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Unlocking the Power of Data: Revolutionizing Intellectual Disability Care

Symposium

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1 november 2024

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Harnessing Population Data for Intellectual Disability Health Monitoring

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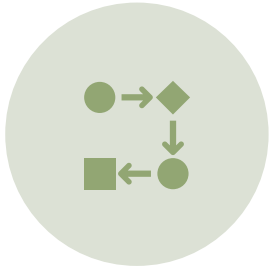
1 november 2024

COI

- No disclosures
- Funding from Dutch Ministry of Health (VWS) and The Netherlands Organisation for Health Research and Development (ZonMw)

Outline

WHY



HOW

WHAT

DISCUSSION

Background


THE LANCET
Public Health
CORRESPONDENCE | VOLUME 5, ISSUE 8, E423, AUGUST 01, 2020
Disability and COVID-19: who counts depends on who is counted
Nicholas S Reed • Lisa M Meeks • Bonnielin K Swenor
Open Access • Published: July 21, 2020 • DOI: https://doi.org/10.1016/


THE LANCET
Public Health
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EDITORIAL | VOLUME 6, ISSUE 6, E346, JUNE 2021
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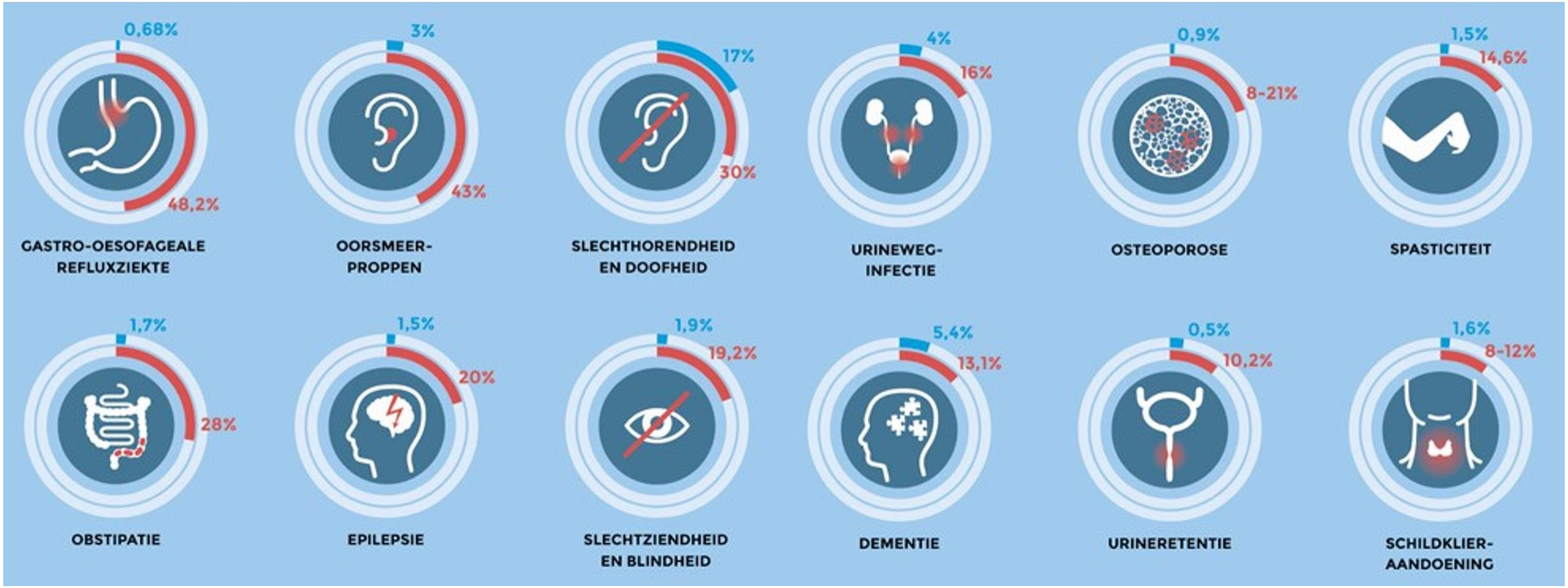
Disability—a neglected issue in public health
The Lancet Public Health
Open Access • Published: June, 2021 • DOI: https://doi.org/10.1016/S2468-2667(21)00109-2 •
Check for updates

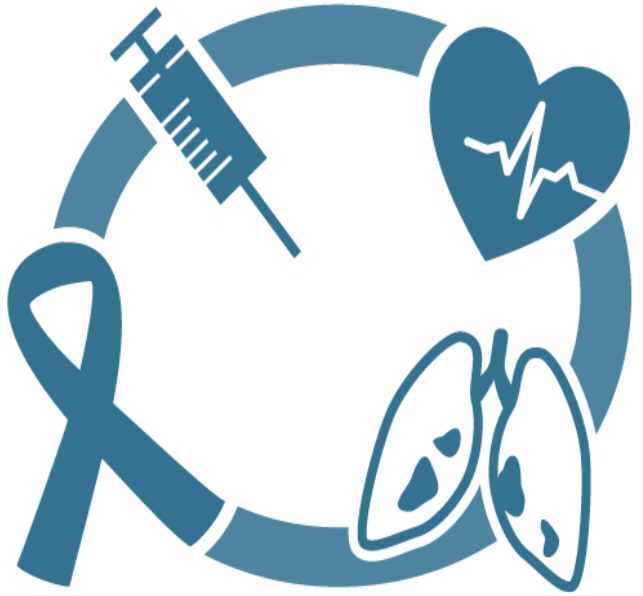
Knowledge about problems associated to ID



K. Schipper, Ned Tijdschr Geneeskd. 2014;158:B1105

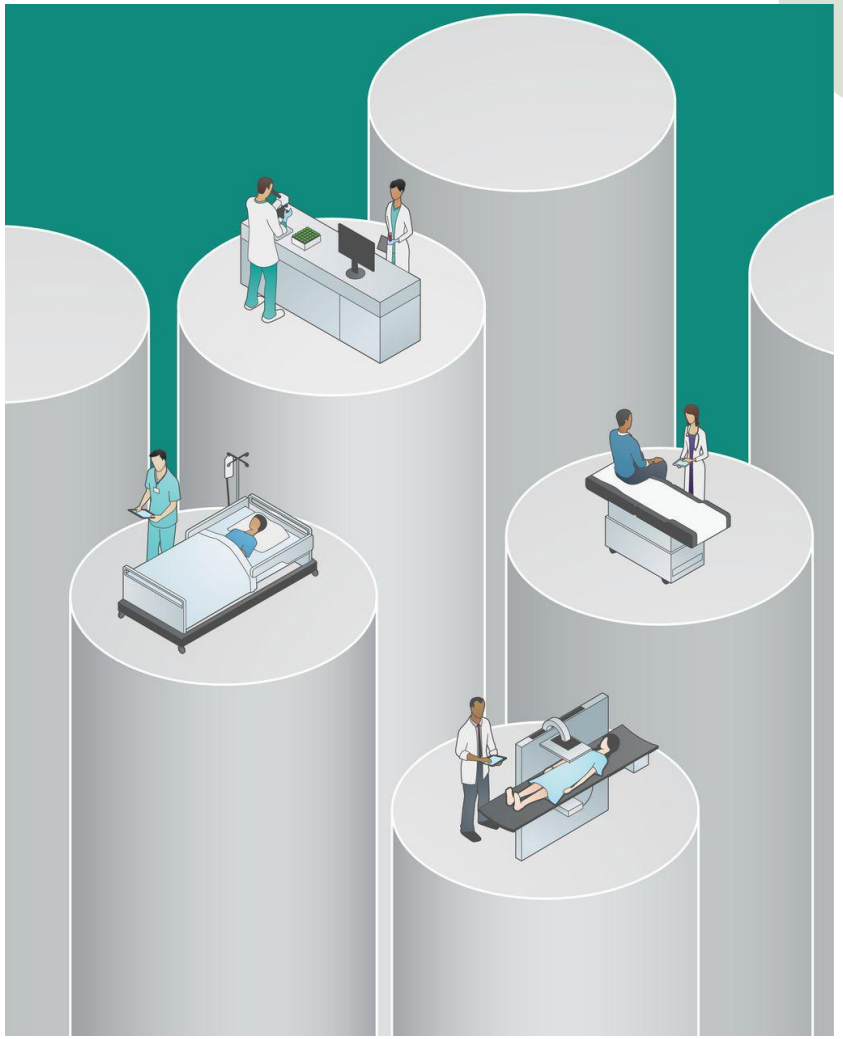
And in those areas common to the general population

- Chronic illness
- Cancer
- Organization of care
- Public health



Why relevant?

