A PRO-ACTIVE HEALTH ASSESSMENT INSTRUMENT FOR PEOPLE WITH INTELLECTUAL DISABILITIES

TOWARDS REDUCING HEALTH INEQUITIES

ESTHER J. BAKKER-VAN GIJSSEL

A pro-active health assessment instrument for people with intellectual disabilities

Towards reducing health inequities

Esther J. Bakker-van Gijssel

Colophon

This thesis has been prepared by the Department of Primary and Community Care- Intellectual disabilities and health of the Radboud University Medical Centre, Nijmegen, the Netherlands. The work presented in this thesis was carried out within the Radboud Institute of Health Sciences and the academic collaborative ‘Stronger on your own feet’. This is a collaboration between the Radboud university medical centre and nine care provider organizations for people with ID.

Cover	Rachel Wols
Design & Layout	Ferdinand van Nispen, Citroenvlinder DTP&Vormgeving, *my*-thesis.nl
Print	ProefschriftMaken.nl Vianen
ISBN	978-94-6380-059-4

Financial support

This thesis was made possible by

-The Academic collaborative ‘Stronger on your own feet’

-Siza

Nijmegen, september 2018

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Op weg naar het verminderen van gezondheidsongelijkheden

Proefschrift

ter verkrijging van de graad van doctor
aan de Radboud Universiteit Nijmegen
op gezag van de rector magnificus prof. dr. J.H.J.M. van Krieken,
volgens besluit van het collega van decanen
in het openbaar te verdedigen op dinsdag 4 december 2018
om 16.30 uur precies

door

Esther Jacoba Bakker-van Gijssel
geboren op 22 juni 1965
te Zwolle

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Doctoral Thesis

to obtain the degree of doctor
from Radboud University Nijmegen
on the authority of the Rector Magnificus prof. dr. J.H.J.M. van Krieken,
according to the decision of the Council of Deans
to be defended in public on Tuesday, December 4, 2018
at 16.30 hours

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APPENDICES

1

General introduction

General introduction

A narrative

A 78 year old man called Mr P. was referred by his general practitioner (GP) to our out-patient clinic for people with intellectual disabilities (ID), the “AVG Praktijk/ ID Practice”, at the Radboud University Medical Centre. The question posed in the referral letter was; “Can you prescribe medication to reduce his agitation and hallucination? His neighbourhood complains about his behaviour.” It was impossible to have a good conversation with this mild intellectual disabled patient. His professional caregiver had to explain the situation. Mr P. lived alone in his own house. His parents and sister had passed away. A home care worker/practice nurse visited him every working day, and a professional caregiver came by every other day. Mr P.’s strange behaviour consisted of acting suspiciously, shouting, and talking to himself. He had been admitted to a psychiatric hospital for several weeks at the age of 73. He was diagnosed with schizophrenia of the paranoid type. All this information points to a psychiatric illness, however, in people with intellectual disabilities (ID) challenging behaviour can also be caused by somatic illnesses (1, 2). As an ID physician, I therefore first started the investigation with an exploration of possible somatic causes of challenging behaviour. As we will further explain in the discussion, Chapter 7, this proved to be worthwhile. The following question arose: “Could a pro-active comprehensive health assessment, conducted in primary care by a GP, have prevented the deplorable condition he was in when I first met him?

Definition of ID

Individuals are said to have an intellectual disability in cases of limited intelligence (IQ ≤ 70) and a reduced ability to cope with social, conceptual or practical changes. These impairments manifest before the age of 18 and persist throughout life (3). These disabilities manifest in all areas of life, including the individual’s health.

Health of people with ID

A recent study in England showed that the life expectancy at birth of people with ID is 20 years lower than that of people in the general population (4). People with ID are confronted with health inequities. Apart from the intellectual disability in itself, the aetiology of the intellectual disability also determines this inequity. For example, it is known that people with Down syndrome may have congenital heart disease. The extent of this congenital heart defect will partially determine their life expectancy. Moreover, persons with profound intellectual and motor disabilities (PIMD) demonstrated the presence of a wide range of physical health problems, with a mean of 12 problems per person (5). Epilepsy, one of the most prevalent health problems in this PIMD group, affects life expectancy negatively (6).

There are other factors that influence life expectancy and health, however. First, having a low socioeconomic status is a fundamental determinant of health. People with ID often belong to this vulnerable group (7). Second, there are problems in accessing health care (8). Half the ID participants in an interview study felt discriminated against by negative staff attitudes and behaviour. The willingness of the staff to make reasonable adjustments (i.e in communication) was low. Third, there are obstacles to receiving appropriate care, due to delays in, or problems with, investigating and diagnosing illnesses (9, 10). These problems are so serious that they can cause premature death. Fourth, patients with ID often do not notice or discuss unusual health signs, or do not respond to abnormal symptoms (11). Difficulties in recognising and expressing the signs of disease can lead to delays on the part of both patients and doctors (12). Fifth, the top twenty most common health problems in people with ID differs from the top twenty in the general population (13, 14). This can mislead doctors when they assume the same morbidity patterns as in the general population. Sixth, adults with ID are less likely to undergo recommended age- and gender-specific screening, as has been shown for the detection of, for example, colorectal -, breast -, and cervical cancer (15, 16) Seventh, people with ID face more risk factors, such as overweight or obesity (17, 18). Eighth, treating patients with ID seems complicated (10). Patients with ID receive four times more prescriptions than patients in the general population, most often psychotropic drugs (12, 19). The off label prescription of psychotropic drugs is more the rule than the exception (20). The side effects (e.g. tardive dyskinesia, metabolic syndrome) are very serious. These eight factors are part of the 'cascade of disparities'(18). Some of these factors cannot be changed (e.g. the aetiology of ID) but others could and should be addressed. In this thesis we want to pay attention to this.

Health care provision for people with ID in the Netherlands

There is no exact record of the number of people with intellectual disabilities in the Netherlands; the prevalence is estimated to be between 112,000 and 231,000 individuals (0.7-1.4% of the population) (13, 21). Half of these individuals live in residential care facilities, the other half live in the community.

In 2000 the Dutch Minister of Health recognised the medical care of people with ID as a new medical specialisation. ID physicians (Arts voor Verstandelijk Gehandicapten, AVG) are medical physicians who have undertaken a three-year vocational training course. The postgraduate training takes place at the Erasmus University in Rotterdam. The medical care of people with ID in residential care facilities in the Netherlands is subject to change, and in the recent past their medical care (i.e. that of half the ID population) was often exclusively delivered by specialised ID physicians. Nowadays, more GPs, in cooperation with the ID physicians, are involved in the medical care of people with ID in these residential care facilities. Meanwhile, ID physicians have started to provide care to people with ID in the community, in outpatient clinics. Many Dutch residential care facilities have an outpatient clinic for people with ID to which GPs can refer patients. At present, there are 88 outpatient ID clinics spread throughout the Netherlands (22). These outpatient clinics for people with ID can be found in hospitals or at the medical office of a residential care facility. The other half of the population with ID live in the community and receive medical care from their own GP.

The provision of primary care for people with ID has changed considerably since 2015. The Netherlands Institute for Social Research (Sociaal Cultureel Planbureau, SCP) investigated the cause of the rapidly increasing demand for health care for people with ID, and found that the citizenship paradigm is one of the reasons. The paradigm means that people with ID tend to live longer in the community than in residential care facilities; they should live the same life as anyone else as much as possible. The ratification of the Convention on the Rights of Persons with Disabilities (CRPD) in 2016 by the Dutch government should support them in this. As a result, the financial expenses related to this care and support increased considerably. This led the government to change their arrangements and laws for people with ID, with financial sustainability as an important focus. The legal changes accompany financial constraints. This resulted in less financial potential for patients with ID to live in residential care facilities, and consequently an increasing number of people with ID continued to live in the community. Society has also become increasingly complicated and individualistic in many different ways. This means that people with ID require more support from the healthcare sector, and Dutch GPs are increasingly faced with people with ID in their practice.

GPs and their patients with ID

The increase in ID patients who are dependent on GPs for their health care is not without problems. De-institutionalisation in the Netherlands started later than in neighbouring countries such as the UK and Sweden. In 1997 GPs in Wales and England were interviewed about this subject. They agreed that medical care for people with ID living in the community was their responsibility. They thus experienced a higher workload and could use some help and support from ID support workers (23). A Dutch study, conducted in 2014, showed similar results. Dutch GPs experience difficulties in providing medical care to the group of patients with ID, partially because of a lack of knowledge about diseases specific to these patients, and due to time constraints (24).

Health assessments (of people with ID) in primary care

Health assessments in the general population are mostly focussed on specific health topics, such as cardiovascular risk (25, 26). In the Netherlands an example of such an assessment is the prevention consultation for cardiovascular risk (Cardiovascular Risk Management Guideline of the Dutch College of General Practitioners; NHG standaard Cariovasculair risicomanagement) (27). There are also more comprehensive health assessments, such as the personal health check (‘Persoonlijke gezondheidscheck’) (28). Generally, comprehensive health assessments focussing on people in the general population are not very effective (29), but assessments for specific (high risk) populations are more effective (30). Two examples of such comprehensive health assessments for specific populations within primary care, both developed by Dutch researchers, are the Easy Care Standard developed for the geriatric population (31) and the Easy Care TOS, an instrument for the identification of frail older people (32). A meta-analysis has demonstrated that comprehensive geriatric assessments combined with a long-term management plan were effective for improving the survival and functioning of elderly patients (33). In an editorial, Stuck provides a shortlist of studies which show that comprehensive geriatric assessments benefit all ambulatory older patients (34).

Analogous to these examples there is evidence that health assessments for people with ID are also effective. Walmsley even suggested that an annual health assessment is probably the single most important improvement in the primary care of people with ID in the twenty-first century (35). A health assessment instrument consists of a questionnaire to be filled in by the patient (to be reviewed by the GP), supplemented with questions the GP should ask, and suggestions about physical examination and additional investigations and an action plan (36). Health assessment instruments can help GPs to be more aware of the specific health problems of ID patients (37). These instruments could be useful for GPs, who indicated that they have a lack of knowledge in this field. A systematic review of the impact of health assessments for people with ID showed that health assessments consistently lead to the detection of unmet health needs and to targeted actions to address those health needs (38, 39). Health assessments have been shown to positively affect the health and well-being of people with ID (38, 39). In Australia, UK, Scotland, and Canada comprehensive health assessments for people with ID are promoted by government regulations. Studies conducted in these countries, including three cluster randomised controlled trials, have demonstrated increased disease detection, as well as an increase in the uptake of prevention and health promotion activities (40-43). These studies have also shown that health assessments are cost effective (41, 44). People with ID, their caregivers, and their health professionals acknowledge the value of health assessments (45-49). Stake holders strongly supported the implementation of a comprehensive health assessment for people with ID (50).

In summary

People with ID have a considerably lower life expectancy, a pattern of morbidity that differs from the population, and problems noticing abnormal body signs, and when they notice these signs they have problems describing them to health professionals. On the other side, health care professionals lack knowledge about the specific morbidity spectrum of people with ID, have difficulties in communication with people with ID and probably over-prescribe medication. There are good reasons to assume that these difficulties can be tackled by regular screening with a health assessment instrument specific for people with ID. Given the positive results with comprehensive health assessments for people with ID elsewhere and the positive experiences applying pro-active health assessments for specific subgroups, we propose to develop a health assessment instrument for people with ID in order to improve the health status of people with ID in primary care.

We expect that pro-active health assessments for people could lead to the following improvements:

1. Health problems not reported by patients with ID will be detected earlier
2. Unnecessary complications can be prevented
3. Unnecessary medication use can be reduced
4. More attention to prevention and health promotion will be provided
5. Patients and health professionals will be more satisfied with the medical care delivered
6. Cooperation between GPs and ID physicians will be stimulated

Proactive health assessments for people with ID will stimulate a higher quality of primary care for this vulnerable population.

Research questions

Main research question in this thesis:

Can we develop a Dutch pro-active comprehensive health assessment instrument in order to accommodate GPs, support communication with the patient with ID, and thereby improve medical care for people with ID in primary care?

In order to develop a Dutch pro-active comprehensive health assessment instrument, we studied the following research questions:

1. Which pro-active comprehensive health assessment instruments are available and what is the quality of those health assessment instruments?
2. What are the opinions of Dutch general practitioners about applying a health assessment instrument for people with ID in daily practice?

3. Which items should be part of a health assessment instrument for people with ID that is to be used in primary care?
4. How comprehensible and clear is the pro-active health assessment instrument questionnaire for people with ID (and their caregivers)?

Outline of the thesis

Chapter 2

This case report provides insight into issues that affect medical care for people with ID. We will illustrate this with the description of three patients with ID and show that it takes time to discover the health issues that affect patients with ID. This is due to communication problems, the inability to understand bodily functions, symptoms and diseases, multi-morbidity, the atypical presentation of the disease at times, and the different prevalence rates for certain diseases when compared with the general population. This chapter is a prelude to the studies in this thesis.

