



Primary care for people with ID

Meet John, a patient with ID, through four different perspectives from primary care.

Marloes Heutmekers, Milou van den Bemd, Monique Koks-Leensen, Marian Breuer

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Academic collaborative Intellectual disability and Health - Sterker op Eigen Benen (SOEB)*

Meet John



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Meet John

- Male
- 36 years old
- Lives alone
- Works 5 days a week in a factory
- Likes gaming in his free time



Meet John

- Intellectual disability



Intellectual disabilities in NL (Wottiez, 2019)

- IQ < 70: 440.000 people
- IQ 70-85 & significant limitations in adaptive skills: 730.000
- In total, 1.17 million people in NL with ID, 6.4% of Dutch population
- Average GP practice: 120-200 patients

Meet John

- Intellectual disability
- Formal carer 2 times/week
- One friend through internet
- No contact with his family



John visits GP regularly

- Slightly obese
- Experiences hearing loss since 1 month
- Has diabetes since 3 years
- Has panic attacks



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Health problems and consultation patterns of people with intellectual disabilities in Dutch primary care

Marloes Heutmekers, ID physician, PhD

B. Schalk, A. Uijen, G. Leusink, J. Naaldenberg, M. Cuypers

Introduction

- Health problems at general problems
 - 20 years ago
 - Importance article
- Lots of changes since then
 - Electronic registration
 - Changes in healthcare
 - Entering specialist ID physician

Health problems of people with intellectual disabilities: the impact for general practice

Jos MJAA Straetmans, Henny MJ van Schrojenstein Lantman-de Valk, Francois G Schellevis and Geert-Jan Dinant

Table 1. Prevalence of top 10 diagnoses, per 1000 people with intellectual disabilities, compared with the control group.

ICPC code	Per 1000 patients	
	With ID (n = 868)	Control (n = 4305)
Epilepsy	172.8	3.2
Dermatomycosis	123.2	55.5
Diabetes mellitus	111.7	61.5
Acute infection of upper respiratory tract	109.4	62.4
Excess cerumen	95.6	29.5
Eczema by contact/other eczema	86.4	51.3
No illness	76.0	20.6
Insomnia/other sleeping disorder	69.1	20.4
Other infection of skin/subcutis/erysipelas	69.1	9.7
Medication/prescription/injection	67.9	23.0

All diagnoses shown are significantly more frequently diagnosed in people with intellectual disabilities, χ^2 test, $P < 0.001$. ICPC = International Classification of Primary Care. ID = intellectual disability.

Goal

What health problems do people with ID present with in general practice compared with patients without ID?

Source

- General practice dataset Radboudumc with more than 80 general practices with more than 400,000 patients
 - health problems were routinely registered using ICPC

Study design

Retrospective dynamic cohort study

- Study populatie: adult patients or at least 1 year during the study periode
- Study period: 10 years (2012-2021)
- Matching: 1:5, gender, age (+/- 1 jaar), same general practice, presence in practice in the same period

Identification

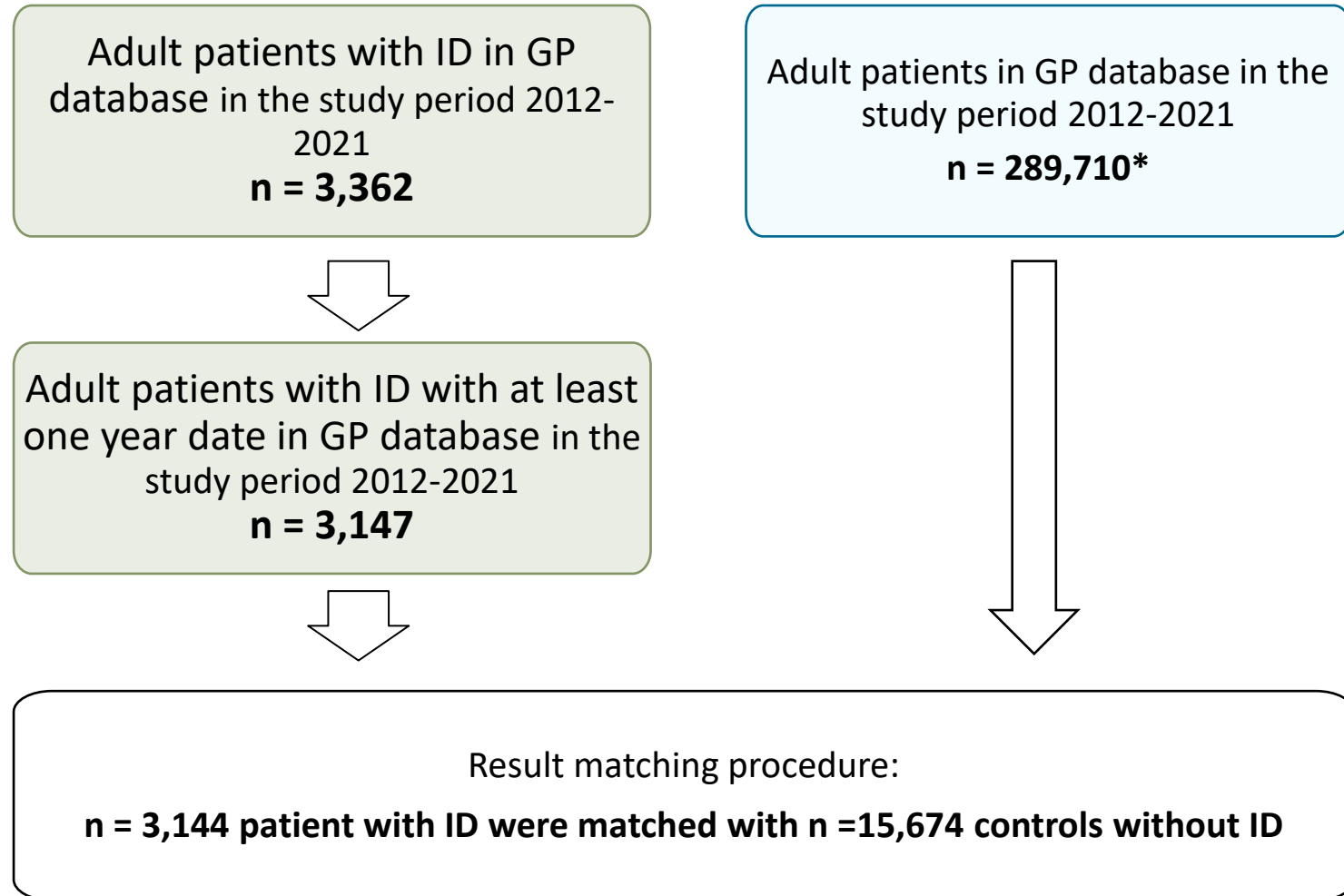
- Intellectual disability P85
- Down syndrome A90.01
- Combination of ICPC¹ codes & the title of an episode
 - *For example if a patient has code P24 and the title of the episode is amended to:*
 - *A specific syndrome like Prader-Willi, Sotos syndrome*
 - *Intellectual limited, low IQ, psychomotore limitation*

ICPC-code	Description
P24	Specific learning problem
P28	Limited function/ disability (p)
P29	Psychological symptom/ complaint other
P85	Mental retardation/ intellectual disability
P99	Psychological disorders, other

Gegevens

- Patient characteristics & number of contacts
- Top 10 complaints and diagnosis
- Per ICPC chapter
- Top 10 prescriptions