- Siloed healthcare
- Little knowledge of ID in routine healthcare and public health settings
- Same standards of care often of out reach
- Cascading disparities
- Avoidable mortality due to treatable or amenable conditions



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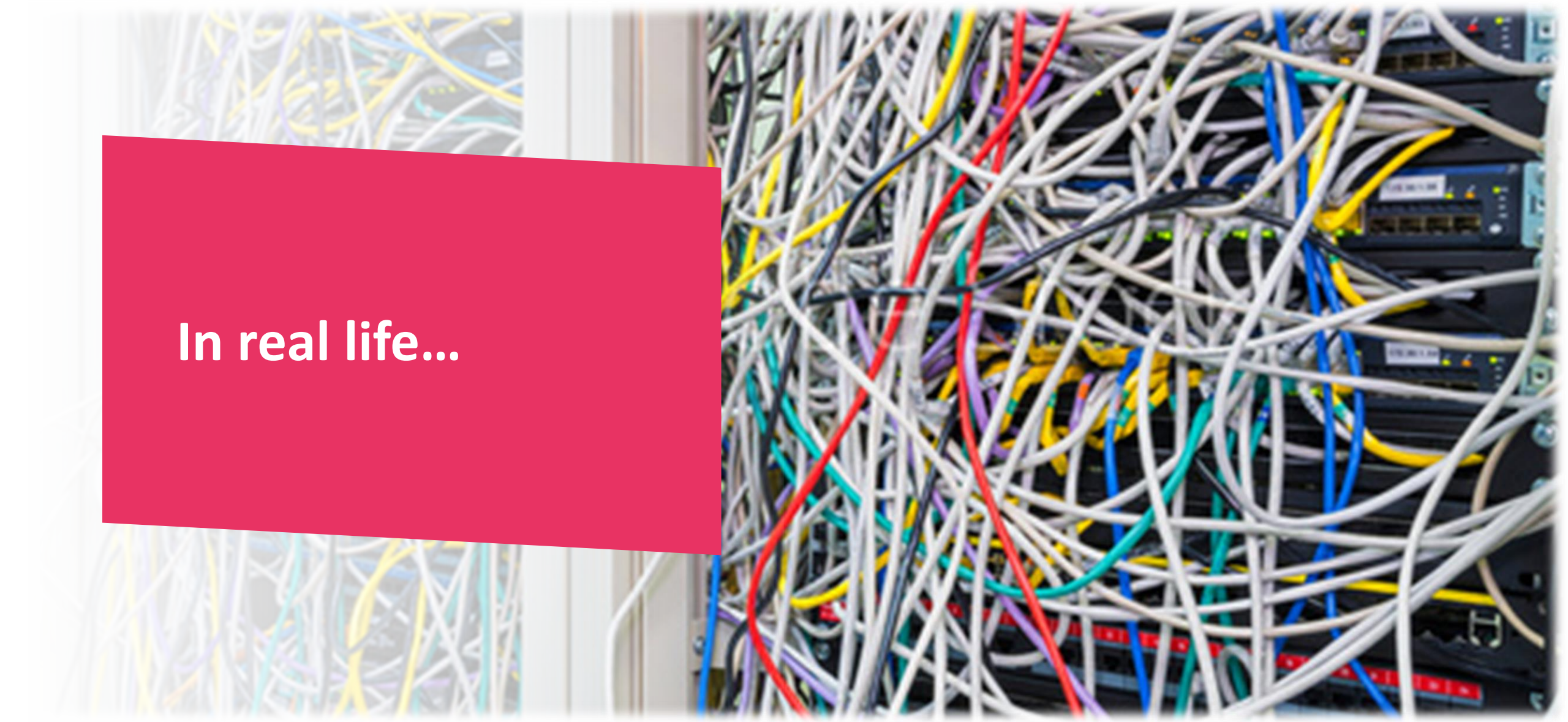
In an ideal world…

In real life…



Dutch context

- Single national system for chronic care
- Single healthcare system with statutory health insurance
- Access to hospital care same for everyone
- GP or ID physician have central role
- National statistics office serves as hub for population-based linkage

Identifying intellectual disability

- ID indicators in population databases
  - Long-term care
  - Welfare and social support
- ID prevalence 1.45%

Contents lists available at ScienceDirect

Public Health

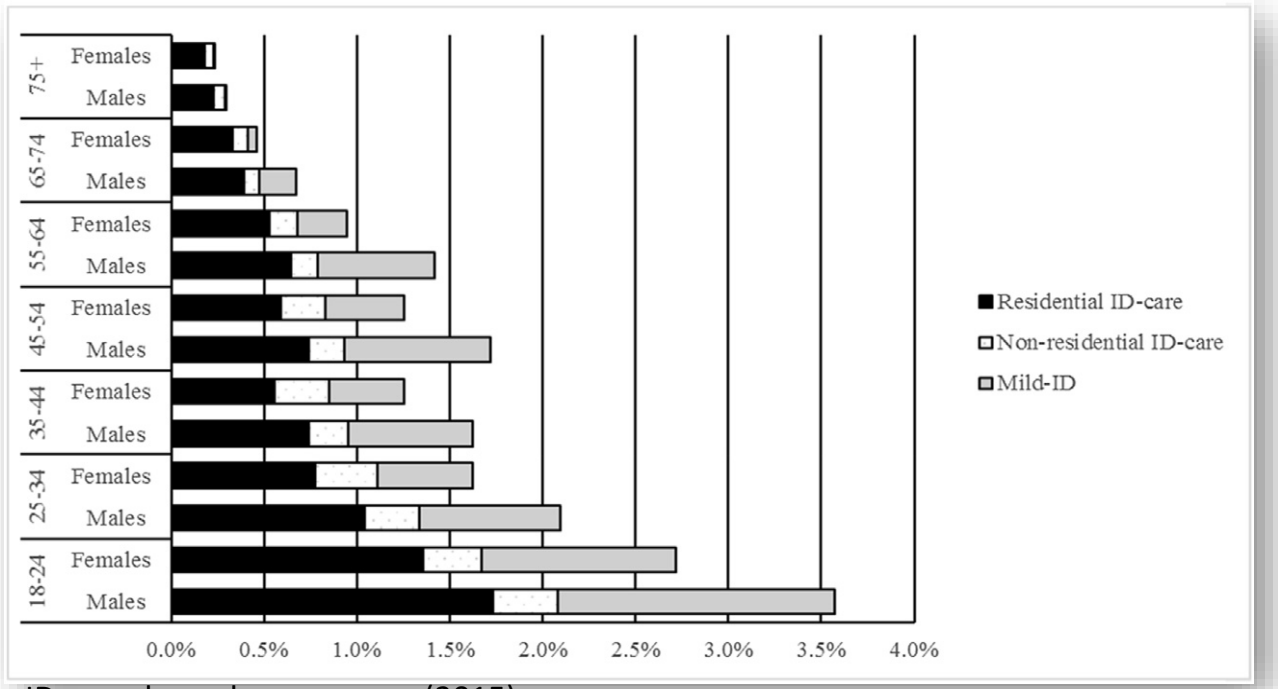
journal homepage: www.elsevier.com/locate/puhe

Original Research

Linking national public services data to estimate the prevalence of intellectual disabilities in The Netherlands: results from an explorative population-based study

Maarten Cuypers [a, *], Hilde Tobi [b], Jenneken Naaldenberg [a], Geraline L. Leusink [a]

