, SE-221 00 Lund, Sweden
2. Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden

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Main results *Prevalence and treatment of diabetes mellitus (DM) and hypertension (HT)*

- People with ID were 20% more likely than the general population to have a diagnosis of DM, and 26% more likely to have prescription of drugs for DM.
- People in the general population were 81% more likely to have a diagnosis of HT, and 9% more likely to have a prescription of drugs for HT.
- Among those with diabetes, ID was associated with higher occurrence of prescription of insulin combination drugs and sulfonylureas, but lower occurrence of prescription of dipeptidyl peptidase (DPP) 4-inhibitors and exenatide/liraglutide.
- Among those with HT, ID was associated with higher occurrence of prescription of diuretics, but lower occurrence of prescription of calcium channel blockers and angiotensin II antagonists.

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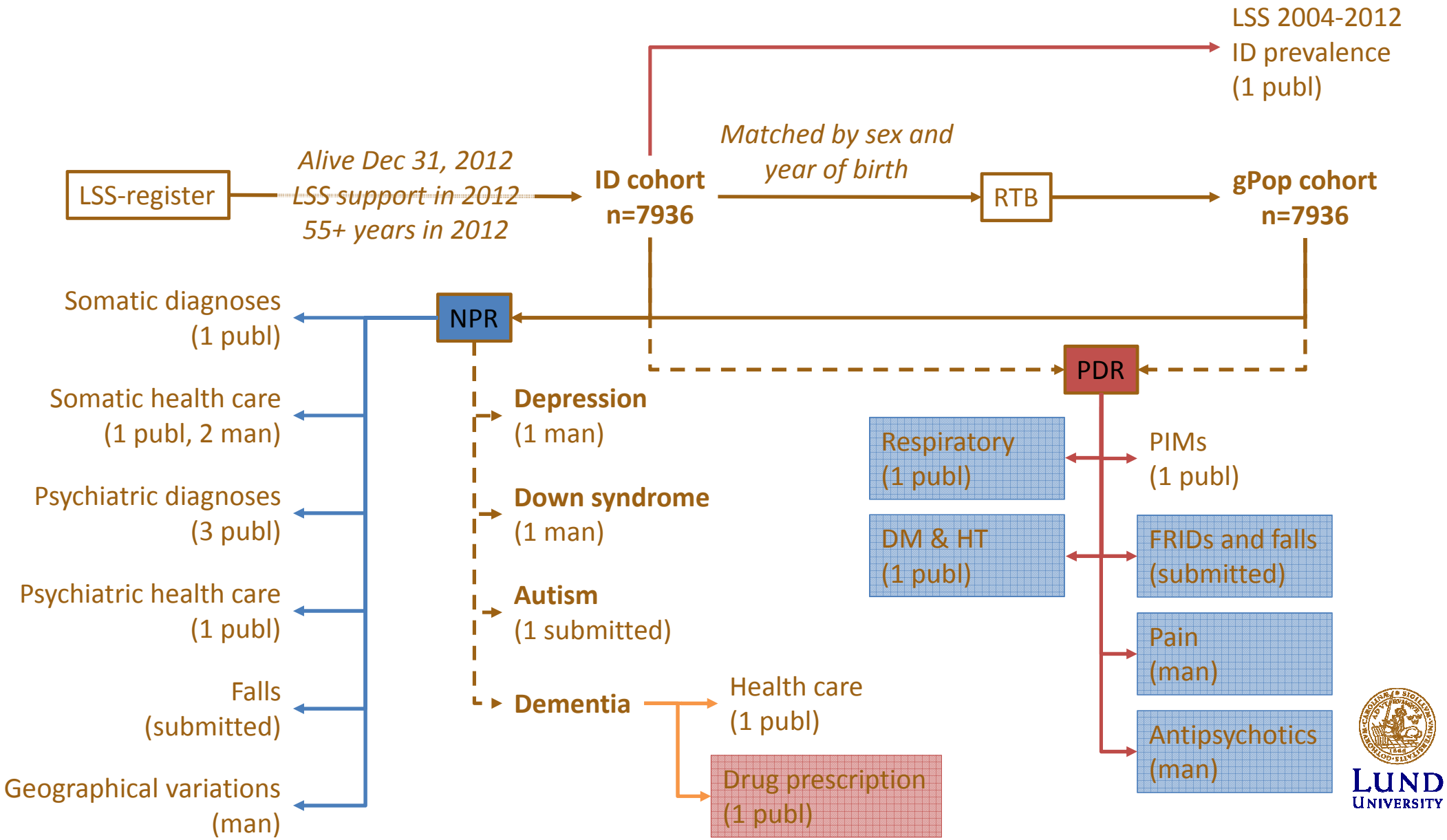
LSS 2004-2012
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Somatic diagnoses
(1 publ)
NPR
Somatic health care
(1 publ, 2 man)
Psychiatric diagnoses
(3 publ)
Psychiatric health care
(1 publ)
Falls
(submitted)
Geographical variations
(man)
Depression
(1 man)
Down syndrome
(1 man)
Autism
(1 submitted)
Dementia
Health care
(1 publ)
Drug prescription
(1 publ)
PDR
Respiratory
(1 publ)
PIMs
(1 publ)
DM & HT
(1 publ)
FRIDs and falls
(submitted)
Pain
(man)
Antipsychotics
(man)
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Contents lists available at ScienceDirect