Inclusion



Preliminary results

- Prevalence of ID in general practice: 1.2% (3,362/289,710)
 - Mean is 29 patients with ID per practice (range 2-249)
 - 77% of these patients are 55 years and younger
 - The average contact frequency per year for all types of contacts combined was 6.5 for patients with ID and 3.0 for the matched controls
- patients with ID had contact with the GP 2.2 times more often

Top 10 health problems

	Patients with ID (n=3,144)		Matched controls without ID (n=15,674)		RR (95% CI)
	n	%	n	%	
Diagnoses and conditions					
1 No disease (A97)	1,587	50.5	5,006	31.9	1.58 (1.40-1.67)
2 Upper respiratory infection acute (R74)	819	26.0	2,912	18.6	1.40 (1.30-1.52)
3 Dermatophytosis (S74)	663	21.1	2,262	14.4	1.46 (1.34-1.59)
4 Dermatitis contact/allergic (S88)	657	20.9	2,972	19.0	1.10 (1.01-1.20)
5 Excessive ear wax (H81)	605	19.2	2,107	13.4	1.43 (1.31-1.57)
6 Injury musculoskeletal NOS (L81)	566	18.0	2,079	13.3	1.36 (1.24-1.49)
7 Allergic rhinitis (R97)	543	17.3	2,806	17.9	0.96 (0.88-1.06)
8 Cystitis/urinary infection other (U71)	542	17.2	1,916	12.2	1.41 (1.28-1.55)
9 Musculoskeletal disease other (L99)	509	16.2	2,275	14.5	1.12 (1.01-1.23)
10 Depressive disorder (P76)	470	14.9	1,261	8.0	1.86 (1.67-2.07)
Complaints and symptoms					
1 Weakness/tiredness general (A04)	736	23.4	2,551	16.3	1.434 (1.33-1.56)
2 Foot/toe symptom/complaint (L17)	650	20.7	2,277	14.5	1.42 (1.30-1.55)
3 Cough (R05)	646	20.5	2,499	15.9	1.29 (1.18-1.41)
4 Chest symptom/complaint (L04)	573	18.2	2,277	14.5	1.25 (1.14-1.37)
5 Laceration/cut (S18)	498	15.8	1,961	12.5	1.27 (1.15-1.40)
6 Back symptom/complaint (L02)	497	15.8	1,804	11.5	1.37 (1.24-1.52)
7 Knee symptom/complaint (L15)	486	15.5	2,078	13.3	1.17 (1.06-1.29)
8 Abdominal pain localized other (D06)	470	14.9	1,636	10.4	1.43 (1.29-1.59)
9 Hand/finger symptom/complaint (L12)	470	14.9	1,702	10.9	1.38 (1.24-1.52)
10 Shoulder symptom/complaint (L08)	459	14.6	1,891	12.1	1.21 (1.09-1.34)

Comparing

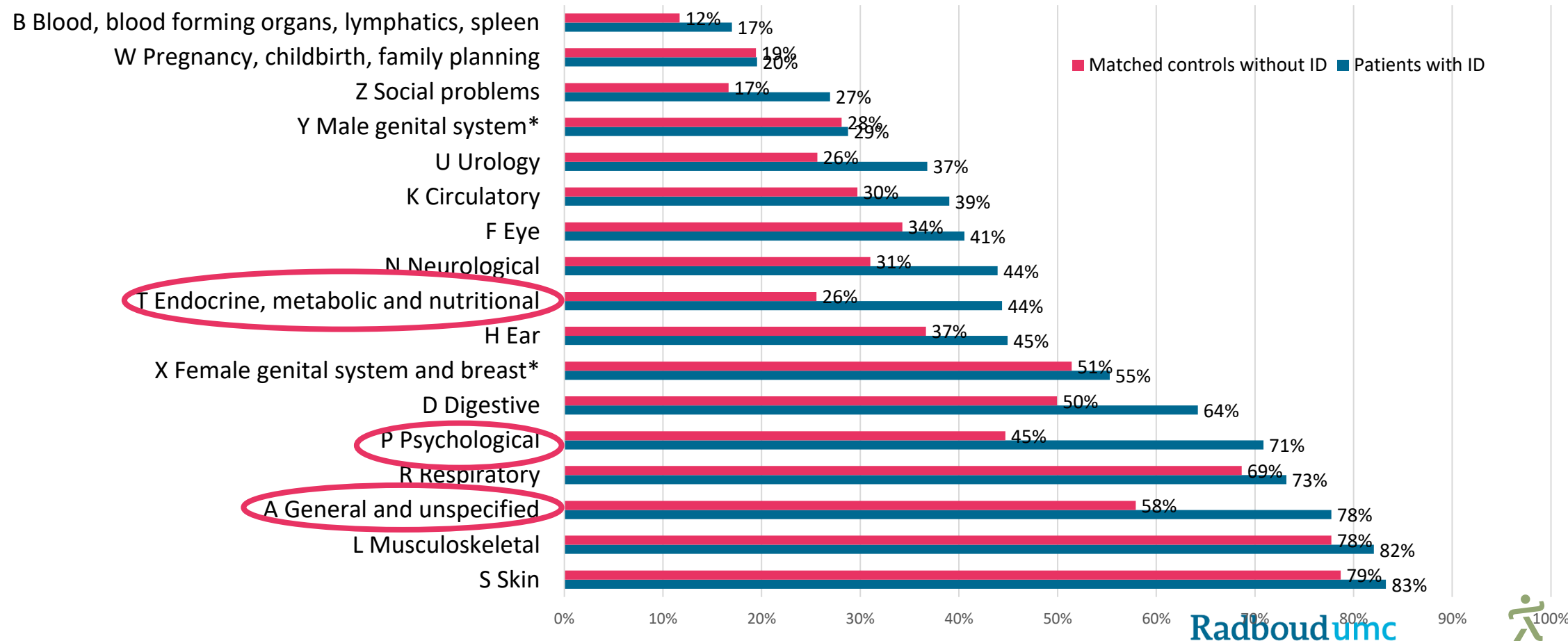
Diagnoses and conditions		%
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ICPC hoofdstukken



Prescriptions

N05: antipsychotics,
anxiolytics, and
hypnotics and
sedatives

N06:
antidepressants,
psychostimulants,
anti-dementia drugs

		Patients with ID (n=3,054)		Matched controls without ID (n=14,965)	
		n	%	N	%
1	Antibacterials for systemic use (J01)	1,919	62.8	8,147	54.4
2	Vaccines (J07)	1,856	60.8	10,324	69.0
3	Antiinflammatory and antirheumatic products (M01)	1,727	56.5	7,613	50.9
4	Psycholeptics (N05)	1,443	47.2	3,158	21.1
5	Drugs for acid related disorders (A02)	1,328	43.5	4,612	30.8
6	Corticosteroids, dermatological preparations (D07)	1,218	39.9	5,180	34.6
7	Drugs for constipation (A06)	1,132	37.1	3,538	23.6
8	Antifungals for dermatological use (D01)	1,091	35.7	3,798	25.4
9	Analgesics (N02)	1,080	35.4	3,916	26.2
10	Psychoanaleptics (N06)	1,029	33.7	2,312	15.4

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Discussion

What about 20 years later?