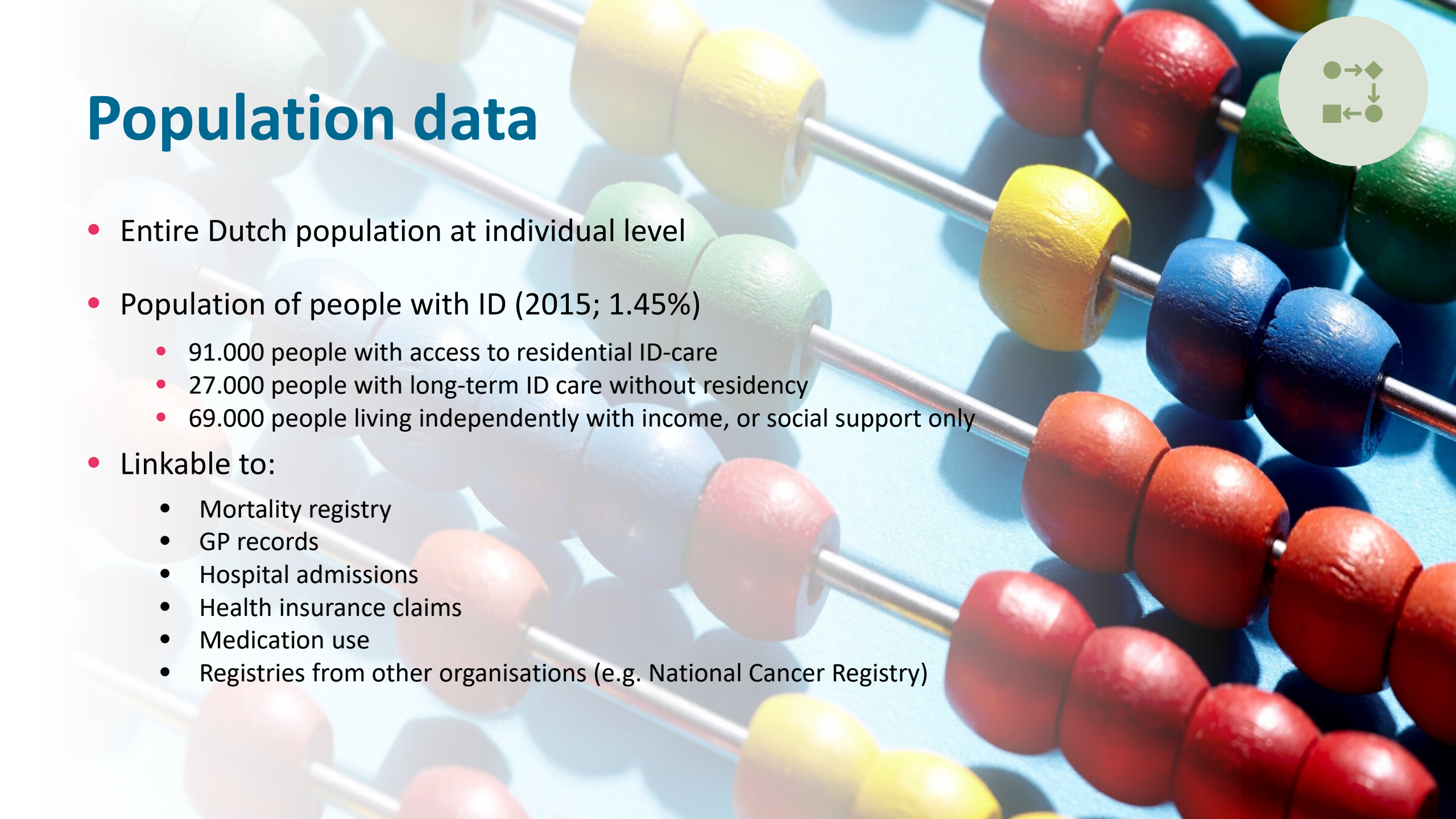
[a] Radboud Institute for Health Sciences, Department of Primary and Community Care, Radboud University Medical Center, Nijmegen, The Netherlands
[b] Biometris, Wageningen University & Research, Wageningen, The Netherlands



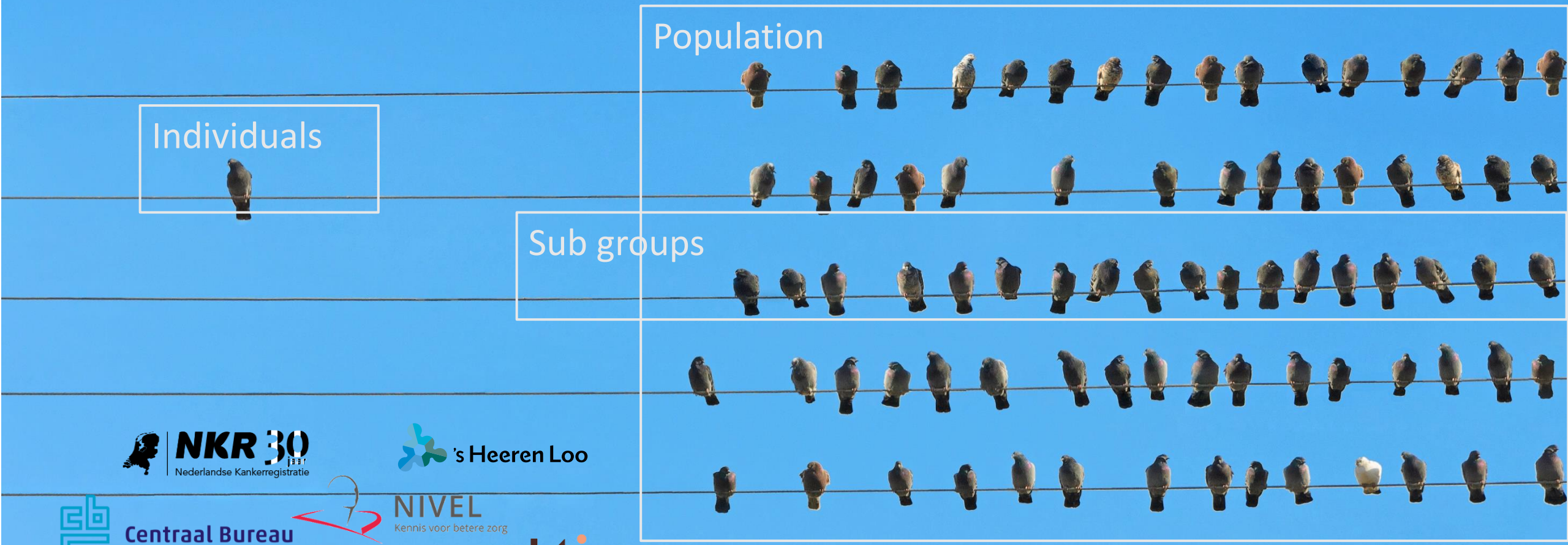
ID prevalence by age group (2015)

Population data

- Entire Dutch population at individual level
- Population of people with ID (2015; 1.45%)
  - 91.000 people with access to residential ID-care
  - 27.000 people with long-term ID care without residency
  - 69.000 people living independently with income, or social support only
- Linkable to:
  - Mortality registry
  - GP records
  - Hospital admissions
  - Health insurance claims
  - Medication use
  - Registries from other organisations (e.g. National Cancer Registry)



Using real world data for research



NKR 30 jaar Nederlandse Kankerregistratie

's Heeren Loo

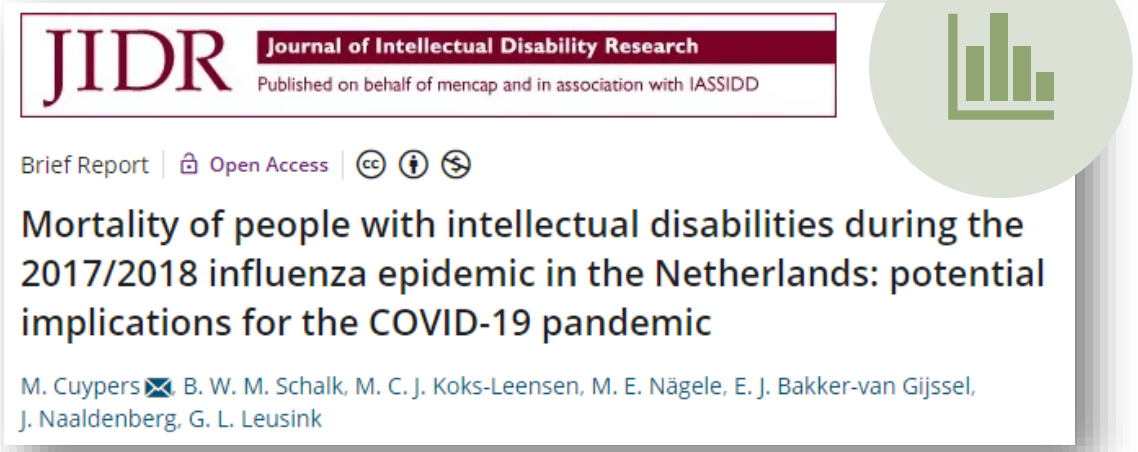
Centraal Bureau voor de Statistiek

NIVEL Kennis voor betere zorg

vektis

Mortality

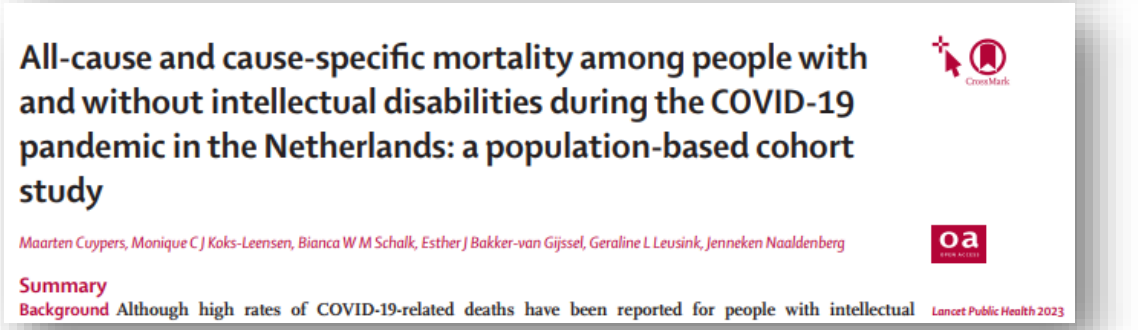
- Key indicator for public health quality
- Linkage of population databases with mortality registry
- Showed disparities for death due to:
  - Influenza
  - COVID
  - Cancer