Chapter 3

We performed a systematic review of the literature to explore the available health assessment instruments for people with ID that can be used in primary care, and to assess their quality. The quality of the studies included was judged on the basis of four domains (*development*, *clinimetric properties* (i.e. validity, reliability, feasibility, acceptability)*, content* (i.e. ID-related health problems, prevention and health promotion topics) and *effectiveness)*. We selected the most appropriate and highest quality instruments as input for the development of our own instrument.

Chapter 4

A successful implementation of health assessment instruments for people with ID strongly depends on how GPs look at the health assessments, as they are the professionals in primary care who have to implement these assessments. We therefore conducted a focus group study with GPs. In this study we assessed the opinions of GPs regarding medical care for people with ID in general and the use of health assessment instruments for people with ID in particular.

Chapter 5

We conducted a Delphi study using the information gathered in the previous studies. In three online rounds, the participating GP experts (GPs experienced in providing care to people with ID) and ID physicians had to reach consensus about the items that should be part of a new Dutch pro-active comprehensive health assessment instrument.

Chapter 6

In our focus group study (Chapter 4), as well as in our Delphi study (Chapter 5), GPs expressed a desire that patients with ID (with or without their caregiver) should complete the health assessment questionnaire at home. We therefore developed this health assessment questionnaire in cooperation with people with intellectual disabilities according to rules provided for developing good survey questions. We used the cognitive interview technique in the study described in this chapter in order to improve the health assessment questionnaire step by step.

Chapter 7

In the final chapter we reflected on the results found in the different studies and considered the implications of our findings from the perspective of the researcher, the patient with ID, the GP, the ID physician and the political field.

Chapter 8

The thesis ends with a summary in English, in Dutch, and with an easy-to-read Dutch version.

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2

Allow enough time

Primary care for people with intellectual disabilities

Case report

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Published as:
Bakker-van Gijssel EJ, Lucassen PLBJ. Neem de tijd; zorg voor mensen met een verstandelijke beperking in de eerste lijn. Nederlands tijdschrift voor geneeskunde. 2014;158:A7995

Abstract

People with intellectual disabilities (ID) have a higher prevalence of health problems than the general population and their health needs are often unrecognized and unmet. In this article we present three cases of patients with ID to illustrate some specific problems. A 22-year-old man, severely intellectually disabled, was presented with an unsteady gait. He had recently been diagnosed with Cohen Syndrome. Since he was unable to express himself, it took some time to discover that he had additional symptoms, e.g. frequent infections. Eventually, all his complaints fit with his syndrome. A 54-year-old woman, severely to moderately intellectually disabled, presented with new behaviour, i.e. loss of appetite, weakness in her legs and excessive thirst. Although she was able to speak, she was unable to explain what was wrong with her. Since we knew of the etiology of her disability, Prader Willi syndrome, we were more aware of the possibility of diabetes mellitus. A 56-year-old man, mildly intellectually disabled, presented with hearing voices for which he received antipsychotic medication. After a conversation in simple language, we discovered that he heard humming sounds rather than voices. He was ultimately diagnosed with tinnitus rather than psychosis. It takes time to discover the health issues that affect patients with ID. This is due to communication problems, the inability to understand bodily functions, symptoms and diseases, multi-morbidity, the atypical presentation of disease at times and the different prevalence rates for certain diseases when compared with the general population.

Ladies and Gentlemen,

Big changes are on the way in the care for people with intellectual disabilities (ID). In the future, approximately half of these individuals – whose care is now financed by the AWBZ (Exceptional Medical Expenses Act) – will fall under the *Wet Maatschappelijke Ondersteuning* (WMO: Social Support Act) and the *Jeugdwet* (Child and Youth Act) (1). As a consequence, an increasing number of people with ID will be living out in the community rather than in care facilities. Increasingly, then, Dutch GPs will be faced with providing care for these people.

In the Netherlands, no exact database is kept on people with intellectual disabilities; the prevalence is estimated to be between 112,000 and 231,000 individuals (0.7-1.4% of the population) (2). Individuals are said to have an intellectual disability in the presence of limited intelligence (IQ ≤ 70) and a reduced ability to cope with social, conceptual or practical changes. These impairments manifest before the age of 18 and persist throughout life. The disabilities are seen in all areas of life, including in the individuals' health. The degree of intellectual disability is expressed in IQ and developmental age (see table 1).

At present, an average general practice is already providing care for 10-15 people with ID. On average, these individuals visit their GP 1.7 times more often than patients without ID, and are prescribed medication four times more often (3). Most GPs (95%) have people in their practice with mild intellectual disabilities. An additional 68% of GPs have in their practice individuals with moderate intellectual disabilities, and 26% have patients with severe or profound intellectual disabilities (4). In this clinical lesson we describe a few patients with ID in order to illustrate specific aspects of potential health problems.

Table 1 Degree of intellectual disabilities classified according to IQ and developmental age (5)

Degree of intellectual disabilities	IQ score	Developmental age
Profound ID	0-20	0-1 yrs
Severe ID	21-35	2-3 yrs
Moderate ID	36-50	4-6 yrs
Mild ID	51-70	7-12 yrs

Patient A was a 22-year-old young man with severe cognitive impairment. He was unable to speak. At the request of the patient's mother, the GP referred him to the ID physician for two reasons. According to his mother, the most important problem at that time was his unsteady gait. Five years previously, because of kyphosis, the patient had undergone a T2-L3 spondylodesis, and for the past two years he had had an unsteady gait. The neurologist and the rehab doctor had not been able to say with certainty if his gait problem had anything to do with his surgery. Following the advice of the primary care physiotherapist, the parents had installed a treadmill at home. Unfortunately, the patient had already fallen off of it a few times. It was difficult to instruct him. The other reason for referral was the transition – because the patient had by that time become an adult – from the paediatrician to the ID physician. After an extensive intake by the ID physician, including a probing medical history, more medical problems came to light. For example, this patient was overweight. He was also prone to frequent infections when in contact with others. His parents' apprehension about these infections had led to them keeping him at home, which had prevented him from participating in a day activity programme. Additionally, he was easily disturbed by unexpected events and loud noises. His parents believed that his appearance and his medical problems were consistent with a specific syndrome. Exome sequencing had been requested 1.5 years previously by the clinical geneticist, and the results of this test had just become available in the Clinical Genetics department. The report showed that the patient had a mutation in the *COH1* gene on chromosome 8, which causes Cohen syndrome. Clinical symptoms consistent with Cohen syndrome are failure to thrive in childhood; severe myopia or retinal dystrophy; microcephaly; developmental delay; joint hyperlaxity; hypotonia; obesity, especially in the abdomen; slender hands and feet; neutropenia; and heart defects such as ventricular septal or valvular defects. The patient's unsteady gait could have been associated not only with vision problems, but also with hypotonia and hyperlaxity. His increased susceptibility to infection, as described by his mother, could very well have been a consequence of neutropenia. In consultation with the GP it was decided that the GP was to continue to manage this patient's care. The ID physician would provide the GP with general information about this syndrome and specific information about this patient, and inform the GP of steps to take. It was agreed to order lab testing with an eye to possible neutropenia. The patient would also be referred to a cardiologist for a single echocardiogram to identify potential heart defects. Because of the potential for retinal dystrophy, another visit to the patient's own ophthalmologist was to be scheduled – important because this patient was not able to report deterioration in his vision. Since activity is vital, he was referred to a physiotherapist experienced in treating people with ID. The patient could be observed clearly enjoying the treatment, training his muscles and his sense of balance, with the help of an air cushion. He was to return to the ID physician once a year, or more often if necessary. Meanwhile, he and his parents had begun looking for a suitable day activity centre.

Patient B was a 54-year-old woman with moderate to severe intellectual disability due to Prader-Willi-syndrome. Generally, her developmental level was consistent with that of a child four or five years of age. This patient lived at an external location of a care facility. She participated in day activities at the facility's primary site. The local GP provided her care, and the aid of the ID physician could be enlisted as necessary. Such was the case one morning when she had become unwell at her day activity centre. The professional caregiver reported what had happened. Normally, the patient could speak and sing songs, but could not say what she was feeling and what was bothering her. The caregiver explained that the patient had recently not been feeling well; she had been complaining more and singing less, had been unsteady on her feet and incontinent of urine, and occasionally pushed her food away yet often requested something to drink. The caregiver found it very strange that the patient did not want to eat since patients with Prader-Willi syndrome usually have an insatiable appetite. Her not wanting to eat, her increased drinking, her weakness and her incontinence were thus to be viewed as serious symptoms and reasons for thorough investigation. Although this was time-consuming, it did result in the diagnosis of diabetes mellitus: the patient's blood glucose value was more than 33.3 mmol/l (reference value: 3.5-7.8). In consultation with the GP it was decided that the GP, together with the GP's diabetes practice nurse, would assume responsibility for diabetes treatment.

Patient C was a 56-year-old widower with mild intellectual disabilities. His developmental level was estimated to be that of a child at the end of primary school. The GP had referred this patient to the ID physician because he had been hearing ‘voices’. These voices had been present especially at night, prevented him from sleeping, and made him anxious. He had been given Haldol 1 mg for night-time use, which did make him feel more calm, but had not resulted in better sleep.

The patient came to ID physician consultation hours accompanied by his professional caregiver from the regional health care agency for independent living, day activities and psychiatric conditions. An exhaustive, time-consuming interview shed an entirely new light on the voices. The patient’s wife, it turned out, had died a number of years earlier. At that point there had been no time to grieve: he had had to go right back to work at the sheltered workshop. Now there was no work for him there and he sat at home all day. The voices – in his right ear – had begun around the anniversary of his wife’s death. In attempts to flee from the voices, he was spending a great deal of time with family members, who were now indicating that his long, frequent visits were a burden. The patient preferred to stay overnight as well, in order to feel less anxious. The voices were drowned out when there was sufficient sound in his environment, such as when he was with his family or his household help. When asked precisely what the voices were saying, the patient replied that they were not voices, but rather a buzzing sound with an occasional beep in his right ear. He then added, ‘I am not crazy, doctor, but it drives me crazy.’

On the basis of this new information we suspected that the patient had been suffering from tinnitus rather than hallucinations. It was agreed that the GP would provide him with more appropriate sleep medication. In addition the GP referred him to the ear, nose and throat specialist. The case manager at the regional agency would find out whether the patient might be better off switching from the present support he was receiving, organised for people with psychiatric conditions, to support organised for individuals with ID, so that attention might be devoted to day activities, grief resolution, assistance in making appointments with the ENT specialist, and a healthy lifestyle.

Discussion

We know that the prevalence of health problems is higher in people with intellectual disabilities than in the general population, and that these health problems are often overlooked (6-8). Research in the UK on causes of death among people with ID has shown that, on average, men in this population die 13 years younger, and women 20 years younger than individuals without ID. Premature death in the general population is frequently related to lifestyle factors; among those with intellectual disabilities, however, common additional factors include delayed diagnosis due to problems in the evaluation and treatment of their illnesses (9). These problems occur for many reasons. First, communication with patients who have intellectual disabilities is often complicated, challenging and time-consuming. This is illustrated in all three of the cases presented here. Patient C is the only one who is able to tell his own story, yet he needs plenty of time to do so. To provide these patients with proper care, then, it is essential to reserve sufficient time for them when they come to see us.

Secondly, individuals with ID frequently lack insight into illness and have limited body awareness. The knowledge about illness and understanding of anatomy that members of the general population tend to have are largely absent among those with intellectual disabilities. This is why Patient A cannot indicate whether he has a visual deficit.

Thirdly, there is a high incidence of multimorbidity in this population – which can often be understood better if the etiology of the intellectual disabilities can be clarified, as with patients A and B. Fourthly, the presentation of symptoms in people with ID can be atypical. Patient B, for example, cannot say that she does not feel well; instead, she exhibits unusual behaviour. Fifthly, the prevalence of certain disorders is different in the intellectually disabled population than in the general population. Gastro -oesophageal reflux, for instance, is many times more common in individuals with severe intellectual disabilities than in members of the general population. Diabetes mellitus is also more frequently found in people with Down syndrome and Prader-Willi syndrome, as in the case of Patient B. In addition, many illnesses occur at a younger age among people with ID, and these people age prematurely.

Lastly, many people with ID are extremely dependent on those around them, and their informal carers are generally older than they are themselves. This underscores the importance of addressing the delicate balance between the burden and the supportive capacity of these carers.

Ladies and Gentlemen,

Approximately two-thirds of all GPs encounter difficulties in caring for people with intellectual disabilities (5). This is due to insufficient knowledge regarding behavioural and psychiatric issues, insufficient knowledge about specific clinical presentations, and insufficient time for seeing the patient. Especially this last matter needs to be addressed: making more time available for the visits of people with ID is an essential condition for the provision of good care.