- The most commonly presented health problems fall within the scope of the general practitioner, but there is a need for expertise in psychological and psychiatric health problems in ID.
- There is a possible increase in contact frequency (1,7 > 2,2x higher in ID)
- Health problems are similar, but we no longer see DM and epilepsy in the top 10
- Medication is consistent, but prescriptions for antiepileptics and anticonvulsants went missing

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- Experiences hearing loss since 1 month
- **Has diabetes since 3 years**
- Has panic attacks
- His GP experiences difficulties in providing appropriate care

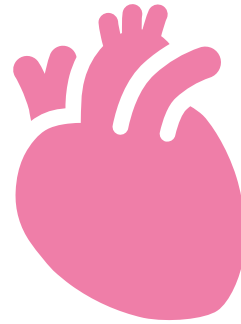


Chronic diseases in people with ID in general practice: Prevalence and care needs

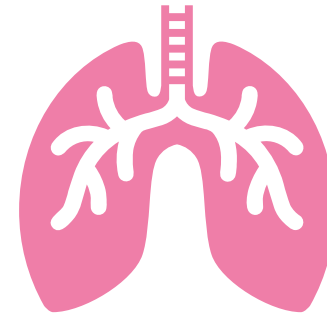
Dr. Milou van den Bemd
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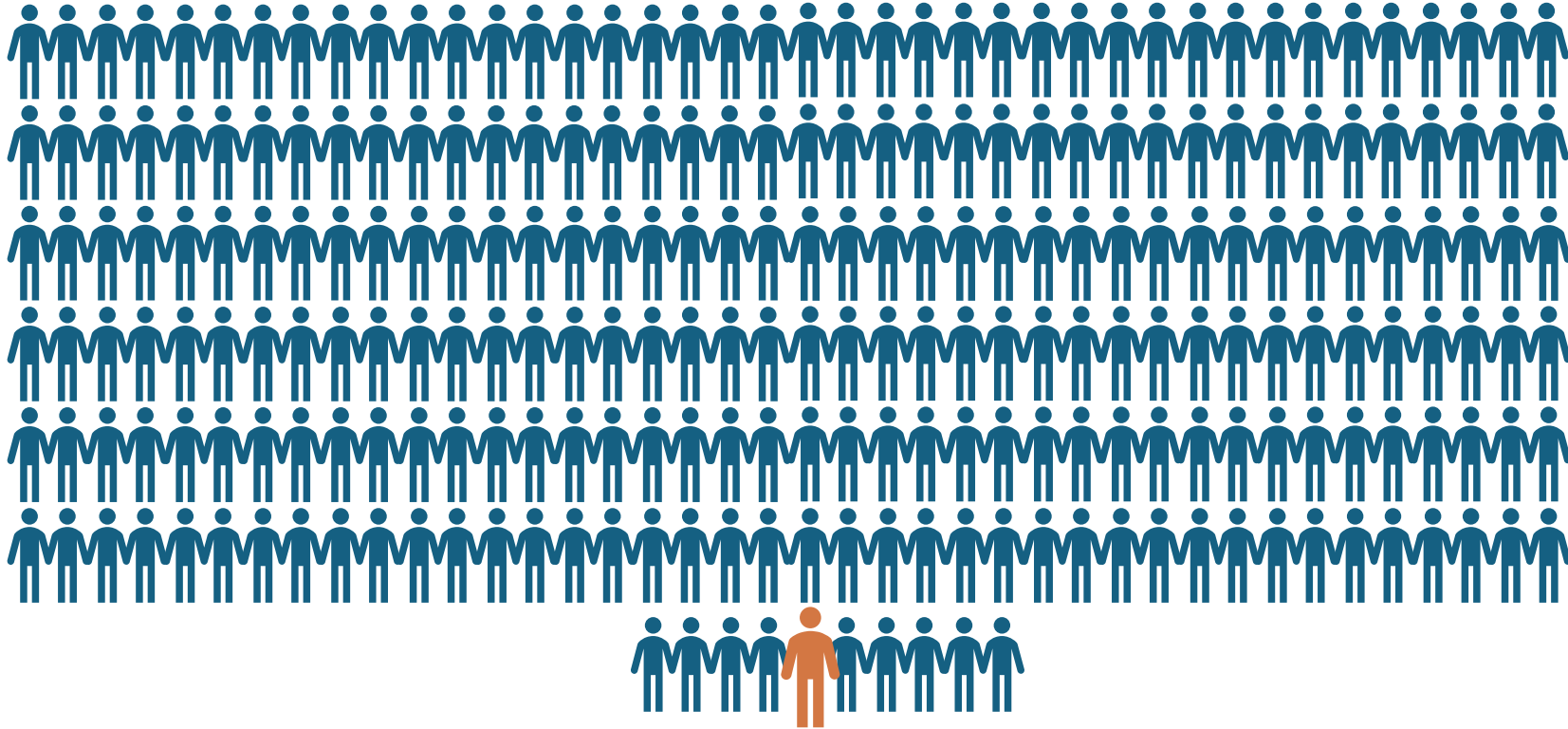
**Diabetes
type 2**



Heart disease



COPD



1 every 250
has diabetes



1 every 5
has diabetes

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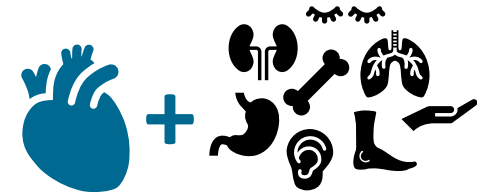
Inconsistencies in the literature



How often are chronic diseases occurring?



More often in people with or without ID?



Comorbidities?

Care needs

- Uncertainty surrounding care needs
- Essential for suitable chronic disease management