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

Brief Report | Open Access

Mortality of people with intellectual disabilities during the 2017/2018 influenza epidemic in the Netherlands: potential implications for the COVID-19 pandemic

M. Cuypers, B. W. M. Schalk, M. C. J. Koks-Leensen, M. E. Nägele, E. J. Bakker-van Gijssel, J. Naaldenberg, G. L. Leusink


All-cause and cause-specific mortality among people with and without intellectual disabilities during the COVID-19 pandemic in the Netherlands: a population-based cohort study

Maarten Cuypers, Monique C J Koks-Leensen, Bianca W M Schalk, Esther J Bakker-van Gijssel, Geraline L Leusink, Jenneken Naaldenberg

Summary

Background Although high rates of COVID-19-related deaths have been reported for people with intellectual

Lancet Public Health 2023

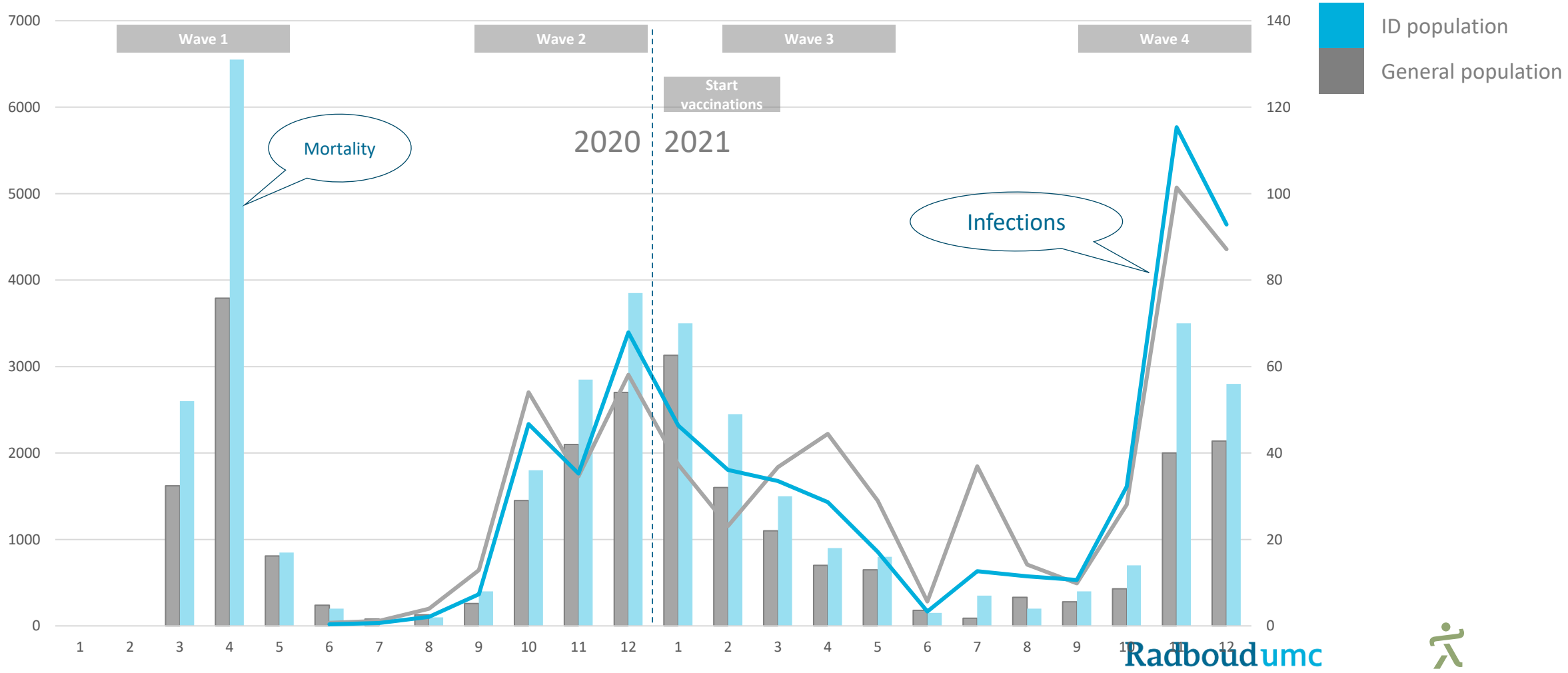

Cancer

Original Article | Open Access

Cancer-related mortality among people with intellectual disabilities: A nationwide population-based cohort study

Maarten Cuypers PhD, Bianca W. M. Schalk PhD, Anne J. N. Boonman MSc, Jenneken Naaldenberg PhD, Geraline L. Leusink MD, PhD

Patterns in COVID infections and mortality



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Primary care and mental healthcare

- Informing care providers of differential needs
  - More knowledge
  - Better able to make adjustments
- Primary care
  - Pregnancy and antenatal care outcomes
  - Prevalence of chronic illness
  - Healthcare utilization (e.g. number of visits)
- Mental healthcare
  - How prevalent are psychiatric problems?
  - Is same standard of care provided?
  - What are key differences compared to the general population?
    - Duration of treatment
    - Diagnostic activities

Special Issue Article

Reproductive health of women with intellectual disability: antenatal care, pregnancies and outcomes in the Dutch population

C. Schuengel,[1] M. Cuypers,[2] L. Bakkum[1] & G. L. Leusink[2]

1 Department of Educational and Family Sciences and Amsterdam Public Health Research Institute, Vrije Universiteit Amsterdam, Amsterdam, The Netherlands
2 Radboud University Medical Center (Radboudumc), Radboud University Nijmegen, Nijmegen, The Netherlands

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

Milou van den Bemd*, Bianca W.M. Schalk, Erik W.M.A. Bischoff, Maarten Cuypers, Geraline L. Leusink

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Mental healthcare for adults with mild intellectual disabilities: population-based database study in Dutch mental health services

Katrien P. M. Pouls, Maarten Cuypers, Mathilde Mastebroek, Jannelien Wieland, Monique C. J. Koks-Leensen, Geraline L. Leusink and Willem J. J. Assendelft