The lack of knowledge among GPs has been better addressed in recent years through consultation with an ID physician; the availability of these consultations has increased through the opening of increasing numbers of ID physician practices and clinics. So far, there are 88 of these, distributed throughout the Netherlands (www.nvavg.nl/poliklinieken.html). As specialist generalists, ID physicians are particularly well-qualified to support GPs in providing medical care for individuals with intellectual disabilities. This is thanks to the knowledge ID physicians have about syndromes, to their competence working with intellectually disabled individuals, and to their expertise in implementing multidisciplinary care.

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3

Health assessment instruments for people with intellectual disabilities

A systematic review

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Published as:
Bakker-van Gijssel EJ, Lucassen PLBJ, Olde Hartman TC, van Son L, Assendelft WJJ, van Schrojenstein Lantman-de Valk HMJ. Health assessment instruments for people with intellectual disabilities-A systematic review. Res. Develop. Disabil. 2017;64:12-24

Abstract

Background People with intellectual disabilities (ID) experience health disparities. They are less likely to undergo recommended age- and gender-specific screening and health promotion. New diagnoses are frequently missed. Assessments with the aid of health assessment instruments are a way to address these problems.

Aim The aim of this review is to find the available health assessment instruments for people with ID used in primary care and evaluate their quality.

Methods We conducted an electronic literature search between January 2000 and May 2016. After a two-phase selection process (kappa: 0.81 and 0.77) we collected data from the 29 included peer-reviewed articles on the following four domains; *development*, *clinimetric properties* (i.e. validity, reliability, feasibility, acceptability), *content* (i.e. ID-related health problems, prevention and health promotion topics) and *effectiveness* of the instruments.

Results/Conclusions We distinguished 20 different health assessment instruments. Limited information was found on the *development* of the instruments as well as about their *clinimetric properties*. The *content* of the instruments was rather diverse. The included papers agreed that health assessment instruments are effective. However, only three instruments evaluated *effectiveness* in a randomized controlled trial. Patients with ID, carers and general practitioners (GPs) generally appreciated the health assessment instruments.

Implication Two instruments, "Stay well and healthy - Health risk appraisal (SWH-HRA)"and the "comprehensive health assessment programme (CHAP)", appeared to have the highest quality. These instruments can be used to construct a health assessment instrument for people with ID that meets scientific standards.

1. Introduction

People with ID are a vulnerable group in society. They have twice as many health problems as the general population, and their health needs are often unrecognized and unmet (1, 2). Furthermore, patients with ID receive four times more prescriptions as the general population, often for psychotropic medication(1). Reducing psychotropic medication leads to better behavioural functioning, and reduces the BMI, waist circumference and systolic blood pressure (3). People with ID are at risk of significant patient and/or doctors delay in recognizing diseases (4). Adults with ID are less likely to undergo recommended age- and gender-specific screening. This has been shown for example, for colorectal, breast and cervical cancer (5, 6). People with ID also face more risk factors, such as overweight or obesity (7, 8).

Health assessments can bridge the gap described above (9-14). The prevalence of certain specific diseases (e.g. gastro-oesophageal reflux disease, epilepsy, osteoporosis, visual impairment) in the population of people with ID differs from those in the general population (15). Health assessments for the general population often on one specific disease (e.g. cardiovascular risk) and are not comprehensive (16, 17). People with ID often do not come forward with their health complaints and GPs are not always aware ofthe highly prevalent diseases in this group. Health assessment instruments specific to people with ID can help the GPs tofocus on health problems that have a relatively high prevalence among people with ID (e.g. epilepsy, reflux disease). Health assessment instruments for people with ID often consist of three elements: new disease detection, age- and gender-specific preventive screening and health promotion. One study on a comprehensive health assessment programme (‘CHAP’) for people with ID, showed increased detection of vision impairment, hearing loss and new diseases in adults with ID living in the community (18). A systematic review and its recent update on the impact of health assessments for people with ID showed that health assessments consistently led to detection of unmet health needs and targeted actions to address those health needs (19, 20). Furthermore, a longitudinal cohort study that used data from the Health Improvement Network primary care database showed that more blood tests, more general health measurements and more medication reviews were done (21).

In most countries, GPs and nurses are involved in delivering health care to people with ID. However, these primary care professionals often lack the knowledge about specific diseases in patients with ID, and the time to deliver the necessary care (22). GPs indicate that they valued the use of a health assessment instrument in the care for patients with ID, as such an instrument structures the medical care for these patients (23). However, in the presence of a broad range of health assessment instruments it is unclear which instrument is most valuable in primary care. This systematic review aims to detect the available health assessment instruments and their quality for people with ID in primary care and evaluate their quality.

2. Methods

We performed a systematic review to detect the available health assessment instruments for people with ID in primary care and collect information about their *development, clinimetric properties (i.e. validity, reliability, feasibility, acceptability), content,* and *effectiveness*. We applied the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for systematic reviews (24).

2.1 Search strategy

We conducted a search in December 2013, which we updated in May 2016, in the electronic literature databases PubMed, CINAHL, Embase, PsycINFO. An information specialist assisted in building the search strategy. The search strategy covered two topics: (1) intellectual disability; and (2) health screening (Table 1).

We included all peer-reviewed articles about health assessment instruments for people with ID, published between January 2000 and May 16th 2016, in English, French, German and Dutch. We included papers of various designs; case reports, case series, case control studies, cohort studies and randomised controlled trials (RCTs). In order to include articles published before 2000, the reference lists of the retrieved publications were checked.

2.2 Study selection

The selection process consisted of two phases: a screening of title and abstract, followed by a selection based on a complete reading of the articles selected in the first phase. Two reviewers (EB, LvS or EB, PL) performed the selection independently. The level of agreement was calculated using Cohen's kappa (25) Disagreements about in- or exclusion were solved through discussion.

Table 1: Search strategy

Database	Block 1 Intellectual disabilities	Block 2 Health screening
PubMed	("Intellectual Disability"[Mesh:noexp] OR "Mentally Disabled Persons"[Mesh] OR "Developmental Disabilities"[Mesh] OR intellectual disab*[tiab] OR intellectually disab*[tiab] OR learning disab*[tiab] OR developmental disab*[tiab] OR developmentally disab*[tiab] OR mental disab*[tiab] OR mentally disab*[tiab] OR mental retard*[tiab] OR mentally retard*[tiab] OR mental handicap*[tiab] OR mentally handicap*[tiab] OR mental deficien*[tiab] OR mentally deficien*[tiab])	(("Mass Screening"[Mesh:noexp] OR "Outcome Assessment (Health Care)"[Mesh:noexp] OR "Preventive Health Services"[Mesh:noexp]) OR health screening[tiab] OR health protocol*[tiab] OR health guideline*[tiab] OR health assessment[tiab] OR health check*[tiab] OR health maintenance[tiab] OR preventive health research[tiab] OR preventive health service*[tiab] OR proactive healthcare[tiab] OR pro-active healthcare[tiab] OR pro-active health care[tiab] OR proactive health care[tiab] OR preventive care[tiab] OR preventive health care[tiab] OR preventive healthcare[tiab] OR proactive disease prevention[tiab] OR pro-active disease prevention[tiab])

Final search performed on 13 December 2013; plurals were allowed by including wildcards (*).
Blocks 1 and 2 were combined by the use of the Boolean operator AND.

2.3 Inclusion criteria

We included articles about health assessments for people with ID in a primary health-care setting. We defined a health assessment as a screening appropriate for all people with ID, irrespective of a presumed underlying cause of disability. Screening for an individual health condition (e.g. breast cancer screening) was not included. The screening had to be part of a more comprehensive health assessment instrument. The content of the health assessment instrument had to be described in the publication. If the health assessment instrument was not described, we only included the publication when the authors referred to an already known health assessment instrument described elsewhere. If that was not the case, we requested authors to send the instrument. Articles about adjusted instruments were also included in the review.

2.4 Exclusion criteria

We excluded articles about: prenatal and postnatal screening for ID, screening of children with ID, syndrome-specific health monitoring programmes (e.g. health watch Williams syndrome), screening for specific ID-related syndromes (e.g. fetal alcohol syndrome), for specific diseases (epilepsy), for a specific cause of

ID (phenyl-ketonuria), for specific issues (hearing impairment), and for specific psychiatric disorders (depression). Furthermore, we excluded articles with specific physiotherapy or occupational therapy screening instruments.

2.5 Data extraction

Two reviewers (EB, LvS) independently extracted the data from the included articles, using a pretested data extraction form, in which the following domains can be distinguished: *development, clinimetric properties (validity, reliability, acceptability, feasibility), content,* and *effectiveness*. The choice of these domains is based on the recommendations of De Vet and Steiner on how to assess the quality of measurement instruments (25, 26). Regarding development, we explored whether the instrument was built through scientific procedures (e.g. Delphi consensus method) or not. In the latter case, we studied the process of inclusion of content into the questionnaire. When the instrument was a modification of another instrument, we studied the modification process. With regard to content, we checked whether diseases with a higher prevalence in the ID population were included. Highly prevalent diseases in the ID population should therefore be part of the health assessment instrument. Regarding clinimetric properties, we searched for data on the assessment of validity, reliability, acceptability and feasibility. Finally, we extracted data about the effectiveness of the health assessment instruments. We used a pretested data extraction form to collect all information. After filling in the forms, the two reviewers discussed the differences and agreed on the final version.

As we included papers of various designs, we used the method of Naaldenberg et al. to assess the quality of the included papers (27). The criteria were as follows: (1) clear description of aim(s) and research question(s); (2) description and discussion of rationale for sample size chosen; (3) description and discussion of research population; (4) description and discussion of attrition rate; (5) description and discussion of measurements used; (6) discussion of study limitations; (7) description of intervention development; and (8) description of intervention content. In total, 16 points could be assigned to each paper, two points per criterion if information was provided and elaborated, one point if marginal information was provided and discussion or elaboration was lacking and zero points if no information was provided. Some criteria were not applicable for some studies. This is shown in total amount of points that could be assigned per study. We therefore calculated the proportion of the maximum score as a quality measure. Again two reviewers (EB, LvS) independently assessed the quality of the papers and discussed the outcome.

3. Results

3.1 General characteristics

We identified 5970 articles (see Fig. 1). After applying exclusion criteria and removing double citations, 2983 articles remained. These articles were screened on title and abstract. For this first level of screening the calculated kappa was 0.81, indicating good agreement between the two reviewers. (25) Of the retrieved 65 articles, two reviewers (EB, PL) independently assessed the full text of each article. For this second level of screening, kappa was 0.77. With reference checking we found no new instruments, but we did find additional information on one of the instruments (28). Finally, we included 29 publications on 20 instruments, all written in English. Not all these instruments are true measurement instruments, but e.g. diagnostic instruments, health checklists, or a mixture. As an example, “the user led health assessment” and “the SWH-HRA” use quantitative measurement scales (e.g. Townsend disability scale, Geriatric depression scale), while the “CHAP” uses a comprehensive health checklist. The instruments could be completed by patients with or without their carers, by doctors or nurses, or by doctors and nurses, together with the patient with or without carers.

Most studies originated from the United Kingdom (n=18) (9-11, 28-42) The other studies came from Australia (n=6)(13, 18, 43-46), USA (n=4)(47-50), and Canada (n=1) (51).