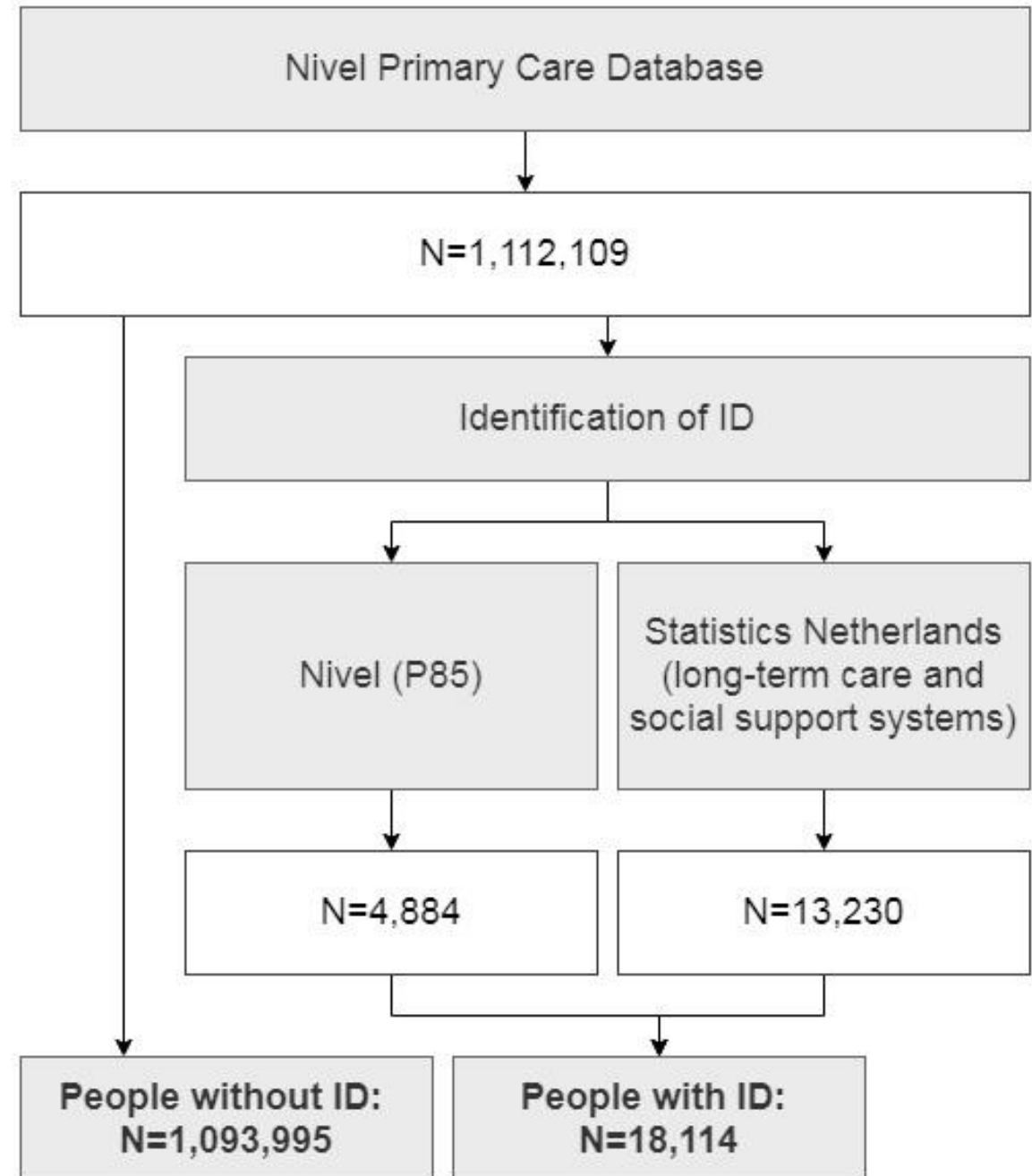
Objectives

- Study 1 – to examine **chronic disease prevalence** and **comorbidity patterns** by age and sex in people with and without ID;
- Study 2 – to explore the **needs of patients with ID** from perspectives of both patients and of healthcare providers (HCPs) in the context of chronic disease management in general practice.

Study 1 – prevalence of chronic diseases

Study 1 – Methods

- Nivel Primary Care Database
- 1,1 million patients registered in 420 general practices (2021)
- National population database (Statistics Netherlands)
- Indication for long-term ID-related care



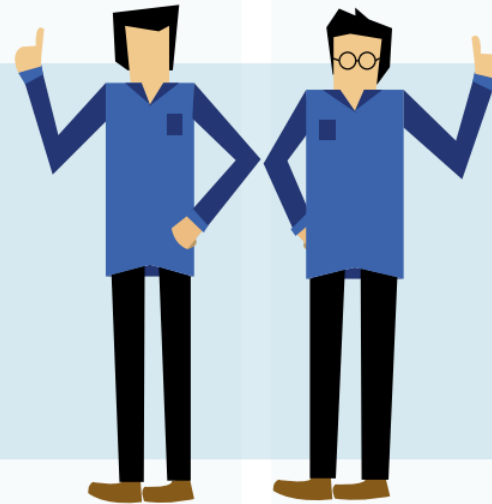
Study 1 – Methods

- Chronic disease = occurrence of diagnosis in medical file in 2018 of:
 - Ischaemic heart disease (IHD)
 - Cerebrovascular disease (CVD)
 - Diabetes mellitus (DM)
 - Chronic obstructive pulmonary disease (COPD)
- Comorbidities (108 via algorithm)
 - % people with 2 or more comorbidities

Study 1 – How often are chronic diseases occurring?

People with intellectual disabilities

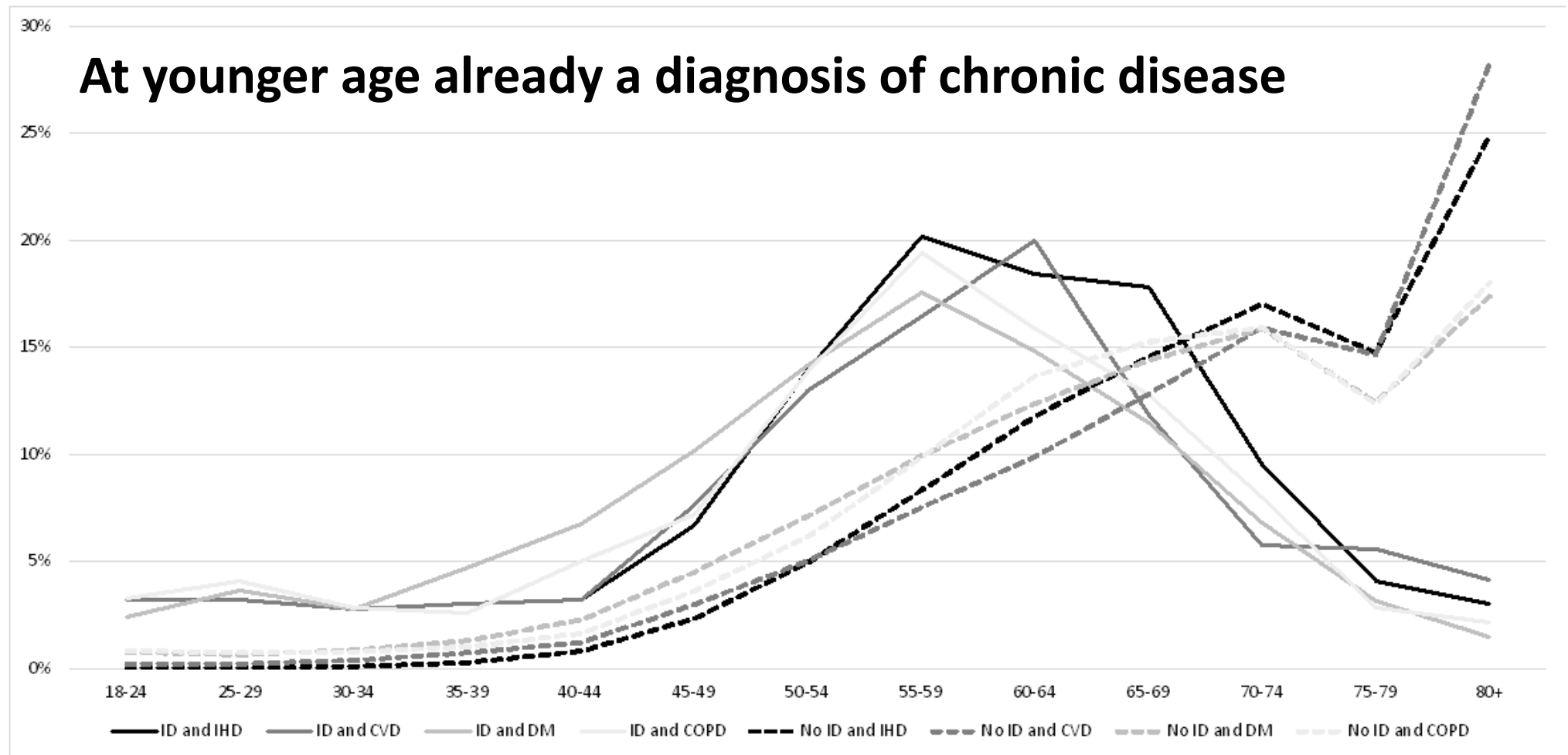
18,114 people, of which
2,653
(14.9%) have at least one
chronic disease