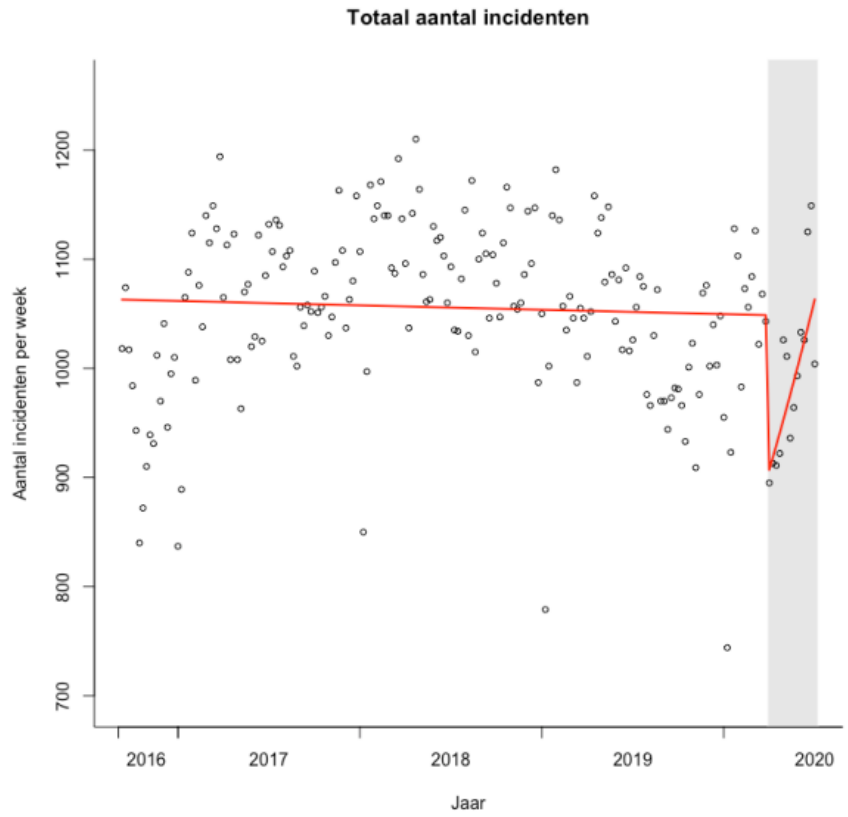
Oncology care

- Linkage with insurance claims
  - Oncology care utilization

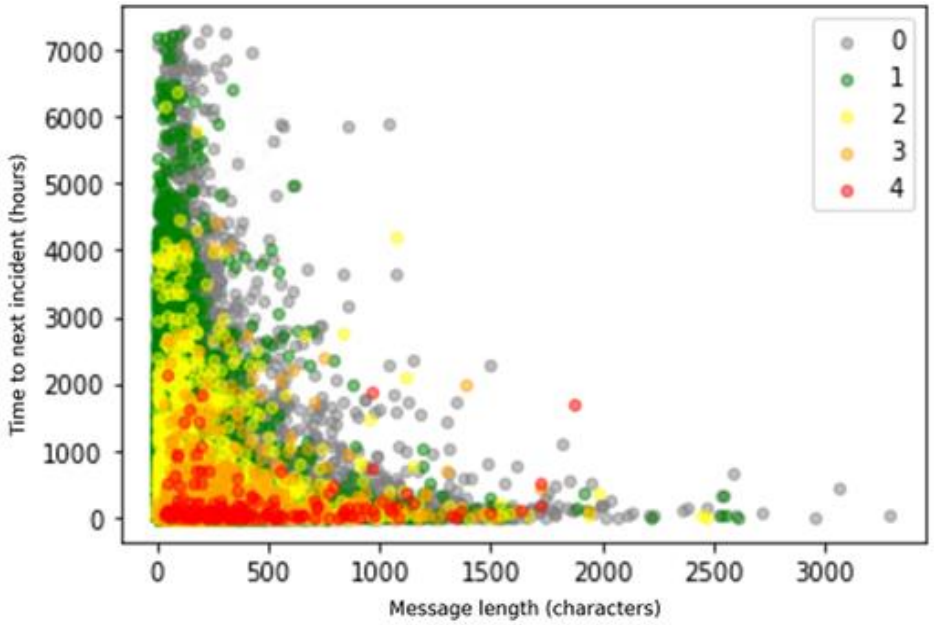
- Linkage with National Cancer Registry
  - Cancer incidence (presented on Monday)
  - Diagnostic characteristics
  - Primary treatments
  - Survival

Using data for individual predictions

- Evaluation: which patterns appeared?



- Prediction: What are the risks of behavioral incidents?



Time to next incident by sentiment and length of report (66,7% accuracy)

Discussion

- Knowledge development
- Guiding policy and practice
- Evaluate, monitor, and predict
- Improve quality of care
- Barriers in data access and linkage
- Legal and privacy issues

Thank you for your attention

Collaborators

Jenneken Naaldenberg, Lynette Oost, Joep Tummers, Geraline Leusink

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Funders and partners

Ministry of Health, Welfare and Sport

's Heeren Loo Koraal dichterbij Philadelphia Siza Radboudumc

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General practitioner data and specialized outpatient intellectual disabilities clinic data: opportunities for healthcare improvement

Exploring Data Integration for Enhanced Healthcare Delivery

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Intellectual Disability and Health

August, 2024

1 november 2024

COI

- No disclosures
- Funding from Dutch Ministry of Health (VWS) and The Netherlands Organisation for Health Research and Development (ZonMw)

Overview of the presentation

1. Introduction followed by the aim
2. Two data sources:
   a) General practice
   b) Outpatient clinic data
3. Data collection and storage
4. Key findings
5. Future data linkage, potential hypothesis and research questions and examples
6. Conclusion

Introduction

- General practitioner
- Specialized outpatient intellectual diabilities (ID) clinic

Aim

1) To highlight the extensive information obtained from **GP data** and **ID outpatient clinic data** separately

2) To demonstrate how their linkage enhances our understanding of health care delivery.

General practice (GP)

- Persons with ID living semi-indepently/ outside of care facilities
- Recognize ID (or bring up ID)
- Difficulties in communication

- Awareness increased need for healthcare – health disparities

Specialized outpatient ID clinic

- ID physician:
  - Specialized physicians with ID-specific medical knowledge and skills
- Unique in the Netherlands

- Patients are most often referred to by GPs
- After consultation and check ups referred back to GP

Data sources – GP

- Medical records of patients who visited the general practitioner
- Longitudinal data available since 2010 and ongoing
- Patients can be followed in given care
- Patients with ID are identified using specific method
- GP data from approximately 100 GPs
- Software: GP information system
- Medical records are pseudonymized & accessible research data
- Opt out

Data sources – GP: measurements

Patient characteristics

Consult information

Diagnoses and symptoms (Episodes + titles episodes) – ICPC codes*

Laboratory results

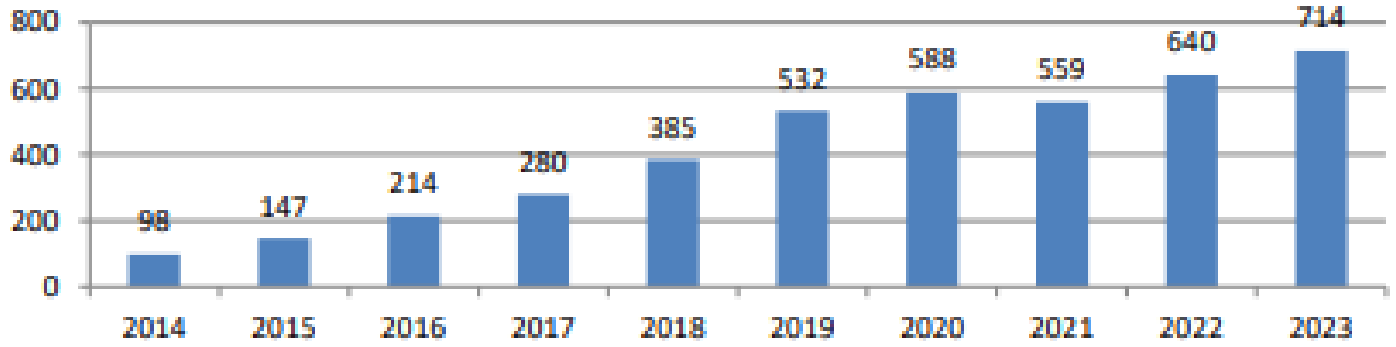
Medication

Referals

Data sources – outpatient ID clinic -1

- Medical records of patients who visited the clinic
- Longitudinal data

- One outpatient clinic in Nijmegen
  - More than 700 consults in 2023
  - Approximately 250+ patients per year



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Data sources – outpatient ID clinic -2

- Software: GP information system
- Since 2021 available & organized comparable to GP data:
  - Medical records are pseudonymized
  - Created accessible research data
- Informed consent
  - Before 2020, earlier visits from ID patients and their caregiver
  - From 2020 onwards at first consultation

Data sources – ID clinic: measurements

Patient characteristics

Reasons for consultations - ICPC-code

Consult information

Diagnoses and symptoms (Episodes + titles episodes) – ICPC codes

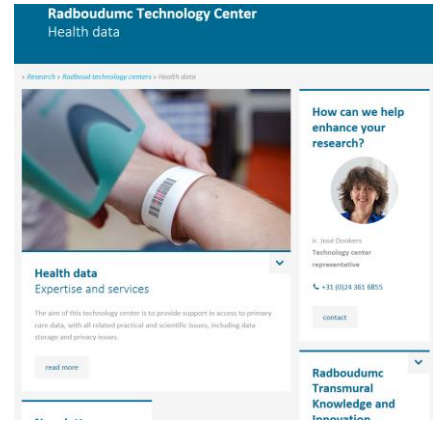
Open tekst with Laboratory results, Medication and refferals

Data collection and storage

- GP data annually extracted since 2010

- Outpatient ID clinic data, first extraction in 2021
  - First study with registered data available
  - Conform GDPR & NEN7510

- Radboud Technology Center (RTC) – Health data
  - Data Transfer Agreement



Key findings in General practice

- In GP database:
  - annually identify persons with ID,
  - using ICPC codes and ID related titles