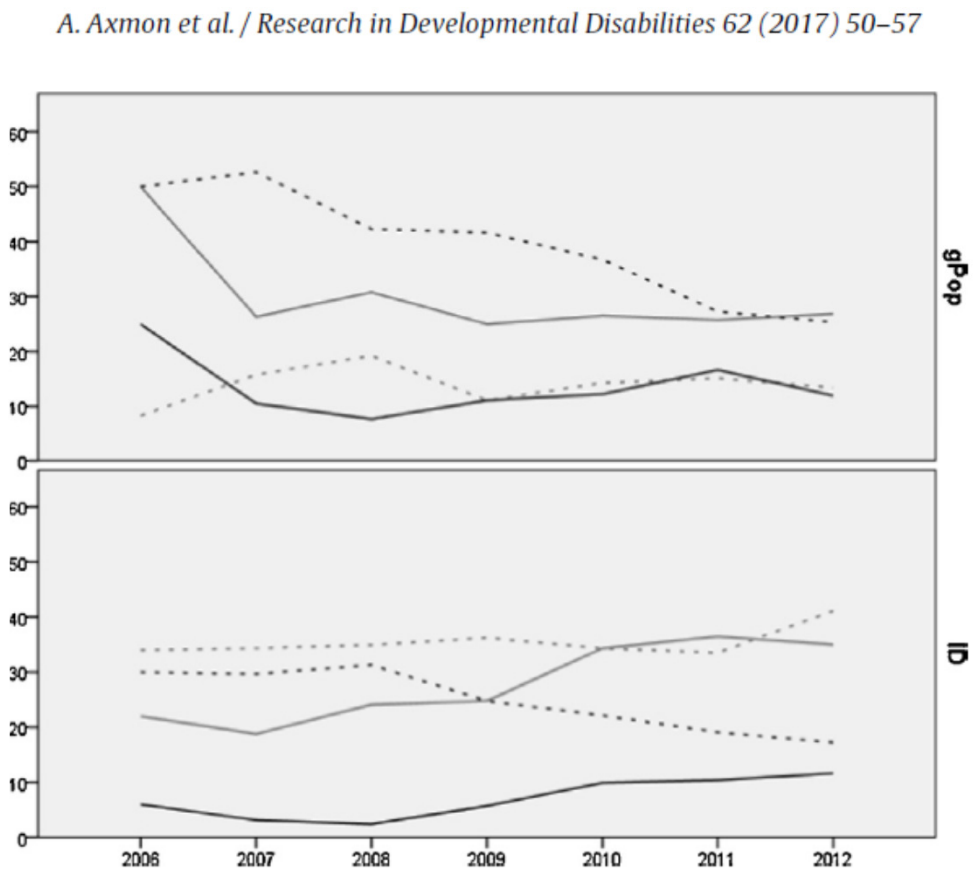
Research in Developmental Disabilities

Use of antipsychotics, benzodiazepine derivatives, and dementia medication among older people with intellectual disability and/or autism spectrum disorder and dementia, 2017 Mar;62:50-57. doi: 10.1016/j.ridd.2017.01.001. Epub 2017 Jan 18.