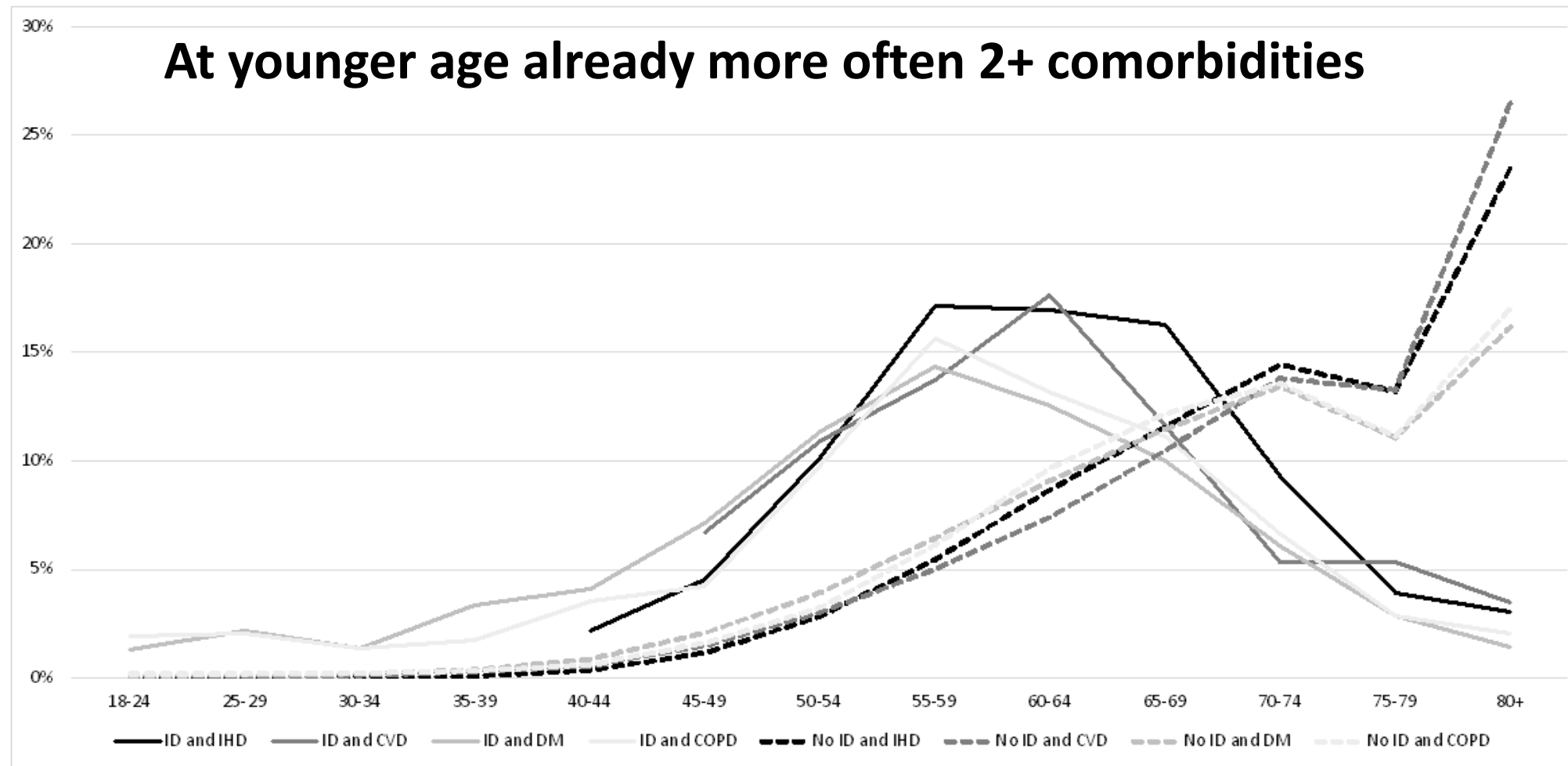
People without intellectual disabilities

1,093,995 people, of which
184,681
(16.9%) have at least one
chronic disease

Study 1 – How often are chronic diseases occurring?



Study 1 – How often are comorbidities occurring?



ANNOUULIUM

Study 1 – Most common comorbidities (ranked)

	IHD	CVD	DM	COPD
Hypertension	1	1	1	1
Diabetes mellitus				
Lipid disorder				
Epilepsy				
Asthma				

Summary study 1

People with intellectual disabilities:

Chronic diseases are more often occurring at **younger ages**



People **more often** have multiple diseases at the same time



Men most often have one or more chronic diseases



Study 1 – Implications




- Different disease patterns
 - Particularly younger people
- Awareness of differences between people with and without ID
- Collaboration between GPs and care professionals in specialised ID-care (i.e. ID physician)



Family Practice, 2022, **39**, 1056–1062
<https://doi.org/10.1093/fampra/cmab042>
Advance access publication 17 May 2022
Epidemiology

OXFORD

Chronic diseases and comorbidities in adults with and without intellectual disabilities: comparative cross-sectional study in Dutch general practice

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Study 2 – patients' care needs

Study 2 – Care needs

- Uncertainty surrounding care needs
- Essential for suitable chronic disease management

Study 2 – Methods

- **Face-to-face interviews with patients (n=14)**
 - 18+ years
 - Chronic disease (cardiovascular disease, diabetes mellitus, asthma/COPD)
 - Actively received chronic disease management
 - Could communicate verbally in an interview
 - Borderline/mild/moderate ID

Study 2 – Methods

- **Focus groups with primary healthcare providers (n=32)**
 - General practitioners
 - Practice nurses
 - Provide chronic disease management to patients with (suspected) ID
- Purposive sampling: variation in perspectives and backgrounds (age, sex, living arrangement, diagnosis, experience with ID)
- Reflexive thematic analysis

Study 2 – Results

1. **Trusting relationship** between patient and healthcare provider
2. Clear **expectations**
3. Support in **chronic disease management**
4. Directive **decision-making processes**
5. Support in maintaining and achieving a **healthy lifestyle**
6. **Accessible** medical information

Study 2 – Patients' care needs



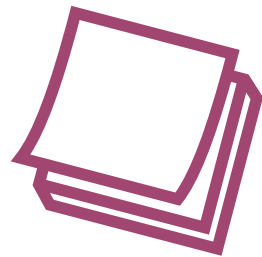
Easy language = trust



Support



“The doctor knows what’s best”



Accessible information

Study 2 – Implications

- Awareness of more complex care needs
- Increased consultation time
- Supported decision making (not paternalism)
- Access to / knowledge of easy-language information



Research | [Open access](#) | Published: 14 June 2024

Care needs of chronically ill patients with intellectual disabilities in Dutch general practice: patients' and providers' perspectives

[Milou van den Bemd](#) , [Monique Koks-Leensen](#), [Maarten Cuypers](#), [Geraline L. Leusink](#), [Bianca Schalk](#) & [Erik W. M. A. Bischoff](#)

BMC Health Services Research **24**, Article number: 732 (2024) | [Cite this article](#)

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John visits GP regularly

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- **Has panic attacks**
- His GP experiences difficulties in providing appropriate care



Primary mental health care to people with mild intellectual disabilities

Dr. Monique Koks-Leensen - Presenting the work of Katrien Pouls Mathilde Mastebroek, Suzanne Ligthart, Pim Assendelft, Geraline Leusink