Research using this data and identification:

A. Common health problems[1]

B. Skin cancer[2]

C. Gastrointestinal diseases[3]

 1 Heutink at all. 2. IASSIDD Schalk at all. 3. not yet published or presented

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Key findings in Outpatient clinic

- In Outpatient ID clinic database:
  - Annually extractions
  - Increased number of patients with ID
  - Data improved, due to coding agreements

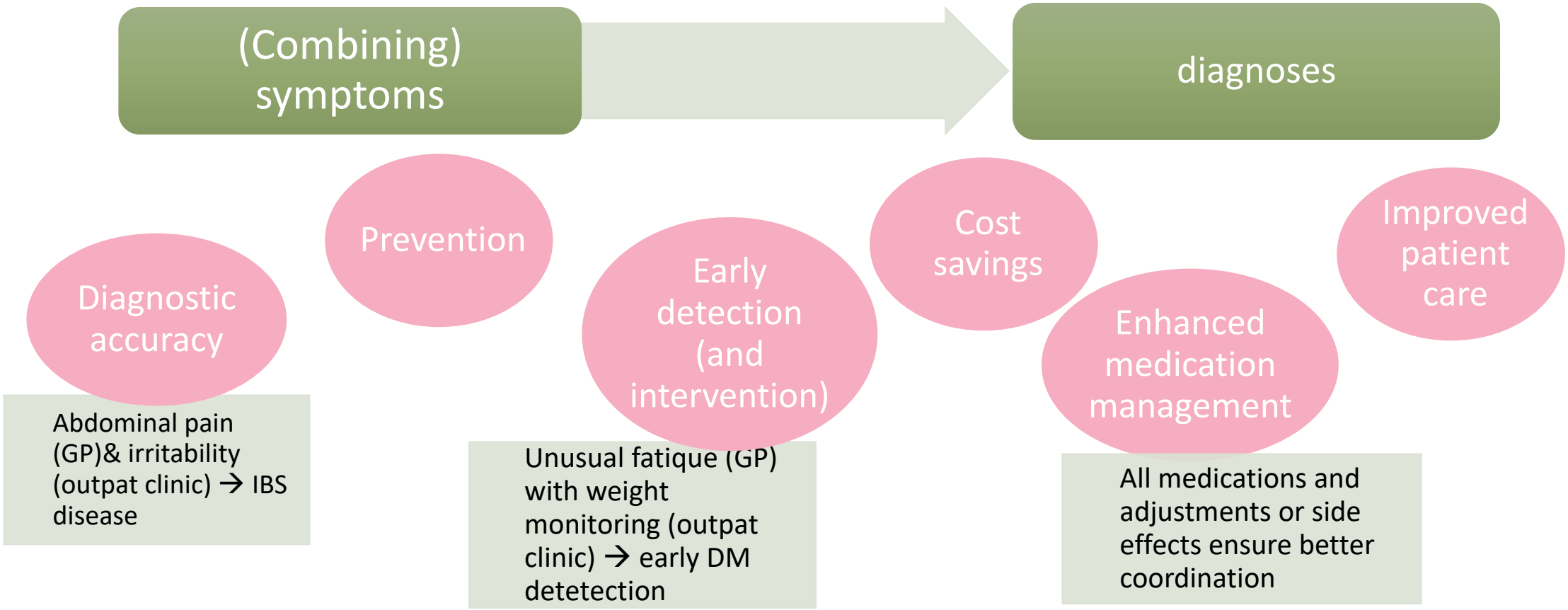
Research:

- Recently first publication[1]

Future data linkage

- Great potential for linking both data sets
- Benefits of linking GP and specialized outpatient ID clinic data
  1. Provides a complete patient's health journey: from GP to outpatient clinic and back including the medical history
  2. Early identification of common health issues: patterns in data might reveal certain symptoms prior to a specific diagnosis
  3. Streamlines an optimizes the referral process by identifying common reasons for referral→ help GP make more timely referrals

Potential hypotheses



Example of research questions

Which patterns can be revealed using linked data from GP and specialized outpatient ID clinics:

- Which symptoms and/or behaviors lead to (early or more accurately) detection of chronic conditions such as diabetes and cardiovascular diseases in patients with intellectual disabilities using data from both GP and ID outpatient clinics?

Example

- symptoms and/or behaviors
  - GP: gastrointestinal complaints such as chronic abdominal pain, unexplained weight loss
  - Outpatient clinic: certain behaviors such as changes in eating habits, increased irritability
- chronic conditions: diagnosis of a gastrointestinal disorder

- In this example: Healthcare providers can identify early warning signs and intervene sooner

Example

- symptoms and/or behaviors
  - GP: psychological problems or challenging behavior
  - Outpatient clinic: context-related problem such as funeral close friend and hearing problem
- conclusion: in retrospect, this patient got hearing aids, and because of accumulating unnoticed ailments had lead to severe disturbed behaviour.

Conclusion

- The results from both data sources are of evident value of utilizing healthcare information from both datasets
- The potential of data linkage can:
  - Improve early detection
  - Enhance diagnostic accuracy
  - Optimize patient management
  - Facilitate preventive care
- Overall the combination of these data sources leads to enhanced healthcare delivery.

Thank you for your attention

Collaborators MSc Marian Breuer, Dr. Annemarie Uijen, Dr. Maarten Cuypers

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Overcoming Data Integration Challenges in Intellectual Disability Care:
a case study approach

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

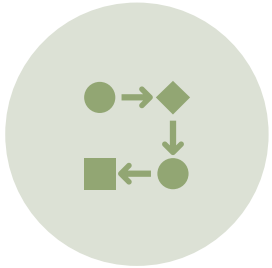
1 november 2024

COI

- Also employed at Wageningen University & Research, no conflict of interest with role.
- Funding from Dutch Ministry of Health (VWS)

Outline

DATA LANDSCAPE



OBSTACLES

SOLUTIONS

DISCUSSION

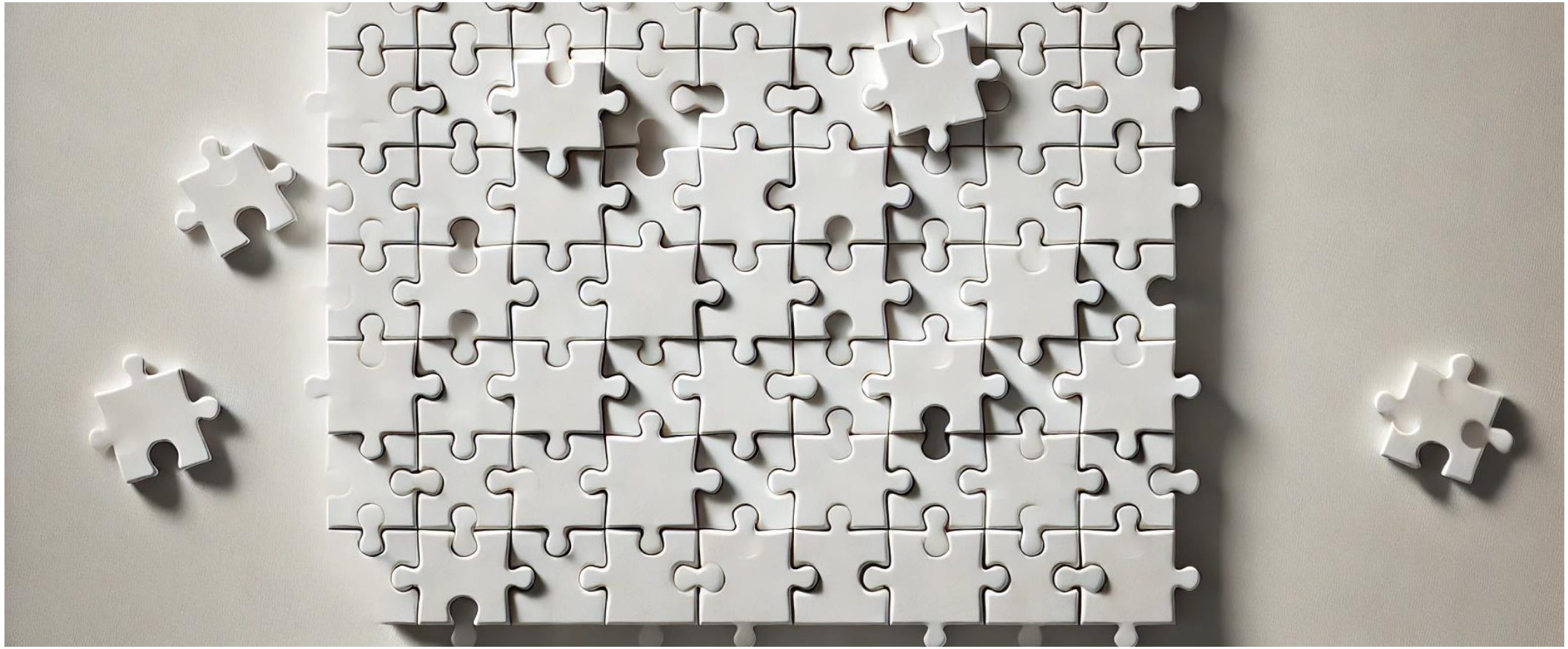
Three data types

	Population data	Medical data	Care data
Sources	Bureau of statistics, Health insurers	Electronic Patient Dossiers from GPs + Hospitals	Electronic Client dossiers
Frequency	Yearly	Varying	Up to two times per day
Content	Satistics	Medical coding, SOAP notes, medical history	Daily reports for continuation of care
Data type	Structured	Structured + Textual	Mainly Textual