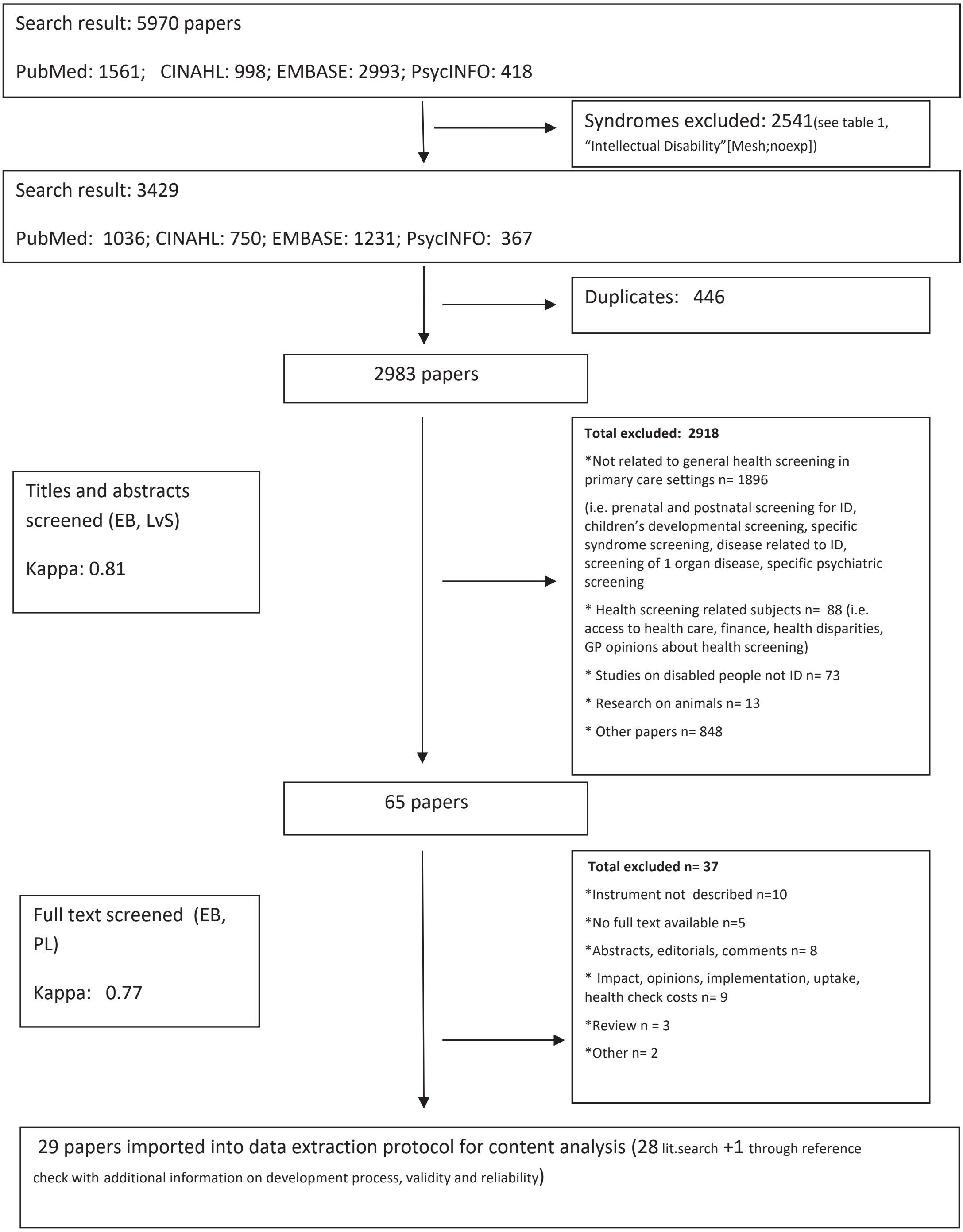

Fig. 1: Flowchart structured literature search.

3.2 Development of the health assessment instrument

For four instruments the formal procedures of development were described (Table 2) (28, 35, 49, 51). Two of these (“health toolkit” and “let’s get healthy together”) used focus groups for the construction of the instrument (35, 49). The qualitative method of the focus group that led to the “let’s get healthy together” instrument was described clearly (49). For “the health toolkit” this information was limited (35). The other two instruments (the “preventive care checklist for adults with developmental disabilities” and the “OK health check”) were developed in a (Delphi) consensus procedure (28, 51). The Delphi procedure was adjusted for “the OK health check”; experts met each other in small groups or as individuals (28). To discuss and reach consensus about “the preventive care checklist for adults with developmental disabilities” experts met each other in a four-day colloquium (51)

It appeared that three instruments originated from a previously developed scale (10, 31, 33). Two of them (“User led health assessment” and “21st health check Glasgow U.A.P.”) are modified versions *of* the “CHAP” (10, 33). For the “user-led health assessment” a focus group of five older adults with Down syndrome voted on the potential items to be included from the “CHAP”. They also suggested additional items to be included (33, 52). Nor the development of the “CHAP” itself, nor the modification process of the “21st health check Glasgow U.A.P , are described. The health check developed by Chauhan was based on a combination of the “Cardiff Health Check” and the “QOF” (Quality and Outcome Framework) (31). Chauhan modified the “Cardiff Health Check” by excluding the specific system inquiry sections, which require a yes or no answer. The “Welsh health check for adults with a learning disability”, adopted by entire Wales, is also a modification of the ‘Cardiff health check” (40). The modification process is not described. The development of the Scottish health check programme for adults with learning disabilities was not described, nor found at the website link provided in the article (41).

Table 2: Quality domain criteria of health assessment instruments

Author **Name instrument**	**Quality of study**	**Development described**	**Validity/ reliability tested**	**Feasibility /acceptability tested**	**Content:** **1.Disease detection** **2.Prevention** **3.Health promotion**	**Effectiveness tested**
Hunt ^{2006} *Health toolkit*	1. 10/16	focus	-	-	1,2,3	-
Sullivan ^{2006} *Preventive care checklist for adults with DD*	2. 11/16	consensus meeting	-	-	1, 2, 3	-
Aronow ^{2005}, Hahn ^{2011} *SWH-HRA*	3. 13/16 4. 12/16	-	validity reliability	feasibility	1, 2, 3	-
Klimon ^{2007} *Let's get healthy together*	5. 14/16	focus-groups	-	-	1, 2, 3	-
Codling ^{2007} *My little health booklet*	6. 10/16	-	-	-	1, 2, 3	-
Cassidy ^{2002}	7. 10/16	-	-	-	1, 3	-
Chauhan ^{2010}	8. 13/16	*Cardiff health check* modification	-	-	1,2,3	-
Fernando ^{2001}	9. 11/16	-	-	-	1, 2, 3	-
Lewis ^{2002}	10. 14/16	-	-	-	1, 2, 3	-
Martin ^{2003}	11. 11/16	-	-	-	1, 2, 3	-
Martin ^{2004}	12. 7/16	-	-	-	1, 2, 3	-
McConkey ^{2002}	13. 13/16	-	-	-	1,3	-
Fender ^{2007} *The user led health assessment*	14. 15/16	*CHAP* modification	-	feasibility	1,3	-
Cooper ^{2006} *The 21st health check*	15. 11/14	*CHAP* modification	-	-	1, 2, 3	–
Baxter ^{2006}, Felce ^{2008}, McConkey ^{2014} *Cardiff health check*	16. 11/16 17. 13/16 18. 11/16	-	-	acceptability	1, 2, 3	-
Anderson ^{2015} *The Welsh health check for adults with learning disabilities*	19. 9/16	*Cardiff health check* modification	-	-	1,2,3	-
Hunt ^{2001}, Marsh ^{2008}, Matthews ^{1997} *The 'OK' health check*	20. 8/14 21. 6/10 22. 12/16	delphi study	validity reliability	-	1,3	-
Lennox $^{2001,2006,2007,2008, 2010}$, Byrne ^{2014} *CHAP*	23. 13/16 24. 11/16 25. 12/16 26. 11/16 27. 13/16 28. 8/14	-	-	acceptability	1, 2, 3	+
Lennox ^{2010} *Ask, health diary*	**27. 13/16**	-	-	acceptability	1	+
Cooper^{2014} *The Scottish health check*	**29. 14/16**	-	-	-	1,2,3	+

3.3 Clinimetric properties

The *validity* and *reliability* were evaluated for two instruments (Table 2). The “Stay well and healthy- Health risk appraisal (SWH-HRA)” has been evaluated on face validity, criterion validity, test–retest reliability and internal consistency (50). The “SWH-HRA” consists of more than 20 subscales. For validity assessment, six SWH-HRA subscales were compared with comparable measures used in the advanced practice nurse (APN) intervention. These scales showed significant correlation between 0.390 ($P<0.01$, medical risks/health problems) and 0.739 ($P < 0.001$, number of medications) with the APN intervention. For test–retest *reliability* correlations ranged between low 0.476 (single item scale health) to a high 0.992 (basic activities of living scale). The average per cent agreement for dichotomous risk factor scales was 92.9%.

The “OK health check” was tested for construct *validity* and inter-rater *reliability*. The use of the “OK health check” provided more extensive information (mean of 7.75 more items per patient) than care as usual. The inter-rater reliability showed a mean agreement of 92.5% (28).

Two instruments were tested for *feasibility* (33, 48) and three instruments for patients’ *acceptability* (Table 2) (42, 45) *Feasibility* was tested in the “SWH-HRA” and the “user led health assessment”. The “SWH- HRA” was adjusted after a pre-pilot phase with simplifications of the vocabulary and adding visual analogue faces. Qualitative interviews after these adjustments of the “SWH-HRA” showed that participants experienced less difficulty in responding. They were interested in receiving their results and understood what they could do to diminish identified health risks. (48) In the “User led health assessment” people with ID were able to participate in 21 of the 32 physical assessment items (33).

Acceptability for patients was tested in the “CHAP” and the “Ask health diary” in 32 adolescent students with ID of a special school. Baseline and exit interviews were available for only nine students. Seven students indicated a positive impression (45). No information was found on patients’ acceptability of the “CHAP” tested in an adult population. Patients’ satisfaction was tested with a brief questionnaire at the end of the (Cardiff) health check appointment (42). Of the 58% of the patients who filled in the questionnaire, 100% were happy with the health check, and 96% reported they had been told how to improve their health. All were willing to come back next year.

Physicians' opinions were globally assessed in two instruments. GPs preferred to be involved in the assessment directly and not after referral by another physician (38). Furthermore, a significant number of GPs agreed to use the "CHAP" (44).

In the other studies, most patients valued the use of health assessment instruments positively (9, 30, 33, 36, 45). For one instrument they hesitated at the start, but ended with great enthusiasm (49). Cares mostly supported the idea of using the assessment instrument (9, 18).

3.4 Content of the health assessment instruments

Health assessment instruments often consist of three elements: (new) disease detection, prevention, and health promotion. Fifteen of the twenty instruments contain all three elements, four instruments contain two elements and one instrument contains one of these elements (Table 2)

The size of the health assessment instruments is rather diverse; from 14 items (i.e. visual assessment, BMI) in the health check according to Chauhan (31) to 100 pages with questions in "the 21st health check" (10). We did not find a complete description of the entire content of Hunt's "health toolkit" (35).

All included instruments pay attention to (new) disease detection, in particular ID-related health problems (Table 3). Three ID-related health problems are included in nearly all health assessment instruments: oral health/dental care, visual impairment, and hearing impairment. All possible ID-related health problems to detect (new) diseases are addressed in the extensive "21st health check" (10).

Sixteen instruments included prevention. According to the authors this concerns immunizations and cancer screening programmes (e.g. colon cancer screening, breast cancer screening, testis screening, pap smear). Immunization issues are covered in 12 instruments. The "CHAP" covers the total package of prevention activities (13, 18, 43, 44). Like the "CHAP", the "Welsh health check for adults with learning disabilities" also pays attention to many prevention subjects. There is one difference: where the first includes the testis screening, the latter has an item about aortic aneurysm (40). Sullivan's "Preventive care checklist for adults with ID" and Codling's "My little health booklet" only contain immunization issues (32, 51). Hunts' "Health toolkit" includes at least pap smear and breast cancer screening (35). In the other eight instruments, besides immunizations, the cancer screening programmes (most often mammography screening and pap smear) are partly covered(9-11, 18, 29, 34, 37, 45, 47, 48, 50).

With regard to health promotion subjects, in all but two instruments questions about diet, exercise, alcohol and drugs use, and smoking, are part of the health assessment of patients with ID.