Mental health in people with Mild-ID

People with Mild-ID:

- Experience more MH problems than the general population
- Do often not receive appropriate care
- Psychotropic use is high

- Insights into MH care for people with MID is needed
- Focus on primary care: GP is first to encounter and essential in MH care

Primary mental healthcare to people with MID

Is complex

- GPs do not feel equipped
- MID is not always recognized
- Diagnostic overshadowing



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Aim

- Provide insight into the quantitative and qualitative characteristics of MH care for people with MID, with a main focus on the Dutch primary care setting.
- The findings may provide guidance to improve MH care for people with MID

3 studies providing more insight into



Quantitative characteristics of primary mental healthcare diagnosis and care provision



Primary mental healthcare experiences from interviews with patients with MID and MH problems



Qualitative characteristics of primary mental healthcare from focus groups with health care providers

Study 1 - Quantitative methods

- MID identification
 - SN-MID database, 2015

	MID	No-ID
n	11,877	1,464,196

Study 1 - Quantitative methods

- MID identification
 - SN-MID database, 2015
 - Checked for P85 medical record

	MID	No-ID
n	11,877	1,464,196
No GP registration of ID	80,3%	

- Outcome measures primary care
 - Having one or more MH problems: ICPC-P codes
 - Number and type of consultations
 - Number and type of medication prescriptions

Study 1 - most striking results

People with MID reported

- MH problems more often 49% vs 30%
- MH problems at a younger age 37y vs 51y
- Multiple MH problems 2.0 vs 1.0

People with MID and MH problems reported

- A higher number of GP consultations 6.4 vs 4.0
- A higher number of psychotropics 55% vs 48% - 2.7 vs 2.0

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Study 1 - Conclusions

- Half of the patients with MID showed mental health problems
- This group visited GP more often -> high demand on GP
- Is this indication of higher / different care needs?
- Do healthcare providers recognize and meet these?
- Additional qualitative research to interpret these findings perspectives of patients (study 2) & care professionals (study 3)

Study 2 & 3 - Qualitative characteristics

Focus of this research:

- Patients', GPs' and practice nurses' experiences, needs, and suggestions for improvement regarding primary MH care to people with MID
- Study 2 - 11 semi-structured interview with MH-patients with MID
- Study 3 - 4 focus groups with GPs (n=19) and practice nurses (n=9)

Study 2 & 3 - Overarching themes



Vulnerable and complex



GP-patient relationship



Patient's network



Organisation of care

Overall experiences



- Feeling vulnerable
 - Do I have an MH problem?
 - GPs' accessibility for MH problems
 - Difficult to talk with my GP
 - What to do with the GP advice?



- Complex patients
 - No clear reason for encounter
 - Multiple problems
 - Communication problems
 - Takes a lot of extra time and effort
 - MID not always known or recognized

GP-patient relationship



- Feeling safe to share emotions
- Knowledge of past and personal context essential for opening up
- Scared to be misunderstood or stigmatized



- Mild-ID recognition
- Challenging

Patient's network



- Signalising MH problems
- Limited or absent network
- Can they be burdened?



- Can be very supportive and helpful
- Can contribute to the complexity
- Lack of continuity in formal network
- Extra time and effort

Organisation of care



- Desire to be self-determined, despite vulnerability and need for support
- Experience problems in overseeing and coordinating all care related



- Finding care and support
- Challenges in providing care in the health care chain

Take home messages from these studies

- Patients with both MID and MH problems feel extra vulnerable in primary care
- The GPs/PNs perceive this patient group as challenging
- Extra investment in a good GP-patient relationship is important
- Actively involving the patient's network can be of great value
- Cooperate with patients' network, other care professional including social domain en MH services



John visits GP regularly

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- Experiences hearing loss since 1 month
- Has diabetes since 3 years
- Has panic attacks
- His GP experiences difficulties in providing appropriate care -> ID physician



The role of specialized medical ID expertise in the medical care for people with ID

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ID physician

- Population-oriented generalist (comparable to pediatrician and geriatrician)
- Expertise in providing medical care for people with ID of all ages and ID levels
- Works in care organizations, specialized day centers, or outpatient practices
- Most often referred to by GPs

Aim

Explore the characteristics of specialized medical care for people with ID provided by the ID physician

1. Reasons for consultation, identified problems & involved disciplines
2. Patients' and their caregivers' experiences with a medical consultation of the ID physician

Focus on people with ID living outside of care facilities

Study 1 - Methods

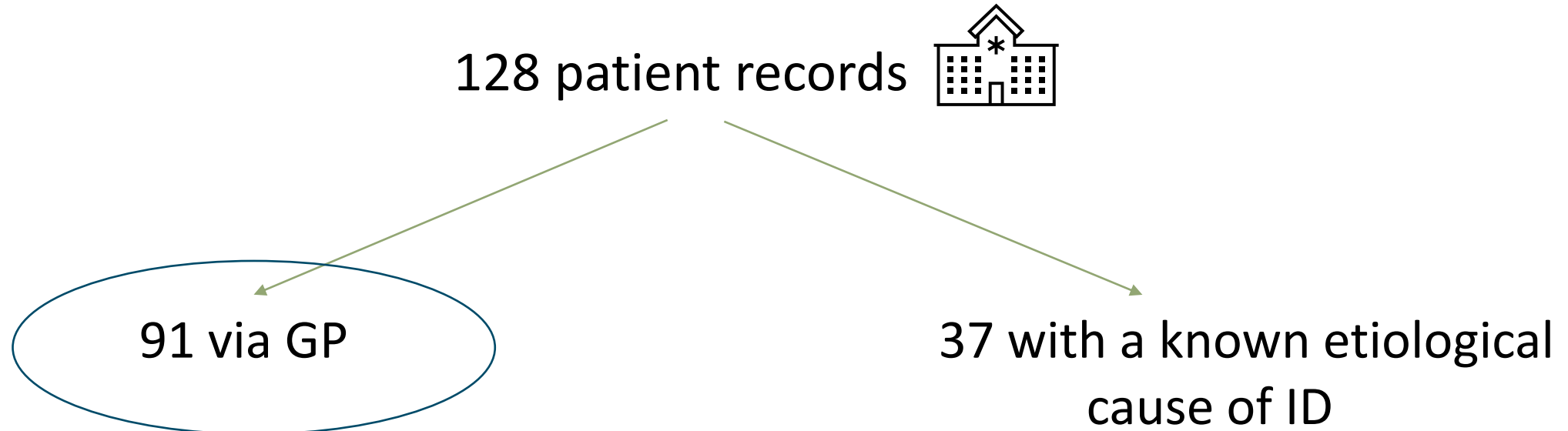


Retrospective cohort study using medical records (N=128) of patients with ID who visited the specialized outpatient ID clinic in Nijmegen, the Netherlands