Data potential

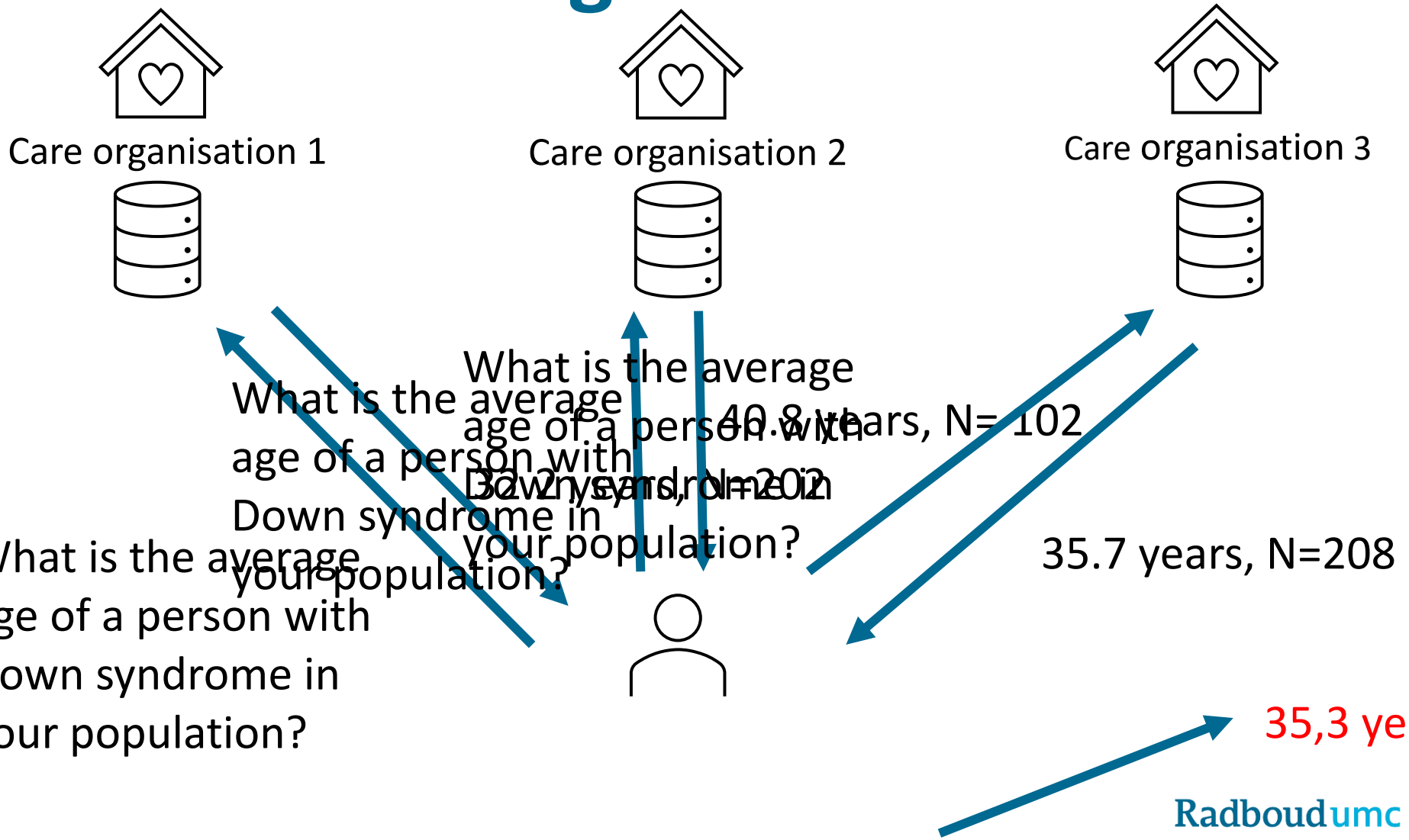
Ethical and legal obstacles

Technical obstacles



Solutions

Federated learning



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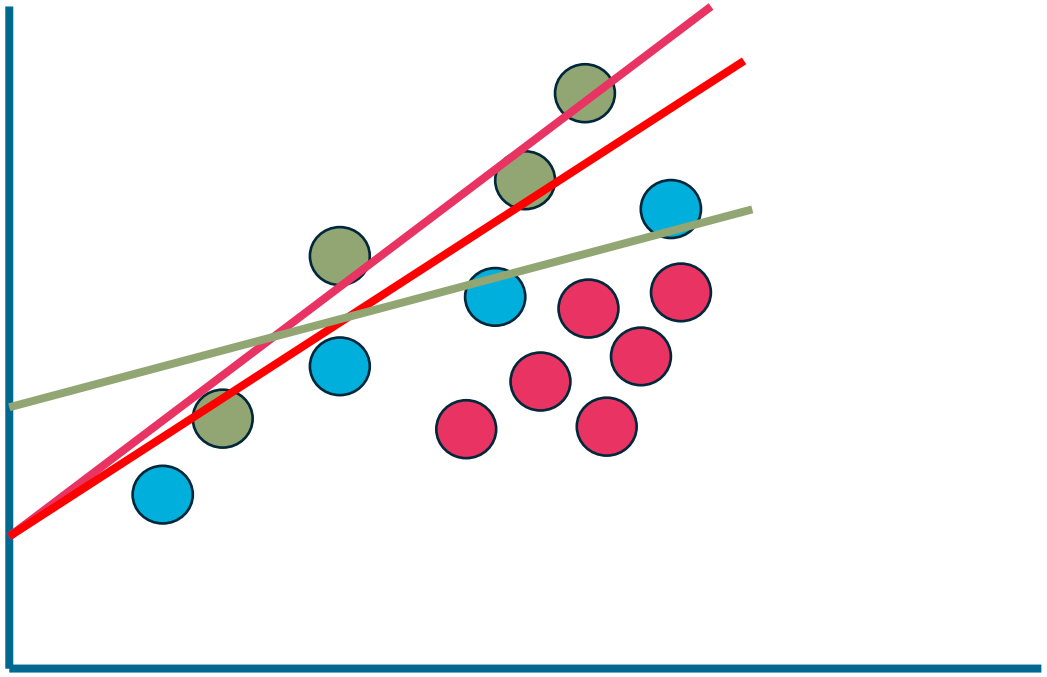
Federated learning 2



$$Y = \alpha x + \beta$$

Ethical and Legal solutions

Technical solutions

Case studies

- “Predicting changing care demands for better healthcare planning”
- "Earlier detection of cancer symptoms in people with intellectual disabilities"
- “Optimal staffing and appropriate care”
- “Predicting behavioral incidents (based on behavior history)”

What's in it for ID care

- (Medical) insights
  - Alerts
  - Signaling
- Knowledge
  - Disease progression
  - Behavior
  - Well-being
- Scientific articles

Next steps

Set up case studies

Set up technical requirements

Continue studies with population data
Start with Use cases

Boundary conditions: Ethical and Legal

Thank you for your attention

Collaborators: Lars Spekschoor, Maarten Cuypers, Pim van Oirschot, Thorsten Blokzijl, Joep Tummers, Geraline Leusink

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Funders and partners

Ministry of Health, Welfare and Sport

Images generated by Dall-E

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Improving suitability of intellectual disability care: the value of (linking) data for policy

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vgn vereniging gehandicaptenzorg nederland

COI

- No disclosures
- Funding from Dutch Ministery of Health (VWS) and the Netherlands Organisation for Health Research and Development (ZonMw)

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What is VGN?