Most health assessment instruments contain additional content besides (new) disease detection, prevention and health promotion (Table 4). Although medication is not always reviewed, sixteen instruments address medication use

Table 3: Health assessment focus on ID-related health problems (a–z)

Author *Name instrument*	Abuse/ sexual health	Be-havioural problems	BMI	Choking	Constipation	Epileps	Falls/ accident	Feet problem
Hunt ^{2006} *Health toolkit*	?	?	?	?	?	?	?	+
Sullivan ^{2006} *Preventive care checklist for adults with DD*	+	+	+	+	+	+	-	-
Aronow ^{2005}, Hahn ^{2011} *SWH-HRA*	+	+	+	+	+	-	+	+
Klimon ^{2007} *Let's get healthy together*	-	-	-	+	-	+	-	-
Codling ^{2007} *My little health booklet*	-	-	-	-	-	+	-	-
Cassidy ^{2002}	+	+	+	-	-	+	-	-
Chauhan ^{2010}	-	+	+	-	+	+*	-	-
Fernando ^{2001}	-	-	+	-	-	+	-	+
Lewis ^{2002}	+	+	+	-	-	+	-	-
Martin ^{2003}	-	+	+	-	+	+	-	+
Martin ^{2004}	-	+	+	+	+	+	-	-
McConkey ^{2002}	-	-	+	-	-	-	-	+
Fender ^{2007} *The user led health assessment*	-	-	+	-	+	-	+	+
Cooper ^{2006} *The 21st health check*	+	+	+	+	+	+	+	+
Baxter ^{2006}, Felce ^{2008}, Mc Conkey ^{2014} *Cardiff health check*	-	+	+	-	+	+	-	-
Anderson ^{2015} *The Welsh health check for adults with learning disabilities*	-	+	+	-	+	+	-	-
Hunt ^{2001}, Marsh ^{2008}, Matthews ^{1997} *The 'OK' health check*	-	+	+	+	+	+	-	+
Lennox $^{2001,2006,2007,2008, 2010}$ Byrne^{2014} *CHAP*	+	+	+	+	+	+	-	-
Lennox ^{2010} *Ask, health diary*	-	+	-	-	-	+	-	-
Cooper ^{2014} *The Scottish health check programme*	-	+	+	+	+	+	+	+

+	included in the health assessment instrument
–	not included in the health assessment instrument
?	no information
+*	part of QOF, but not described in paper

Gastro-oesophageal reflux disease	Hearing impairment	Hear	Lung	Mental illness	Mobilit	Oral health	Osteoporosis	Sleep problems	Thyroid disease	Visual impairment
?	+	?	?	?	?	+	?	?	?	+
+	+	+	+	+	-	+	+	+	+	+
+	+	+	+	-	+	+	+	+	-	+
-	-	+	-	-	+	+	-	-	+	+
-	+	-	-	-	+	+	-	-	-	+
-	+	-	-	+	+	+	-	+	-	+
-	+	+*	+*	+*	-	-	+*	-	-	+
-	+	+	+	-	+	+	-	+	-	+
-	-	-	-	+	+	+	-	-	-	-
+	+	-	-	+	+	+	-	+	+	+
+	+	-	-	+	+	+	-	+	+	+
-	+	+	+	-	-	+	-	-	-	+
+	+	+	+	-	-	+	-	+	-	+
+	+	+	+	+	+	+	+	+	+	+
+	+	+	+	-	+	+	-	-	+	+
+	+	+	+	-	+	+	-	-	+	+
-	+	+	+	+	+	+	-	+	-	+
+	+	+	+	+	+	+	+	-	+	+
-	+	-	-	-	-	+	+	-	+	+
+	+	+	+	+	+	+	+	+	+	+

Table 4: Additional content of health assessment instruments

Author *Name instrument*	Weight, length, blood pressure	System check/ physical examination	Additional investigation (e.g. urine/blood tests)	Medication 1=Review 2=Actual	Action plans
Hunt [2006] *Health toolkit*	?	?	+	?	?
Sullivan [2006] *Preventive care checklist for adults with DD*	-	-	+	1	+
Aronow [2005], Hahn [2011] *SWH-HRA*	+	+	+	2	-
Klimon [2007] *Let's get healthy together*	+	-	-	1	-
Codling [2007] *My little health booklet*	+	-	-	2	+
Cassidy [2002]	+	-	+	2	+
Chauhan [2010]	+	-	+	-	-
Fernando [2001]	+	+	+	-	+
Lewis [2002]	+	-	+	2	-
Martin [2003]	+	-	+	1	+
Martin [2004]	+	-	+	1	+
McConkey [2002]	+	+	+	-	-
Fender [2007] *The user led health assessment*	+	+	-	2	-
Cooper [2006] *The 21st health check*	+	+	+	1	+
Baxter [2006], Felce [2008], McConkey [2014] *Cardiff health check*	+	+	+	1	-
Anderson [2015] *The Welsh health check for adults with learning disabilities*	+	+	+	1	+
Hunt [2001], Marsh [2008], Matthews [1997] *The 'OK' health check*	-	+	-	1	+
Lennox [2001,2006,2007,2008, 2010], Byrne [2014] *CHAP*	+	+	+	1	+
Lennox [2010] *Ask, health diary*	+	+	-	1	+
Cooper [2014] *The Scottish health check programme*	+	+	+	1	-

\+ included in the health assessment instrument
\- not included in the health assessment instrument
? no information.

A physical examination is part of all health assessment instruments, with the exception of the "preventive care checklist for adults with developmental disabilities" and the "health toolkit" (35, 51). However, the extent of the physical examination differs. Weight, height and blood pressure are part of most of the health assessment instruments. Other instruments contain a more extensive physical examination (10, 11, 13, 18, 29, 33-36, 38-46, 48, 50). Fifteen assessment instruments require additional testing (urine/blood) (9-11, 13, 18, 23, 29-31, 34, 35, 37, 38, 40-48, 50, 51). In more than half of the health assessment instruments, an action plan is included (9, 10, 13, 18, 30, 34, 36-40, 43-46, 51). This sequence of actions to be performed after the health check is discussed with the patients with ID and their carers. The action plan consists of referrals to specialists, advice about laboratory investigations, and information about public health or health promotion activities.

3.5 Effectiveness of the health assessment instruments

Studies evaluating the effectiveness of the health assessment instruments were scarce.

Three instruments were tested in a (cluster) RCT (13, 18, 41). The "CHAP" was tested in a cluster RCT and compared to care as usual. This trial found an increase in health promotion, prevention and new disease detection in the group using the health assessment instrument compared to the control group (13). For example, detection of visual impairment increased more than 6-fold (RR 6, 95% CI: 1.1–40), hearing testing 30-fold (RR 30, 95% CI: 4–230,) and detection of new diseases 1.6-fold (RR 1.6, 95% CI: 0.9–1.8,). Furthermore, immunization updates showed a 9-fold (RR 9, 95% CI: 4.2–19) increase and cervical smears showed an 8-fold (RR 8, 95% CI: 1.8–35) increase.

The "Ask health diary" was tested in a cluster RCT. The 2 × 2 treatments were: care as usual, "Ask health diary" alone,"CHAP" alone, and both "CHAP" and "Ask health diary". In contrast to the "CHAP", using the "Ask health diary" did not improve health promotion, prevention and new disease detection (18). The "CHAP" alone showed an increase in hearing testing (OR 4.5, 95% CI: 1.9–10.7) and vision testing (OR 3.4, 95% CI: 1.4–8.3) as well as an increased disease prevention activity (increased pneumococcus vaccination (OR 7.4, 95% CI: 1.5–37.1), hepatitis A vaccination (OR 5.4, 95% CI: 1.8–16.3)) and increased health promotion (increased weight measurement (OR 3.1, 95% CI: 1.5–6.4).

In the “Scottisch health check programme for adults with learning disabilities” more newly detected health needs were met in the intervention group, although not statistically significant (OR 1.73, 95% CI: 0.93–3.22, p=0.085) Significantly more health monitoring needs were met in the intervention group. (OR 2.38, 95% CI: 1.31–4.32, p=0.0053) (41).

3.6. Quality assessment of the included papers

The designs of the studies were very different. The aims of 26 studies were described well. As already mentioned, we found little information on the development of the instruments. Convenience samples were very often used. In 4 studies, which included participants, a power calculation was performed. Information about inclusion or exclusion of participants often missed. The quality ratings of the papers are shown in Table 2. The lowest rating was 7/16 and the highest was 15/16.

4. Discussion

4.1 Main findings

We detected 20 different health assessment instruments for people with ID. The instruments vary in size, content, the way they are administered, and in their design. This implies that not all quality criteria used apply to all instruments. The process of *development* of the instruments has been described for four of the instruments, but only for two it was described clearly. We found limited information about the *clinimetric properties* of the instruments. The reliability and validity were tested for two instruments; the “OK health check” and on subscales of the “SWH-HRA”, whereas we would expect information about at least face validity and content validity for all instruments. While the acceptability and feasibility are important quality criteria, we found only two feasibility studies. Limited specific information on acceptability was available, but in general, patients with ID, carers and primary care professionals appreciated the health assessment instruments. In terms of *content,* only oral health/dental care, visual impairment, hearing impairment were asked for in nearly all health assessment instruments. Other highly prevalent diseases were often missing, but there was considerable variation. Prevention and health promotion topics were often incomplete or absent, whereas physical examinations, medication reviews and action plans were part of half of the instruments. Three instruments (i.e. “CHAP”, “Ask health diary” and “the Scottish health check programme”) were tested for *effectiveness.*

We did not find any instrument that met all the important quality aspects. Based on the results with respect to the domains, two instruments are potentially better than others, the “SWH-HRA” and the “CHAP”. Others, the “preventive care checklist for adults with developmental disabilities” and the “Scottish health check programme for adults with learning disabilities” are promising, but need further investigations.

We also evaluated the quality of the papers in which the instruments were found. The best paper according to the qualification method was the study of Fender et al (33).

4.2 Strength and limitations

This is the first systematic evaluation of the quality of health assessment instruments for people with ID. In this systematic review we used an extensive search strategy, with the help of an information specialist, to identify relevant studies. We searched in all relevant databases for articles in English, Dutch, German and French. We conducted this review in accordance with the available scientific standards on in- and exclusion of studies and data extraction by employing two reviewers independently. Furthermore, we found a good inter-observer agreement for in- and exclusion.

As we did not search the so-called “grey literature” we may have missed one or more instruments. However, we screened the reference lists of all included studies and did not identify missing instruments. We did not succeed in obtaining the complete version of one of the instruments (i.e. “Health toolkit” (35)) despite having contacted the authors of the instrument. We decided to judge the quality of the available instruments with broad quality indicators that were scored rather subjectively, because we are not aware of any validated instrument being available for this specific broad task. The scoring of the quality indicators was done by two reviewers independently. Almost all ID-related health problems identified in the health assessment instruments are grounded in the scientific literature. A formal list of ID-related health problems does not exist. Therefore we could have missed any ID-related health problems. To describe the quality of the studies we applied a published method developed to evaluate studies with greatly different designs.

4.3 Comparison with other literature

There are no reviews available on the quality of health assessment instruments for people with ID. An example of a similar review, but for a different population, with different instruments, is a study on screening tools for frailty in elderly in primary care (53). The results of this study show remarkable similarities with our own findings: the assessment instruments vary greatly in design, content, size, and scientific quality.

Three reviews related to health problems for people with ID are relevant here. The systematic review by Balogh on organizing health care services for persons with ID points out that there is an urgent need for research to identify optimal health services for people with ID and concurrent physical problems (54). Our study confirms this, and can be a first step in fulfilling this need by giving insight into the available health assessment instruments. The reviews of Robertson et al. aimed to assess the impact of health checks on health and well-being of people with ID. They showed that health assessments consistently led to detection of unmet health needs, including life-threatening conditions, and targeted actions to address these(19, 20). These findings are in line with ours. GPs indicate that they are willing to use a health assessment instrument if it is evidence-based, but they expect barriers for implementation (55, 56).

5.Conclusions

Health assessment instruments can help primary care professionals to provide better medical care to people with ID, and are a way to bridge the health disparity gap. In general, such instruments are well appreciated. However, the results of this review show that there is room for improvement in the application of more rigorous methods for the development and evaluation of high-quality health assessment instruments for people with ID. Such instruments should be appropriate, evidence-based and acceptable. The instruments found in this review can be used to construct such a health assessment instrument.

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4

GPs' opinions of health-assessment instruments for people with intellectual disabilities

A qualitative study

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Published as:

Bakker-van Gijssel EJ, olde Hartman TC, Lucassen PLBJ, van den Driessen Mareeuw F, Dees MK, Assendelft WJJ, van Schrojenstein Lantman-de Valk HMJ. GPs' opinions of health-assessment instruments for people with intellectual disabilities: a qualitative study. Brit. J. Gen. Pract. 2017.

Abstract

Background General practitioners (GPs) provide healthcare to people with intellectual disabilities (ID). People with ID find it difficult to express themselves concerning health-related matters. Applying health assessments is an effective method to reveal health needs, and can play a role in prevention and health promotion.

Aim The aim of this qualitative study is to explore GPs' considerations about applying a health assessment for people with ID.

Design and Setting This focus group study was conducted among a selection of Dutch GPs.

Method An interview guide was developed. All discussions were audiorecorded and transcribed. Analysis was performed using the framework analysis approach. Two researchers independently applied open coding and identified a thematic framework. This framework and the summaries of views per theme were discussed in the research team.

Results After four focus groups, with 23 GPs, saturation was reached. Three main themes evolved: health assessments in relation to GPs' responsibility; the usefulness and necessity of health assessments; and barriers to using health assessments on people with ID. A health assessment instrument for people with ID can help GPs to focus on certain issues that are not so common in the general population. GPs are motivated to use such a tool if it is scientifically tested and results in significant health gains. However, GPs identify barriers at the level of GP, patient and organisation.

Conclusion Most GPs in our focus groups consider providing medical care to people with ID their responsibility and indicate that a health assessment instrument could be a valuable tool. In order to deliver good care, they need education and support. Many barriers need to be overcome before a health assessment instrument can be implemented.