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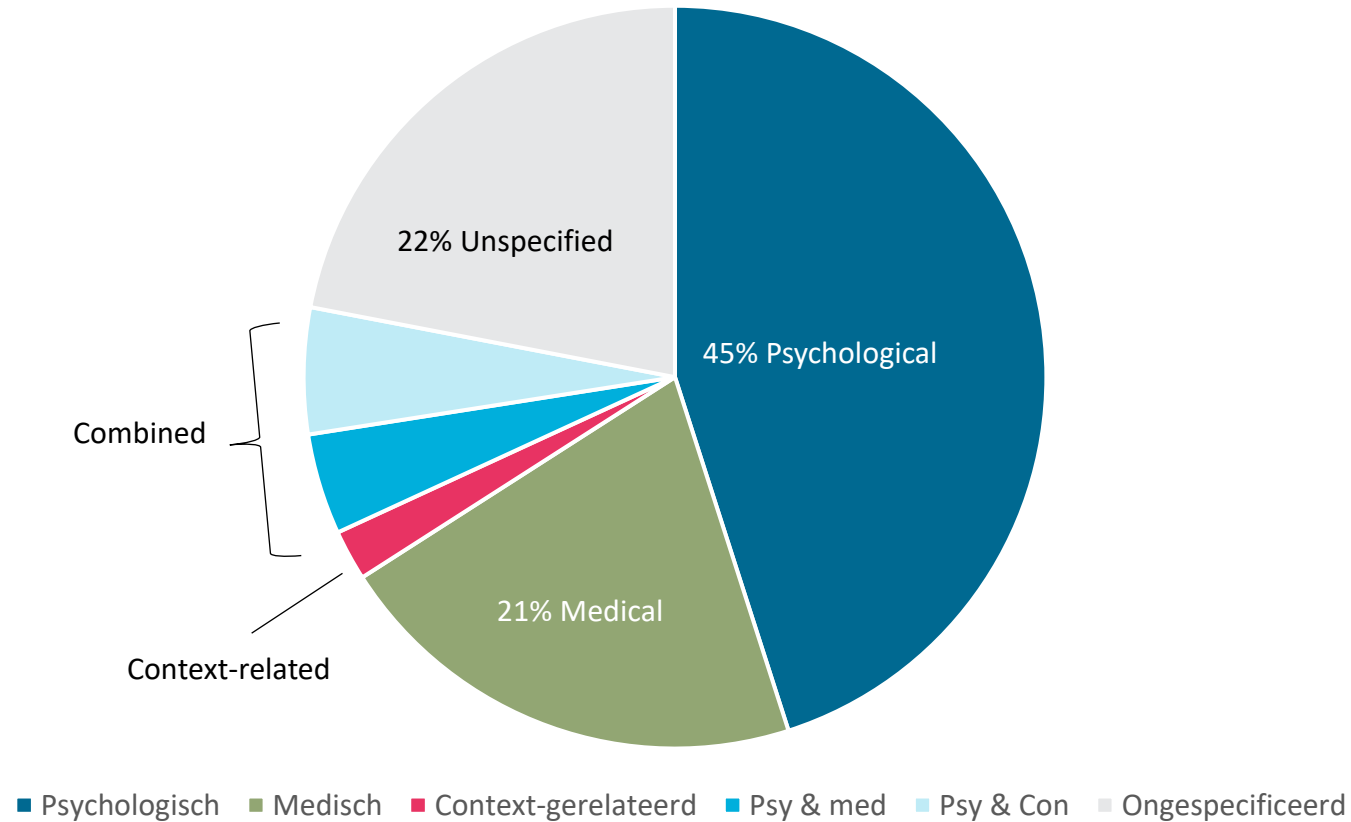
Study 1 - Methods



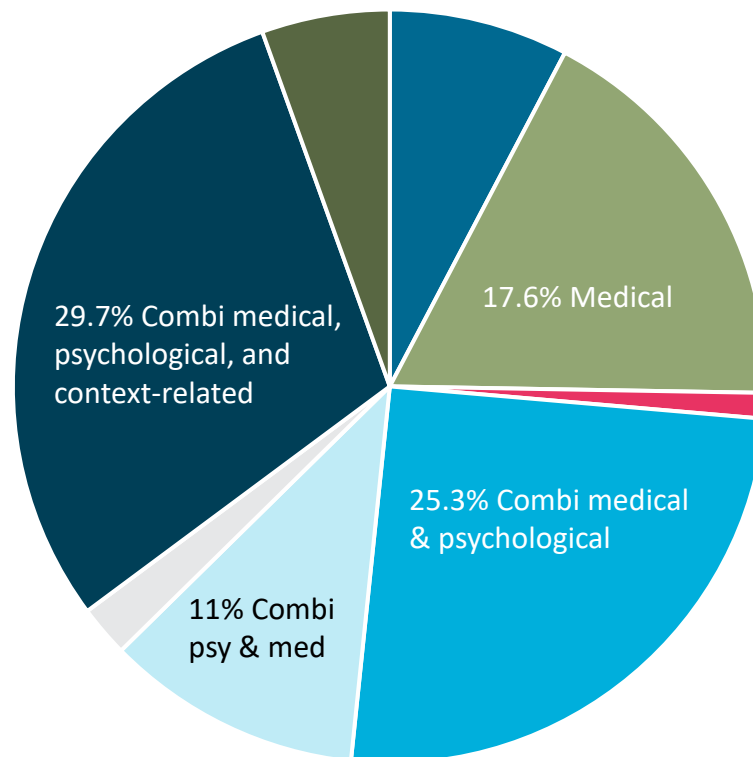
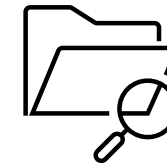
3 types of health-related problems were distinguished:

1. Medical
2. Psychological
3. Context-related

Results - Reason for referral



Results - Identified health problems



■ Psychologisch ■ Medisch ■ Context-gerelateerd ■ Psy & med ■ Psy & Con ■ Ongespecificeerd ■ Med & Psy & Con ■ Med & Con

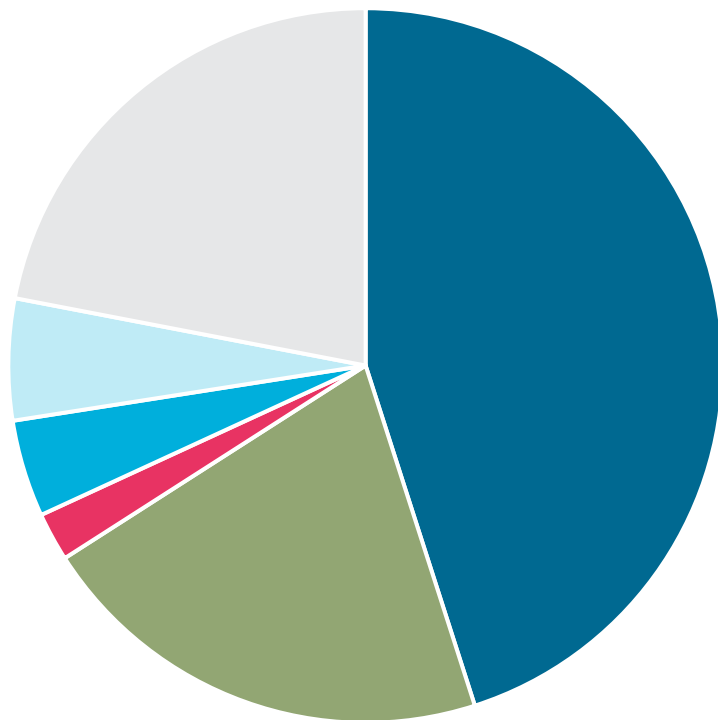
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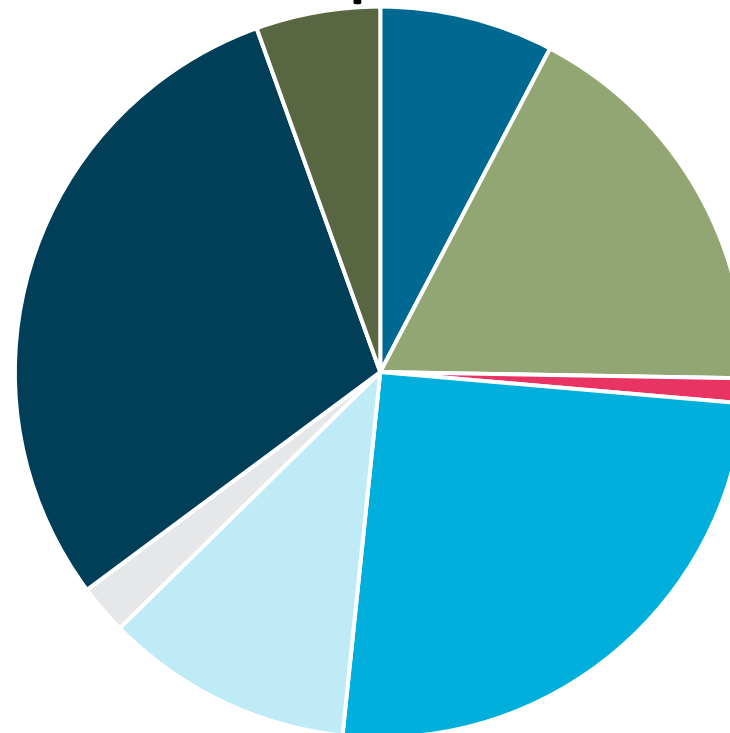
Results