Anna Axmon (1), Jimmie Kristensson (2), Gerd Ahlström (3), Patrik Midlöv (4)

1. Department of Occupational and Environmental Medicine, Lund University, Lund, Sweden
2. Department of Health, Blekinge Institute of Technology, Karlskrona, Sweden
3. Department of Health Sciences, Faculty of Medicine, Lund University, Lund, Sweden
4. Center for Primary Health Care Research, Department of Clinical Sciences in Malmö, Lund University, Malmö, Sweden.

People with dementia with certain prescriptions



- Percentage of people with dementia with prescriptions of antipsychotics (grey dotted line), benzodiazepine derivatives (grey solid line), anti-cholinesterases (black dotted line), and memantine (black solid line) in a group of people with intellectual disability (ID; bottom) and a general populationsample (gPop; top).

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Main results *Use of antipsychotics, benzodiazepine derivatives, and dementia medication*

- People with ID/ASD and dementia were more likely than people with ID/ASD but without dementia to be prescribed antipsychotics (50% vs 39% over the study period; odds ratio (OR) 1.85, 95% confidence interval 1.13–30.3) and benzodiazepine derivatives (55% vs 36%; OR 2.42, 1.48–3.98).

- They were also more likely than people with dementia from the general population to be prescribed antipsychotics (50% vs 25%; OR 3.18,1.59–6.34), but less likely to be prescribed Acetylcholinesterase inhibitor (AChEIs) (28% vs 45%; OR 0.32, 0.16–0.64).

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The Cause of Death Register

- All deaths among Swedish citizens (in Sweden or abroad) (since 2012 all deaths in Sweden, regardless of citizenship)
- Started in 1961
- Cause of death (ICD-10)
- Geographical data
- Administrative data

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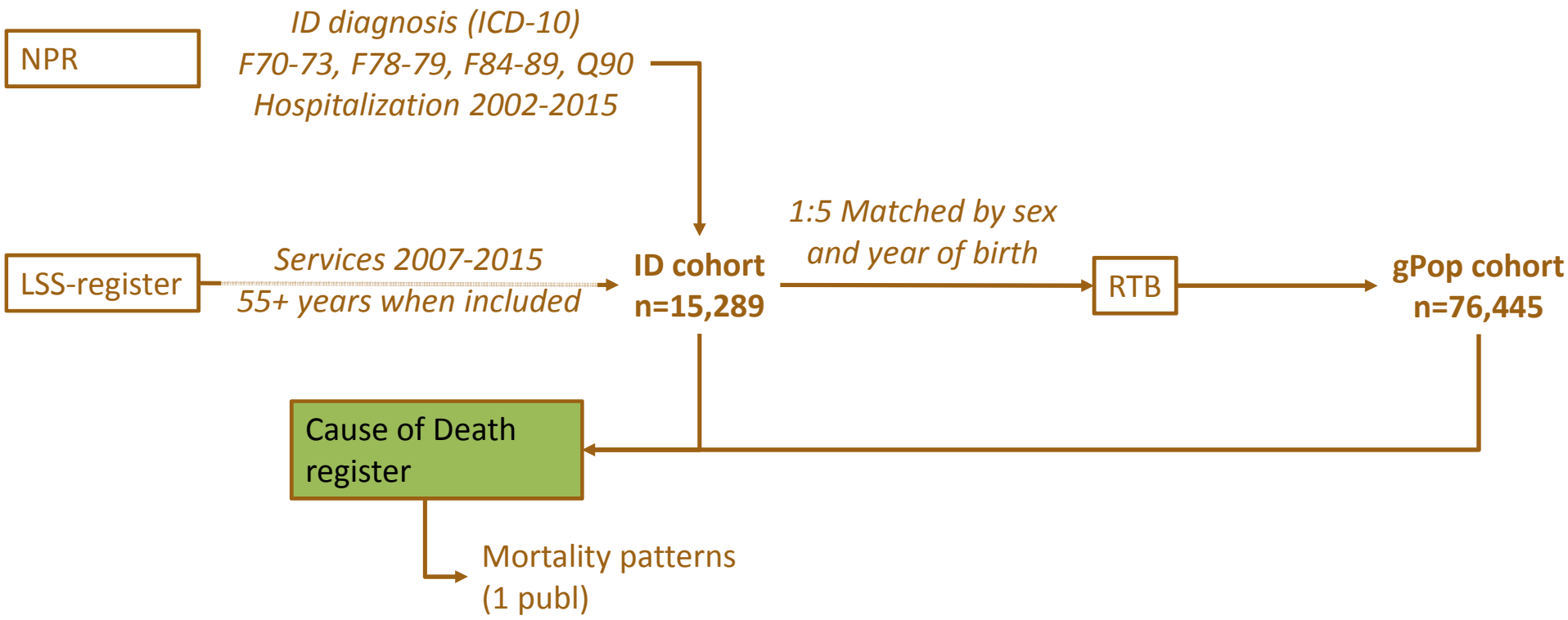