Introduction

People with Intellectual disabilities (ID) have a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). Therefore, the ability to cope independently is reduced, resulting in impaired social functioning(1). People with ID often have difficulties in expressing themselves concerning health issues, leading to health disparities(2, 3). Their difficulties in recognising illnesses and diseases often lead to a significant patient and/or doctor delay(4). Premature deaths for people with ID are mostly due to problems in receiving appropriate care, due to delays or problems with investigating, diagnosing and treating illnesses(5, 6)

Applying health assessments by means of questionnaires, focusing on highly prevalent diseases for people with ID, have proven to be an effective method to detect health needs, and can play an important role in health monitoring and health promotion(7-11). Research has shown increased disease detection as well as an increase in prevention and health promotion activities(7-10). Most patients with ID valued the use of health assessment instruments positively(12-16). In residential care in the Netherlands, medical care for people with ID is often delivered by a specialized intellectual disability (ID) physician. ID physicians are medical physicians who have undertaken a three-year vocational training course. (In 2000 the Dutch minister of health recognised the medical care for people with ID as a new medical specialisation. The 3-year postgraduate training for physicians takes place at the Erasmus University in Rotterdam, as a part of the institute for training of GPs. It consists of a combination of working and learning in the field of care for people with ID. Part of the training is an orientation in closely related fields of medicine, like neurology, genetics, and psychiatry). Nowadays, many Dutch residential care facilities have an outpatient clinic for people with ID to which general practitioners (GPs) can refer patients. Outside the residential care facilities, GPs are involved in delivering healthcare to people with ID. In Australia and the UK, GPs are encouraged by their governments to carry out health assessments on people with ID(17, 18).

GPs experience difficulties in the care of these people. Lack of knowledge and time constraints are among the most important difficulties for GPs (19). A health assessment instrument can help the GP to detect medical problems of people with ID in a structured and comprehensive way. It also helps GPs to overcome communication barriers (20). Health care professionals, including GPs , agreed on the use of a comprehensive health assessment programme (8, 21). In another study, GPs preferred to be involved in the assessment directly and not after referral by another physician (22).

However, health assessment instruments for people with ID are not yet commonly applied in the Netherlands. Therefore, the aim of this qualitative study is to explore Dutch GPs' opinions about applying a health assessment instrument for people with ID in daily practice.

Method

Study design and participants

Focus-group interviews with Dutch GPs were conducted and reported according to consolidated criteria for reporting qualitative research (COREQ) (23). This qualitative method is appropriate to explore and clarify what GPs think about using health assessments for people with ID. As health assessments for people with ID are not yet used in the Netherlands, GPs can only talk about their expectations, as opposed to their own experience. In these case, focus groups are helpful to formulate an opinion on unfamiliar topics through discussion(24). GPs were recruited through e-mail and telephone contact. A purposive sampling strategy was applied to ensure heterogeneity in the characteristics of the participating GPs, such as age, sex, type of general practice and experience with care of people with ID. The aim was to include participants with different levels of medical experience and sympathy for working with people with ID. The target number of GPs in each focus group was five to eight participants. The invitation letter provided information about the research question, the goal of the project, the moderator (GP), the researcher (ID physician), and practical information.

All GPs gave informed consent. Anonymity and confidentiality were ensured, and participants gave permission to audiotape the discussion. Participants were offered a € 20 gift voucher, study points and reimbursement of travel expenses. Approval of an ethics committee according to Dutch legislation was not required.

Focus-group interviews and data collection

The moderator of the focus groups was a female GP and senior researcher with extensive experience in qualitative research. The observer of the focus groups was a female ID physician and PhD student. The observer made field notes. All focus-group discussions took place in the conference room of a general practice.

The authors developed an interview guide based on the literature and discussions within the research group. After each focus-group discussion, the interview guide was slightly adjusted to explore the entire field of the research question (progressive focusing) (25). The discussions lasted 75–90 minutes and all focus-group discussions were audio-taped and transcribed verbatim by a medical student. The observer checked the transcripts and corrected these when necessary.

Analysis

Data analysis was performed using the framework analysis approach. This type of analysis is suitable to meet specific information needs and provide outcomes or recommendations (26, 27). The five key stages of the analysis process (familiarization, identifying a thematic framework, indexing, charting, mapping and interpretation) were included (28). All transcripts were uploaded in ATLAS-ti (version 7.5) to support qualitative data analysis. The transcripts were read frequently to gain familiarity with the data and open (unrestricted) coding was applied. Data collection proceeded until saturation was reached, meaning that no new major themes emerged from the data. The initial coding was discussed, and a code book was developed with definitions of the codes. During this process, themes were identified and discussed. The themes that reflected the research question formed the thematic framework. During the index stage the thematic framework was systemically applied to all data (transcripts). All quotes belonging to a certain theme were charted. Through abstraction and synthesis, summaries of views were formulated per theme. These summaries were discussed in order to define the final concepts.

Results

GP participants

Thirty-six GPs were invited to participate of these, 13 GPs indicated that they were too busy to participate or the date was not suitable for them. In total, 23 GPs participated in four focus groups between December 2014 and February 2015 (Table 1).

Table 1. Characteristics of the 23 participating GPs

	n
Sex	
Male	11 (47,8%)
Female	12 (52,2%)
Mean age GP, years	47,4
(range)	(29-67)
Mean experience as GP, years	16,6
(range)	(0-38)
Location GP practice	
Rural area	6
Urbanized area	5
Urban area	8
Other	4
Experience with people with ID	
Yes	21
Little	2
No	0
Estimated number of patients with ID in GP practice	
Mean	82
(range)	(10-350)

Three main themes were identified from the data: (1) GPs’ responsibilities with regard to health assessments for people with ID in primary care; (2) the usefulness and necessity of a health assessment; and (3) barriers for GPs when using health assessments for people with ID in daily primary care.

GPs’ responsibilities with regard to health assessments for people with ID

Most GPs consider medical care for people with ID their full responsibility as people with ID live in the community. In order to deliver high quality care for people with ID, the GPs emphasized that specific tools, education and support are needed.

> *"I think that all GPs could do with some extra tools, education and support in order to provide this group with good care." (GP B , female, 59 years)*

GPs stated that they are familiar with delivering integrated care to specific groups of patients, such as older patients. Furthermore, they indicated that the practice nurse could play a role in supporting them in this type of care.

> *"Wouldn't it be possible to deploy a practice nurse (PN), just like you do in elderly patients, in order to monitor these people in one way or another?" GP K, female, 57 years)*

Some GPs stated that they would like to see people with ID themselves as this would give them the opportunity to get to know the patient with ID better.
A number of GPs suggested that medical care for people with ID is not a task for the GP, but for the ID physician. They mentioned that GPs are not competent enough with regard to medical knowledge and experience to deliver high-quality medical care for this section of the population.

> *"This is a very specific field, of course. It's too absurd for words that GPs should simply do this 'on the side'. I think it's irresponsible, really." (GP U, female, 47 years)*

Other GPs stated that their ID-physician colleagues could act as a facilitator in the care for people with ID living in the community. The ID physician, for example, could help GPs to identify patients with ID who are in need of a health assessment. However, when complexity increases, GPs prefer the opportunity to refer these patients to the ID physician.

> *"I would be in favour of this… to look more closely as a GP, if I'd have certain information about an elderly patient or if I'd suspect that someone has intellectual disabilities. A first and second level assessment I could do myself. But if an assessment would become more extensive and complex, I'd call in an ID-physician, for instance, and wouldn't do it myself." (GP F , female, 34 years)*

Furthermore, they stressed that GPs already face lots of time constraints and that they are not able to spend much time on the care for people with ID.

Usefulness and necessity of health assessments

GPs indicated that if people with ID experience difficulties in expressing themselves concerning health-related matters, health assessment instruments could help them to deliver proactive care:

> *"Generally speaking, I think that you [as a GP] often need to adopt a much more proactive approach, as you need to know what kind of problems you can expect [when dealing with patients with ID] and check actively whether these problems are indeed present. You need to assume there's every chance that people don't mention that problem themselves or……… if they do, they use other words." (GP B, female, 59 years)*

This proactive care could result in the detection of new diseases and the prevention of serious complications. GPs noticed that this is especially important regarding people with ID, as the impact of medical complications on their lives is often significant:

> *"Yes, because they [patients with ID] have difficulties expressing their health problems in a clear way. The complications are not pleasant for anyone, of course, but things will become even worse for them. She was already deaf and now she has a poor eyesight as well. Yes, I think that it's very important to screen people with ID." (GP U, female, 47 years)*

Furthermore, a health assessment instrument for people with ID might also help GPs to focus on certain specific issues that are more common in the ID population. According to GPs, a health assessment instrument can provide an overview of the multiple problems people with ID encounter. GPs are often not aware of the specific health problems of people with ID:

> *"I think it's a very good idea to be presented with some sort of problem list or such a tool being made available. Then at least you'll have*

> *some sort of guideline, an overview of problems they might have." (GP S, female, 36 years)*
>
> *"I can think of a number of patients I've seen in practice of whom I know by now they have disabilities. They consult me on a regular basis, but it's hard to find out what their request for help is and what is the best way to help them. I would really like to give them such a list." (GP F, female, 34 years)*
>
> *"This group of people [people with ID] has a high rate of comorbidity. So they often have three or four problems instead of one. I think this could help me to be……… constantly aware of that." (GP G, female, 64 years)*

However, at the same time, GPs acknowledge that awareness among GPs is urgently needed as they do not always recognise patients with ID:

> *"Yes, and a question I find very interesting is one that has not yet been fully answered: how are you going to raise awareness among GPs? I think it's a very nice screening instrument and all, but before it can be used something else has to be done. Yes, that's what I think." (GP M, female, 38 years)*
>
> *"I think there's still a very large group [of people with ID] that has not yet been diagnosed and for that reason gets stuck." (GP M, female, 38 years)*

GPs indicated that a health assessment tool for people with ID could help them with caring for these people. However, such a tool should be scientifically tested and result in significant health gains:

> *"I'd be motivated to use such an instrument, if I'd know for certain it'd be of significant benefit." (GP L, male, 67 years)*
>
> *"I would also like to know what research has been done, what the results are, how much is actually being overlooked and whether there*

> *is any evidence before introducing such a comprehensive tool as an integral part of the health care for people with intellectual disabilities.” (GP H , female, 63 years)*

Barriers to using health assessment instruments in daily practice

GPs identified multiple barriers against the use of health assessment instruments in delivering healthcare to people with ID. These barriers are at the patient level, GP level or organisational level (Table 2). This study has separated the barriers, but in daily practice they are intertwined.

Table 2. Barriers experienced by GPs

Patient level	GP level	Organisational level
Group of ID patients is diverse	Don’t recognize ID patients	Extra time needed
Communication problems	Don’t want to stigmatize	Payment needed
Large system around patient	Feeling incompetent	Increased workload
Little continuity of care	Attitude/affinity	More people needed
Care system not medically trained	Don’t want to somaticise	ID patient is not registered
	Fear medicalisation	
	Aversion of checklists	
	Checklists hinder conversation	

Barriers at patient level

GPs stated that the communication with the patient and the whole (care) system that surrounds the patient is often quite complicated. According to GPs, this is due to a lack of continuity of care and the fact that caregivers/daily care professionals are often not medically trained. Urgent medical needs of people with ID can easily be missed or not recognized. They fear that this barrier will also interfere with using health assessments. If daily care professionals do not recognize medical symptoms, they cannot support the patient or the GP during the health assessment:

> *“Yes, that makes it more difficult, I’ve noticed in practice. Communication-wise, it’s very difficult to explain something to them and to deal with that.” (GP O, male 37 years)*

> *“That’s my experience, too. People [care professionals] often have good intentions, which is fine of course. But they lack medical training and knowledge, and information may not be passed on correctly. So if you want to carry out such things [health assessments], you need*

> *someone who can be present, too, a practice nurse for instance.” (GP A, male 62 years)*

Barriers at GP level

GPs indicated that they do not always recognize patients with ID. They experience an enormous heterogeneity in the group of patients with ID and they discuss the uniform approach to this heterogeneous group of patients. Furthermore, some GPs hesitate to label a patient with an ID diagnosis as they do not want to stigmatize them.