- Dutch Association of Healthcare Providers for People with Disabilities
- Umbrella organisation
- Represent and support 180+ care organisations
- Advocacy, policy development, lobby
- **Value of data**:
  - Quality of care
  - Lobby to influence national policy and politics
  - Appropriate care

Appropriate care

- Movement towards more appropriate care to safeguard quality of healthcare
  1. Value-driven
  2. Together with the patient and with people around the patient
  3. Right care in right place
  4. Health instead of illness

- Appropriate for people with intellectual disabilities?

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1. Appropriate care is value-driven

0.1%

between 1908-2024

in top 10 medical journals concerns ID

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1. Appropriate care is value-driven

0.1%

between 1908-2024

in top 10 medical journals concerns ID

- Awareness for lack of visibility of ID
- Outside of ID sector: primary care, higher education, social domain

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2. Appropriate care is together with patient

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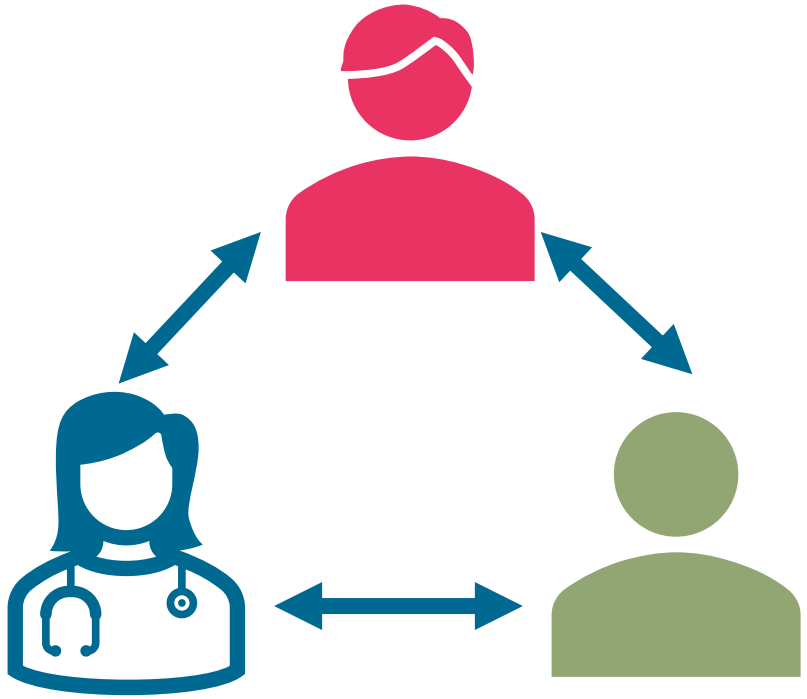
2. Appropriate care is together with patient

Supported decision making



Important role of carers

- Voicing opinions and experiences:
  - Guideline on support plans
  - Independent committee
- Yearly assessment of instruments
- Experiences → improving care
- 14 instruments for mild to severe ID

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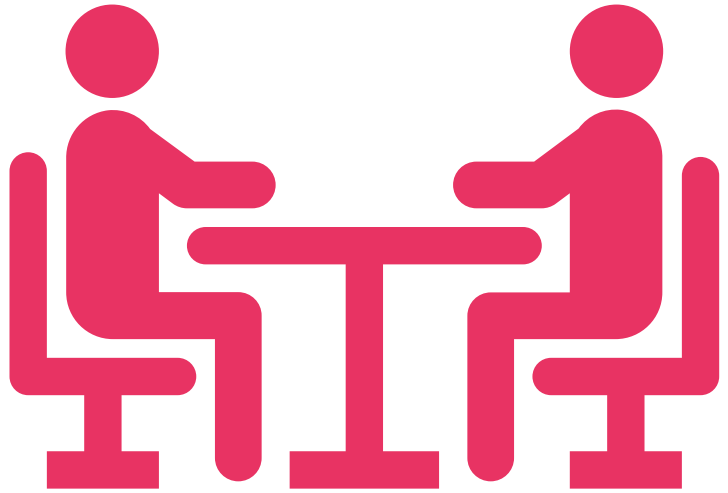
3. Appropriate care is right care in right place



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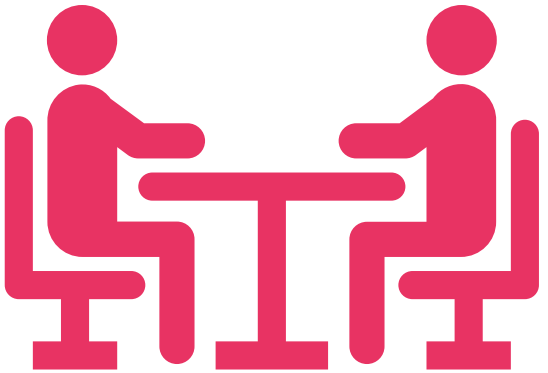
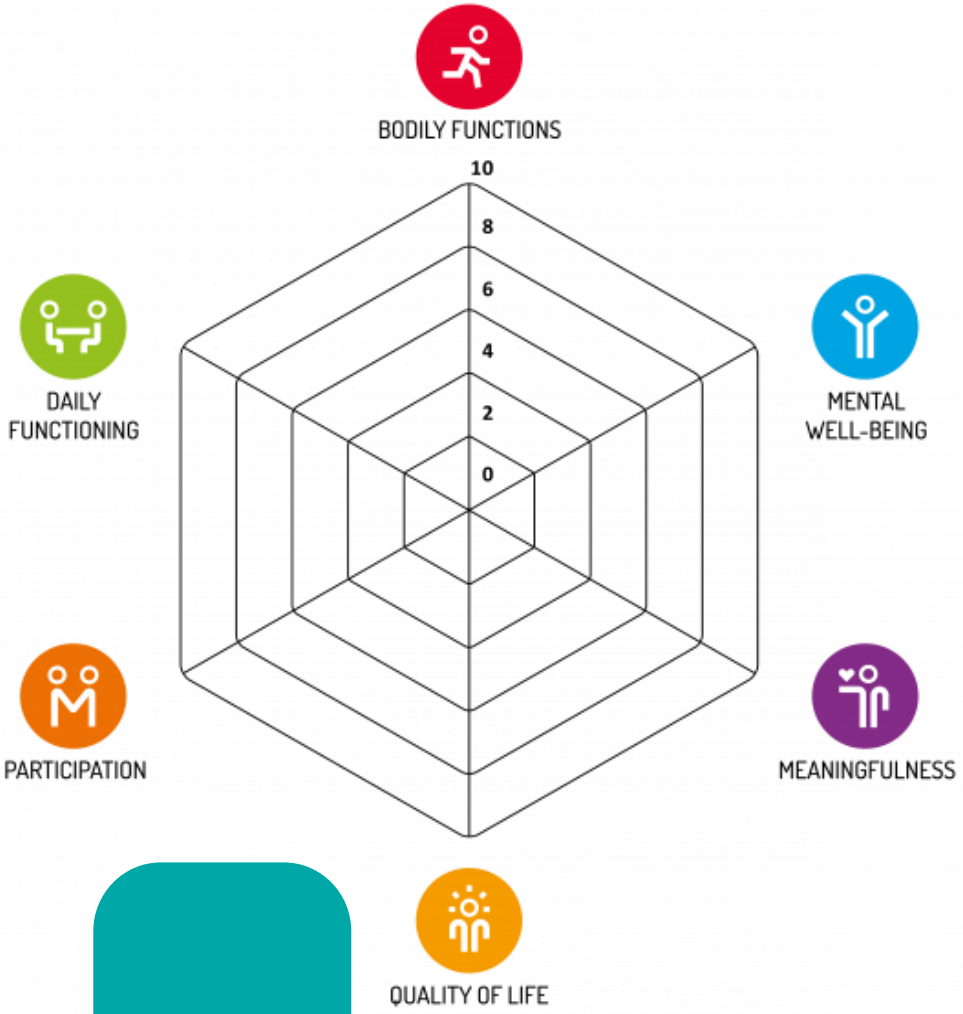
3. Appropriate care is right care in right place



- More consultations
- Increased consultation time
- Importance of collaboration: agreement to facilitate and coordinate collaboration

4. Appropriate care concerns health



Health, not illness

- Positive health
- Multidisciplinary guideline on recognising pain and physical complaints

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0.1%

between 1908-2024
in top 10 medical journals
concerns ID

- Input for medical guidelines
- Input for conversation tools (Positive Health)
- Among healthcare providers

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- Prevalence of ID
- Care needs
- Potential of AI for research and policy

- Input for medical guidelines
- Input for conversation tools (Positive Health)
- Among healthcare providers

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Thank you for your attention!

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