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Ng et al. BMC Geriatrics (2017) 17:269
DOI 10.1186/s12877-017-0665-3

BMC Geriatrics

RESEARCH ARTICLE Open Access

Mortality patterns and risk among older men and women with intellectual disability: a Swedish national retrospective cohort study,

2017 Nov 22;17(1):269. doi: 10.1186/s12877-017-0665-3.

Nawi Ng (1,2), Eva Flygare Wallin (3) and Gerd Ahlström (4)

1. Unit of Epidemiology and Global Health, Department of Public Health
2. Clinical Medicine, Faculty of Medicine, Umeå University, SE-901 87 Umeå, Sweden.
3. Karolinska Institutet (KI), Department of Neurobiology, Care Sciences and Society (NVS), Division of Family Medicine and Primary Care, Alfred Nobels allé 23, D2, SE-141 83 Huddinge, Sweden.
4. Department of Health Sciences, Faculty of Medicine, Lund University, P.O. Box 157, SE-221 00 Lund, Sweden.

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GA1

Main results *Mortality patterns and risk among older men and women with intellectual disability*

- The overall mortality rate among individuals with ID was 2483 per 100,000 people compared with 810 in the control population.
- Among those who died, more individuals with ID were younger than 75 years and unmarried.
- Leading causes of death among individuals with ID were circulatory diseases (34%), respiratory diseases (17%) and neoplasms (15%).
- Leading causes of death in a sub-sample with Down syndrome (DS) were respiratory diseases (37%), circulatory diseases (26%) and mental/behavioural disorders (11%).
- Epilepsy and pneumonitis were more common among individuals with ID than controls.
- Alzheimer's disease was common in the control population and individuals with DS, but not among those with ID when DS was excluded.
- Individuals with ID had a higher overall mortality risk (hazard ratio [HR] 4.1, 95% confidence interval [CI] 4.0–4.3) and respiratory disease death risk (HR 12.5, 95% CI 10.9–14.2) than controls.

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Bild 36

GA1 Care for this group, particularly during the terminal stage of illness, needs to be tailored based on understanding of their main health problem.

Gerd Ahlström; 18-01-24

Summary

- 6 registries
- 15 researchers/authors
- 5 (3?) year project
- 13 accepted publications
- 3 submitted papers
- 7 papers in manuscript