> *“But it’s all relative, of course, as you’re talking about a very large group which is actually very diverse. I think that the majority of patients you see in practice are high-level clients. I experience a big difference between them and the group of obviously lower-level clients. So I find it very difficult to put them all in the same box.” (GP M, female 38 years)*

GPs brought up that they generally felt incompetent to deliver good quality of care for their patients with ID. GPs used the following terms for their own feelings: ignorant, action embarrassment(not knowing how to deal with the situation), feeling powerless, incapable and incompetent. Some GPs showed affinity and a positive attitude with patients with ID, whereas others did not. GPs indicated that they do not like to somatise. patients with ID. GPs fear that applying health-assessment instruments may lead over-medicalisation:

> *“Some people [GPs] don’t like going to an institute at all, because they, well, they just don’t know how to deal with them[people with ID]. I hear a lot of complaining, whereas I just think that people [GPs] often feel powerless and incompetent. So it’s very difficult.” (GP M, female, 38 years)*

> *“You are somatising them [people with ID] a bit, and……, it is often rather troublesome for them to go to a doctor… so it’d better be useful.” (GP S, female 37 years)*

Some GPs pointed out that they have a strong aversion to checklists. In their opinion, checklists can hinder good conversation and communication with the patient:

> *"It seems very useful in some respects, but my reluctance to these types of lists is..... that so many boxes need to be ticked that there's no time to ask them how they are. …that the entire communication process, well, you should watch that filling in these lists doesn't hinder the communication. I'm aware that's not the intention." (GP B, female 59 years)*

Barriers at organizational level

GPs noticed that they do not always label patients with ID with a specific ICPC (International Classification of Primary Care) code in the GPs' medical system. The reason given for this were that some GPs did not know this code, whereas others did not want to stigmatise them. Therefore, it is not easy to select patients with ID from the practice list in order to invite them for a health assessment:

> *"Well, for a start, there is a group of people of whom we don't even know they have intellectual disabilities..... And if we do, we don't write it down. It's taboo to record such a thing." (GP A, male, 62 years)*

GPs indicated that using a health assessment on people with ID will take extra time and increase their workload; therefore, to implement such an assessment more staff would be needed. Furthermore, the additional effort of GPs should be financially rewarded:

> *"Because I'd like that, too, but without good financing and support it's not easily feasible." (GP A , male, 62 years)*

> *"If you'd ask what's been most successful, then it's the list the doctor doesn't need to fill in, you see… Because the management of diabetes improved a great deal when the practice nurses got involved. We [GPs] aren't very good at this. Like I said before, we'll need more people, if they're going to implement these kinds of things." (GP A, male, 62 years)*

Discussion

Summary

A health assessment instrument for people with ID in primary care is a tool to help the GP to focus on highly prevalent diseases in the ID-population, on public health issues, and on health promotion. GPs' considerations about using health-assessment instruments for patients with ID focus on three main themes: GPs' responsibility concerning health assessments for patients with ID; the usefulness and necessity of using health assessments; and barriers GPs expect to encounter. Most GPs consider providing medical care to patients with ID their responsibility; others emphasise cooperation with ID physicians and/or practice nurses; and some believe this specialised care belongs to trained ID physicians. GPs stress that specific tools, education and support are needed in primary care. They are willing to use a health-assessment instrument, if the tool is scientifically tested, and its use leads to significant health gains. However, GPs also identify many barriers, such as the diversity of patients with ID, difficulties with recognition, problems with registration (with the consequence that it is impossible to select patients with ID as a group), communication difficulties with patient and care system, insufficient knowledge, resistance against checklists, fear of medicalisation and lack of resources (time, staff, money). In the light of these findings, it will not be straightforward to implement health-assessment instruments in primary care. A remarkable finding is that GPs hesitate to record people with ID in their system, as they do not want to stigmatise them. Awareness among GPs needs to be stimulated in recognising people with ID. This recognition can lead to better person centered medical care instead of stigmatisation. A recent study showed that 100% of the patients with ID were happy with the health check. All were willing to come back next year (29).

Strengths and limitations

A rigorous qualitative method was applied in this study: data collection continued until saturation was reached and open coding was applied independently. As far as the authors are aware, this is the first study using focus-group discussions with progressive focusing, and in accordance with the COREQ guidelines on this subject in ID literature.

Although measures were taken to include a heterogeneous group of GPs, GPs without affinity to patients with ID may have been missed. GPs without affinity might have mentioned other and/or alternative considerations and barriers. The representative quotations needed to be translated into English. This may have led to some loss of meaning.

Comparison with existing literature

GPs' feeling of responsibility for the medical care of people with ID was also found in other studies (30, 31). The same is true for the fear of an increased workload, and reluctance to carry out health-assessment programmes for people with ID (30, 31). In current study, GPs indicated that the practice nurse and ID physician could play a role in supporting the GP in this type of care. This fits with other studies which show that GPs rely on key support workers to enable them to carry out this role (31). GPs prefer to be involved in the assessment directly and not after referral by another physician (22). Communication difficulties, high staff turnover, poor understanding of a patient's symptoms, mentioned in a study about general medical care to people with ID, resemble outcomes in the authors research (32). A health assessment implementation study noticed better healthcare, uncertain benefits, organisational barriers, and more engagement between the person with ID, their care provider and the GP (20). In contrast with other research, this study did not find that GPs view patient histories as unclear and that they fear a lack of compliance with the GPs management plans (32).

The attitudes of GPs towards other instruments for screening in primary care, such as instruments for screening depression and cardiovascular risk, resemble the attitudes mentioned in our study (33, 34). The GPs in these studies describe the loss of unique information by using an instrument, the uncertainty of how to integrate the instrument in the consultation, the poor fit between the application of a questionnaire with the role of a GP, and time constraints (33, 34).

Implications for the implementation of health-assessment instruments

The evidence of impact of a health check on well-being of people with ID is described in a review study (9, 10). In our systematic review, we found 20 different health-assessment instruments for people with ID (35). However, there were many deficits in the scientific development of all instruments. First there is a need to develop and validate a health-assessment instrument according to evidence-based principles and focus on the suitability of this instrument in primary care. The Dutch primary care system resembles the system in the UK. Every citizen has his own GP. However, at the moment primary care in the Netherlands is subject to major changes. In the slipstream of these changes we hope that more attention will be paid to primary care for people with ID. Second, greater focus is required on a number of organisational barriers, such as the education of professionals in primary care and the implementation of the ICPC code for intellectual disabilities. A first step is the course developed by the Dutch College of General Practitioners together with the Department of Primary and Community Care at Radboud University Medical Centre. Third, as fear of stigmatising patients with ID appeared to be one of the main barriers against good care, this needs to be highlighted when educating GPs.

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5

Development of a health assessment instrument for people with intellectual disabilities

A Delphi Study

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Published as:
Bakker-van Gijssel EJ, Lucassen PLBJ, olde Hartman TC, Assendelft WJJ, van Schrojenstein Lantman-de Valk HMJ. Development of a health assessment instrument for people with intellectual disabilities: a Delphi study. Fam Pract. 2018 1–8 doi:10.1093/fampra/cmy004.

Abstract

Background People with intellectual disabilities (ID) experience health inequalities. Applying health assessments is one way of diminishing these inequalities. A health assessment instrument can support general practitioners (GPs) in providing better medical care to people with ID.

Objectives The aim of this study was to determine which items should be part of a health assessment instrument for people with ID to be used in primary care.

Methods This Delphi consensus study was conducted among 24 GP experts and 21 ID physicians. We performed three anonymous sequential online questionnaire rounds. We started with 82 'general' items and 14 items concerning physical and additional examinations derived from the international literature and a focus group study among Dutch GPs. We definitely included items if more than 75% of the GP experts agreed on their inclusion.

Results The participation rate in all rounds was above 88%. The expert groups proposed 10 new items. Consensus was reached on 64 'general' items related to highly prevalent diseases, public health and health promotion. Consensus was also reached on 18 physical and additional examination items.

Conclusion For the first time, experts in a Delphi study were able to arrive at a selection of items for a health assessment instrument for people with ID. The overall agreement among the GPs and ID physicians was good. Because the experts prefer that patients complete the health assessment questionnaire at home, questions that cover these items must be formulated clearly.

Introduction

People with intellectual disabilities (ID) are a vulnerable group of human beings. They often have low socioeconomic status, a fundamental determinant of health (1). ID are defined as a significant reduction in ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in reduced ability to cope independently, which in turn leads to impaired social functioning (2). People with ID frequently experience difficulties in expressing themselves (3). Difficulties in recognizing the signs of disease and expressing them can lead to delays on the part of both patients and doctors (4). The problems in accessing health care and receiving appropriate investigations, diagnoses and treatments cause premature deaths and increase morbidity (5, 6). All of this results in experiences of health inequalities.

Applying health assessments is one way of diminishing these health inequalities. Patients with ID can be identified through a ‘Read Code’ (as in Great Britain), entitlement to social welfare payment, or ICPC code P85.00, or ICD code F90-73, depending on the identification system used and appropriate in each country.

Studies on primary care for adults with ID have shown that health assessments result in new disease detection, improved health promotion and increased participation in preventive activities (7-9). Felce et al. state that annual health checks are justifiable; these do not reduce the number of needs found (10). People with ID, their (professional) caregivers and health professionals acknowledge the value of health assessments (11-16). Studies have shown that health assessments are cost effective(7, 17). Health assessments for people with ID in primary care are not yet applied in the Netherlands.

Medical care for people with ID in the Netherlands is provided by either general practitioners (GPs) or ID physicians. ID physicians are physicians who have undertaken three years of vocational training. They deliver medical care to people with ID living in residential care facilities. Nowadays, most residential care facilities have an outpatient clinic to which GPs can refer patients with ID. GPs deliver medical care to all patients with ID living in the community. A Dutch study showed that GPs experience difficulties in providing medical care to this vulnerable group of patients. GPs have a lack of knowledge about specific diseases in patients with ID (18). In a focus group study, GPs pointed out that they feel responsible for the medical care for people with ID. To deliver good care, GPs need tools, education and support (19). As a tool, health assessment instruments can support GPs in providing medical care to people with ID. There is, however, no such tool available in the Netherlands. Moreover, the health assessment instruments available present deficiencies in terms of their development, clinimetrics, content and effectiveness (20). Our purpose is to develop a health assessment instrument for people with ID based on valid scientific principles. As earlier research has pointed out that the content of existing health assessment instruments exhibits deficiencies, the aim of our study is to explore among GPs and ID physicians which items should be part of a health assessment instrument for people with ID to be used in primary care.

Methods

Study design

The Delphi technique is a widely used method for gathering data from expert respondents with the aim of achieving consensus on variables for the topic under investigation (21). In our Delphi study we investigated consensus on items to be included in a primary care health assessment instrument for people with ID. We took into account the methodological criteria cited in the review by Diamond et al.(22). In accordance with these Delphi criteria respondents anonymously took part in three sequential online questionnaire rounds. After each round, the respondents received feedback enabling them to reconsider their views based on the report of the overall results including the views of the other members of the group. The advantage of a structured Delphi method is that the opinion of the group cannot be dominated by the views of a few. Communication among experts is avoided. Another advantage of the Delphi method is that less of the experts' time is wasted by travelling and engaging in long meetings.

Participants

We invited GPs interested in this field (GP experts) and ID physicians to participate. GPs are the professionals who have to carry out the health assessments; ID physicians are professionals with a higher level of education and expertise in the ID field. We aimed for 10–15 participants per group (22, 23). The respondents who agreed to participate after this invitation (which implied informed consent) received the questionnaires by e-mail. At the end of the first questionnaire, they filled in some personal questions (e.g. years of experience as medical doctor, specialization, age, sex, the estimated number of people with ID in their practice). The participants were offered a 20 euro gift voucher in appreciation of their contribution. Approval of an ethics committee was not required according to Dutch legislation.

Delphi process

We developed the first set of items based on information extracted from the two most preferred health assessment instruments – the Stay Well and Healthy! Health Risk Appraisal (SWH-HRA) and the Comprehensive Health Assessment Programme (CHAP) – according to an earlier review study and from information from a focus group study with 23 GPs (8, 19, 20, 24). As the total number of items exceeded the number that could be addressed in reasonable time in the online survey, two researchers, PL (a GP) and EB (an ID physician), first independently reduced the set of items, discussed their findings and reached consensus. Next, this reduced set was discussed within the whole research group, who had access to the original information. This reduced set consisted of 82 'general' items and 14 items on physical and additional examinations. At the start of the study, we decided to have a maximum of 3 online rounds. Two review studies on Delphi procedures indicated that this is a reasonable number of rounds (25, 26). We pilot tested the three questionnaires to identify ambiguities and errors.

Consensus definition

We defined consensus as reached when more than 75% of the GP experts agreed (said 'yes') to the inclusion of an item as part of the health assessment instrument (25). This consensus on the part of GP experts was motivated by the fact that the primary care health assessment instrument would be used by GPs. The information and consensus provided by ID physicians was used as additional information for the GP experts as ID physicians are more experienced in medical care for people with ID. The online questionnaires were developed in LimeSurvey (version 1.92). As a formal measure of agreement between the rounds, we calculated the change in percentage agreement per item (25). For the quantitative data analysis, SPSS (version 22) was used.

Procedure

Figure 1 presents an overview of the procedure. In the first round, all the participants (GP experts and ID physicians) were asked to give their opinion (yes, no, no opinion) regarding the inclusion of items. All items were arranged thematically (e.g. gastroenterology; constipation, dysphagia, etc.). Each theme ended with an open field in which the participants could provide comments or suggestions for new items. The information received from the open fields was analysed qualitatively. In the second round, we re-presented the items that obtained 50–75% consensus, together with new items proposed in the first round. These new items could also be 'old' items from the first round presented in a different way based on the suggestions made in the first round. The participants were given information about the exact percentage of agreement in both expert groups, as well as additional information received from the open field comments. In the third and final round, the participants received feedback on the 'near' final list of items included. The new items proposed in the first round, and obtained 50-75% consensus in the second round were re-presented for the last time. In addition, this round was used to pose 10 questions to obtain further information and opinions concerning the application and implementation of the primary care health assessment instrument.