Reason for referral

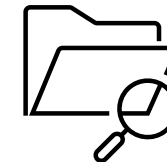


Identified problems



■ Psychologisch ■ Medisch ■ Context-gerelateerd ■ Psy & med ■ Psy & Con ■ Ongespecificeerd ■ Med & Psy & Con ■ Med & Con

Results - Involved disciplines



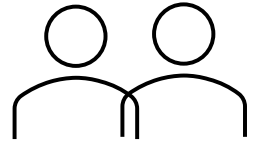
Conclusion



This exploratory study supports the value of specialized medical ID-expertise in two ways:

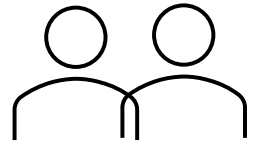
1. Specialized medical ID-expertise helps to look beyond the initial complaint of a patient and identify a multitude of different types of problems, often combining medical, psychological, and context-related factors;
2. Specialized medical ID-expertise helps to organize multidisciplinary medical care for people with ID.

Study 2



**How do patients and their caregivers
experience a medical consultation of the
ID physician?**

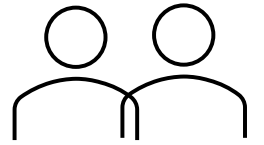
Study 2 - Methods



- 15 semi-structured interviews
- With patients and their caregivers







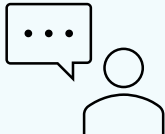
Results



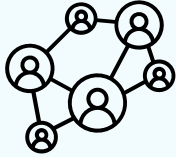

7 themes that represent roles of the ID physician

During consultation



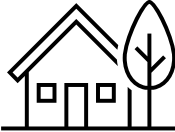

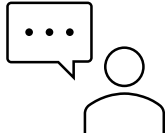
-  1 Clinician
-  2 Patient-centered doctor
-  3 Holistic physician

-  4 Human
-  5 Sparring partner for the patient's network

Around consultation

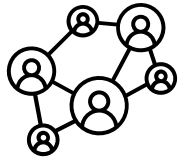
-  6 Coordinator
-  7 Advocate

Roles during consultation

-  **1** Clinician Knowledge and experience
-  **2** Patient-centered doctor Involve patient
Self-reporting
Communication
-  **3** Holistic physician Interconnectedness of physical, social and environmental contributors to health
-  **4** Human Respect
Take time
Take patient seriously
-  **5** Sparring partner for the patient's network Supporting role of caregivers

Roles around consultation

6



Coordinator

Organize & oversee
patient's care activities
Create a care plan

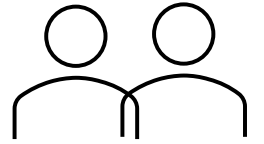
7



Advocate

Innovators
Promote rights of PWID

Conclusion



- Patients with ID and their caregivers value ID physicians' roles beyond clinical skills during consultations
- This includes roles related to care coordination, having a professional network, and advocating in a broader context around medical consultations

Lessons to be learned

Studies 1-4



- High prevalence of (hidden) MH problems and chronic disease
- High burden for GPs
- Recognition of ID is essential but challenging
- Collaborative care is important
- Added value of specialized medical ID expertise

More information?

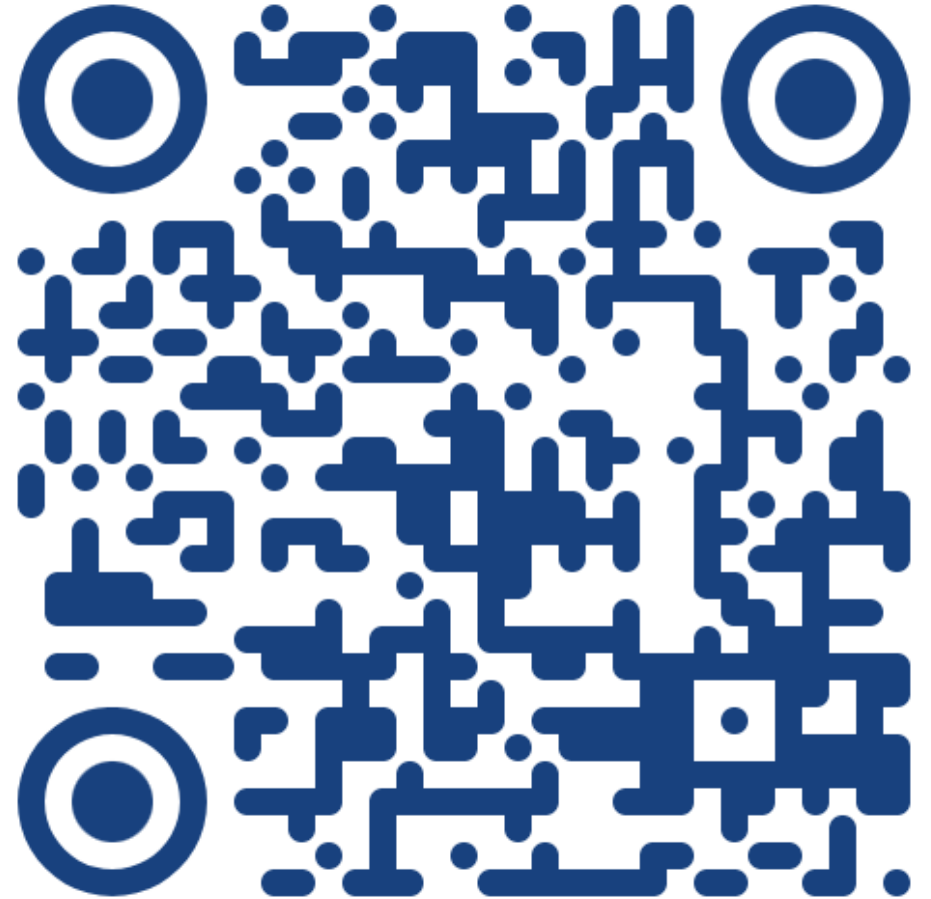
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