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Publication list

1. Prevalence and treatment of diabetes mellitus and hypertension among older adults with intellectual disability in comparison with the general population. Axmon A, Ahlström G, Höglund P. BMC Geriatr. 2017 Nov 23;17(1):272. doi: 10.1186/s12877-017-0658-2.
2. Mortality patterns and risk among older men and women with intellectual disability: a Swedish national retrospective cohort study. Ng N, Flygare Wallén E, Ahlström G. BMC Geriatr. 2017 Nov 22;17(1):269. doi: 10.1186/s12877-017-0665-3.
3. Prescription of potentially inappropriate medications among older people with intellectual disability: a register study. Axmon A, Sandberg M, Ahlström G, Midlöv P. BMC Pharmacol Toxicol. 2017 Oct 25;18(1):68. doi: 10.1186/s40360-017-0174-1.
4. Psychiatric diagnoses in relation to severity of intellectual disability and challenging behaviors: a register study among older people. Axmon A, Björne P, Nylander L, Ahlström G. Aging Ment Health. 2017 Aug 21:1-7. doi: 10.1080/13607863.2017.1348483. [Epub ahead of print]
5. Chronic Respiratory Disorders and Their Treatment among Older People with Intellectual Disability and/or Autism Spectrum Disorder in Comparison with the General Population. Axmon A, Höglund P, Ahlström G. Healthcare (Basel). 2017 Aug 1;5(3). pii: E40. doi: 10.3390/healthcare5030040.
6. Gender differences in psychiatric diagnoses in older people with intellectual disability: a register study. Axmon A, Sandberg M, Ahlström G. BMC Psychiatry. 2017 May 22;17(1):192. doi: 10.1186/s12888-017-1353-8.
7. Psychiatric diagnoses in older people with intellectual disability in comparison with the general population: a register study. Axmon A, Björne P, Nylander L, Ahlström G. Epidemiol Psychiatr Sci. 2017 Feb 23:1-13. doi: 10.1017/S2045796017000051. [Epub ahead of print]
8. Use of antipsychotics, benzodiazepine derivatives, and dementia medication among older people with intellectual disability and/or autism spectrum disorder and dementia. Axmon A, Kristensson J, Ahlström G, Midlöv P. Res Dev Disabil. 2017 Mar;62:50-57. doi: 10.1016/j.ridd.2017.01.001. Epub 2017 Jan 18.
9. Somatic healthcare utilisation patterns among older people with intellectual disability: an 11-year register study. Sandberg M, Ahlström G, Axmon A, Kristensson J. BMC Health Serv Res. 2016 Nov 9;16(1):642.
10. Psychiatric care utilization among older people with intellectual disability in comparison with the general population: a register study. Axmon A, Björne P, Nylander L, Ahlström G. BMC Psychiatry. 2016 Nov 9;16(1):389.
11. Health care utilisation among older persons with intellectual disability and dementia: a registry study. Axmon A, Karlsson B, Ahlström G. J Intellect Disabil Res. 2016 Dec;60(12):1165-1177. doi: 10.1111/jir.12338. Epub 2016 Oct 11.
12. Patterns of Somatic Diagnoses in Older People with Intellectual Disability: A Swedish Eleven Year Case-Control Study of Inpatient Data. Sandberg M, Ahlström G, Kristensson J. J Appl Res Intellect Disabil. 2017 Jan;30(1):157-171. doi: 10.1111/jar.12230. Epub 2015 Nov 6. Erratum in: J Appl Res Intellect Disabil. 2017 Jul;30(4):786.
13. Prevalence of older people with intellectual disability in Sweden: a spatial epidemiological analysis. Ng N, Sandberg M, Ahlström G. J Intellect Disabil Res. 2015 Dec;59(12):1155-67. doi: 10.1111/jir.12219. Epub 2015 Aug 26.

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Thank you for your attention!

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Table 1. Characteristics of the two groups at baseline (2002) and mortality during the follow-up period (up to 2015)

		Individuals with intellectual disability (n=15,289) n (%)			Matched control population (n=76,445) n (%)
		Sub-sample of individuals with DS (n=942) n (%)	Sub-sample of individuals with ID (DS excluded) (n=14,347) n (%)	All individuals with ID (n=15,289) n (%)	
Sex	Men	486 (51.6)	7,844 (54.7)	8,330 (54.5)	41,650 (54.5)
	Women	456 (48.4)	6,503 (45.3)	6,959 (45.5)	34,795 (45.5)
Age group in 2002	42 – 44 year	88 (9.3)	1,720 (12)	1,808 (11.8)	9,040 (11.8)
	45 – 54 year	440 (46.7)	6,044 (42.1)	6,484 (42.4)	32,420 (42.4)
	55 – 64 year	360 (38.2)	4,182 (29.2)	4,542 (29.7)	22,710 (29.7)
	65 – 74 year	50 (5.3)	1,755 (12.2)	1,805 (11.8)	9,025 (11.8)
	75 – 79 year	1 (0.1)	401 (2.8)	402 (2.6)	2,010 (2.6)
	80+ year	3 (0.3)	245 (1.7)	248 (1.6)	1,240 (1.6)
Mean age at death (standard deviation)*		63.5 (5.4)	72.1 (9.4)	70.7 (9.5)	76.2 (10.3)
Number of deaths during 2002-2015 (%)		761 (80.8)	3,977 (27.7)	4,738 (31.0)	8,364 (10.9)
Mortality rate during 2002-2015 (per 100,000 people)*		8,600	2,186	2,483	810

Note: * significantly differences (p<0.001).

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