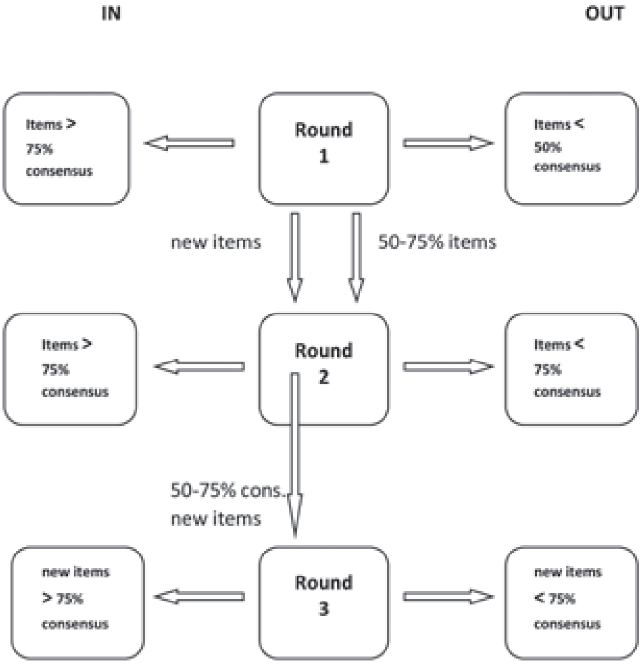


Figure 1. Flow chart of the item-consensus procedure (2016) for the development of a health assessment instrument for people with intellectual disabilities

Results

Participants

Forty GP experts and 25 ID physicians received an invitation to take part in this study. Twenty-four GP experts and 21 ID physicians replied that they were willing to take part. After the first round, two participants (1 GP and 1 ID physician) resigned, one due to time constraints and the other due to feeling uncomfortable with being called an expert. In all the 3 rounds 20 GPs and 18-20 ID physicians participated (Supplementary Figure S1). The participation rate in all rounds was above 88%. In both groups, the range in age (30–65 years) was well-balanced. Overall, 70% of the participants were female (75% in the ID physician group and 60% in the GP group), which resembles the actual situation in the field. The participants had an average of 16 years of medical experience.

Final item selection

Overall, consensus was reached on 64 'general' items to be included in the list (Table 1). The 14 items on physical and additional examinations were rearranged into new items using the information provided during the rounds. Consensus was reached on 18 items concerning physical and additional examinations (see H1, H2 and H3 in Table 1). The overall agreement among the GP experts and ID physicians was good . ID physicians provided more additional comments.

Table 1. Final overview of items on which consensus was reached

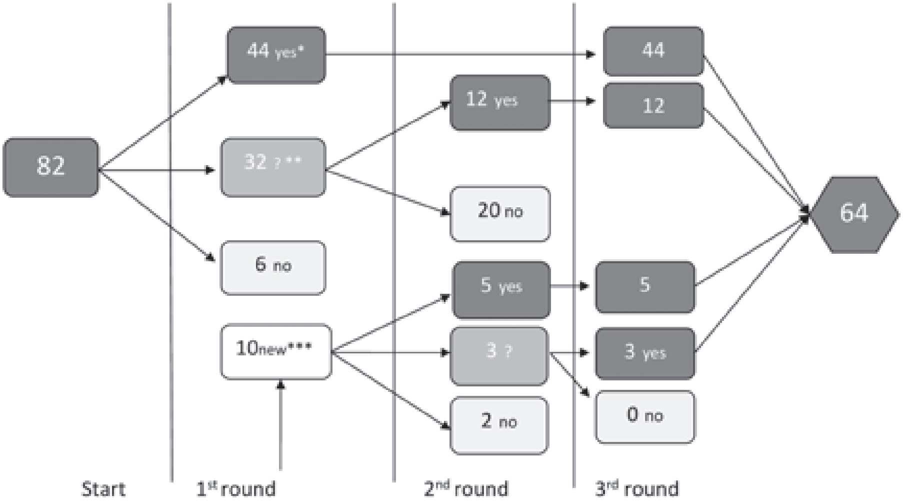
A.	Detection of highly prevalent diseases in the ID population		
A1.	Sensory impairment		
	vision	hearing	
A2.	Gastrointestinal tract		
	GERD	swallowing problems/choking	
	defecation problems	constipation	
	weight gain/loss		
A3.	Urogenital tract		
	Difficulty urinating	urine incontinence	STD
	(rec.)urine tract infections	sexuality	
	menstrual problems	contraceptives	
A4.	Locomotion system		
	moblity problems	falls	
	arthralgia		
A5.	Cardiorespiratory tract		
	sleeping in upright position	respiratory tract problems	cong. hart disease
	chestpain	shortage of breath	aspiration pneumonias
	coronairy problems	allergies	
A6.	Neurology		
	sleep	memory problems	
	pain	epilepsy	
	functional decline		
A7.	Additional		
	dental care		
B.	Detection of behavioural, psychological or psychiatric problems		
	behaviour	behavioural changes	
	psychiatric problems		
C.	Focus on public health		
	breast cancer screening	immunisations	
	colon cancer screening		
D.	Focus on health promotion		
D1.	Substance use		
	smoking	alcohol lconsumptiion	
	drug use		
D2.	Life style		
	sports	outside activities	
	healthy diet		

E.	**Focus on daily living**	
E1.	**Daily activities**	
	meaningful daily activities	
E2.	**Social contacts**	
	support network	relations
E3.	**Additional**	
	use of devices/aids	
	ADL functioning	
	communication (problems)	
F.	**Personal information**	
F1.	**Care providers**	
	involved health care professionals	
F2.	**Personal questions**	
	living circumstances	legal guardian
	general concerns about health	legal status (according Dutch law))
F3.	**(familiy) History**	
	family history	
	level of ID	
	etiology of ID	
G.	**Medication**	
	actual medication use	medication review
	attention for psychotropic medication	
	self medication	
H.	**Physical/additional examination**	
H1.	**Physical examination**	
	general impression	consciousness
	otoscopy	hearing (wispercard)
	length/weight/BMI	pulse/bloodpressure
	auscultation heart	locomotion observation
	communication observation	dysmorfology
H2.	**Blood and urine test**	
	only on indication	
H3.	**Referrals**	
	referral for vision test, hearing test, clinical genetisist (only on indication)	
I.	**Additional**	
	DNR	treatment limitations
	restraints (e.g. door locked)	

Flow of inclusion of 'general' items

Figure 2 shows the flow of inclusion of the 'general' items in all three rounds. Originally 82 'general' items were presented to the participants in the first round. The participants reached consensus (> 75% agreement) on 44 'general' items. An overview of these items can be found in the supplementary material. Six items were rejected (< 50% agreement) in this round (cryptorchidism, male genitals, urinary tract general information, posture, hobbies, reason for medication). Full agreement (100%) in both expert groups was reached during the first round on nine items: vision, hearing, gastro-oesophageal reflux disease (GERD), defecation (problems), behaviour (changes), smoking, alcohol and drug (use) and sports (activities). The GP experts fully agreed (100%) on dental care and weight loss/gain.

In the second round, the remaining 32 'general' items with agreement of 50-75% and 10 new 'general' items (Table 2) were (re)presented to both expert groups. Supplementary Table S2 shows the changes in agreement (%) between the first and second rounds. The items with an asterisk (*) were presented in the second round with additional information from the first round.



* see supplementary table S1
** see supplementary table S2
*** see table 2

Figure 2. Flow of inclusion of 'general' items throughout Delphi rounds one, two and three for the development of a health assessment instrument for people with intellectual disabilities (2016)

Both expert groups reached full agreement (100%) on psychiatric problems. The items work (paid or unpaid) and day care were replaced by a new item, 'meaningful daily activities', on which agreement had been reached.

Table 2. New health assessment items proposed by GPs and ID physicians in the Delphi study (2016)

Subject	GP 2nd round (%)	GP 3rd round (%)	IDphysician 2nd round (%)	IDphysician 3rd round (%)	Decision
Not to be reanimated*	100	-	89	-	in
Treatment limitations*	100	-	78	-	in
Restraints (e.g. door locked)*	85	-	61	-	in
Meaningful daily activities*	80	-	89	-	in
Spasticity*	40	-	72	-	out
Skin diseases/problems*	40	-	78	-	out
Legal status*	90	-	78	-	in
Sexual transmitted diseases**	65	100	72	100	in
Aspiration pneumonias**	65	95	94	100	in
Congenital heart disease**	50	75	61	90	in

* new items presented in round 2 for the first time
** new items in 2nd represented in 3rd round with additional qualitative information
light grey: 100% in 1 expert group
middle grey: > 75% GP expert group: inclusion
dark grey: 100% in both expert groups

Table 2 shows the new 'general' items proposed in the first round. All 10 new 'general' items were suggested by ID physicians. Of these, skin diseases and sexually transmitted diseases (STDs) were also mentioned by the GP experts. Both expert groups reached full agreement on STDs. The GP experts reached full agreement on the items 'Do not resuscitate' (DNR) and 'Treatment limitations'. In total, for another 20 items (Table 2 and supplementary Table S2) the agreement among the GPs was above 75%.

Inclusion of items concerning physical and additional examinations

Both expert groups agreed (95%) that physical and additional examinations should be part of the health assessment instrument. The information provided in the first round on the items concerning physical and additional examinations suggested a rearrangement of those items into new ones. These rearrangements were based on existing guidelines on physical examination in both fields (primary care and ID medicine). Some of the original first round items, i.e. specific blood tests (e.g. haemoglobin/mean corpuscular volume [Hb/MCV], glucose, thyroid-stimulating hormone [TSH] screening, etc.) and urine samples, were omitted. The experts agreed that blood and/or urine tests should only be undertaken when indicated by the results of the questionnaire. New items that came forward were general impression, consciousness, hearing (with the help of the Whispered Speech Picture Chart) (27), dysmorphology, observation of communication and locomotion. Finally, more than 75% agreement was achieved on the following items: general impression, consciousness, length/weight/body mass index (BMI), blood pressure, pulse, auscultation of the heart, otoscopy, hearing (with the help of the Whispered Speech Picture Chart (27), dysmorphology, observation of communication and locomotion. Other investigations/examinations (referrals to a clinical geneticist, referrals for vision or hearing tests) should only take place when indicated by the results of the questionnaire (see section H, Table 1).

Opinions concerning the application and implementation of the primary care health assessment instrument

In the third round it became very clear that the experts (GPs and ID physicians) would like the patient and carer to complete the questionnaire (partly) at home. The experts also agreed on the fact that the outcome of the questionnaire should be easy to introduce in their electronic medical system. The GPs could use some support. The practice nurse was mentioned in this context, but not without training on the subject. Ninety-five percent of the experts were in favour of a final action plan as a follow-up to the health assessment.

Conclusions

Summary

In this study, we aimed to generate agreement concerning a list of items that should be part of a primary care health assessment instrument for people with ID. Our research group selected 82 ‘general’ items and 14 items on physical and additional examinations based on a review of the literature. The experts had the opportunity to propose new items and provide additional qualitative suggestions. They suggested 10 new items and proposed a rearrangement of the items on physical and additional examinations. After three rounds, agreement was reached on 64 ‘general’ items and on 18 items concerning physical and additional examinations. The overall agreement among the GP experts and ID physicians was good.

Strengths and limitations

We conducted this Delphi study according to the key methodological criteria proposed by Diamond et al.’s review (25). For example, before we started, we defined the criteria for agreement (> 75%) on the uptake of an item, specified the planned number of rounds and established criteria for dropping items in each round. The participation rate was high, above 88%, in all three rounds (Figure 2). All experts had experience of and an affinity with medical care for people with ID. This is both a strength and weakness of the study. This study represents the opinions of GP experts and ID physicians with experience in this field. GPs with less experience may not be convinced by these results. The Netherlands is the only country in the world with medical specialists in ID: ID physicians. Their participation reinforced the quality of the procedure of reaching consensus as they suggested all new items and provided more additional comments.

For only five items (osteoporosis, involvement of medical specialists, skin problems, chest pain, arthralgia), we found remarkable differences among GP experts and ID physicians (Table 2, Supplementary Tables S1 and S2). These differences may reflect the different prevalence in primary care versus specialist care(28, 29).

The item set presented to the participants was selected by two researchers (a GP and an ID physician) and discussed by the whole research group. Although the participants were able to come forward with new items, it is possible that a different selection of the items originally presented would have resulted in a different final list.

Comparison with existing literature

In the scientific literature, the development of four other primary care health assessment instruments for people with ID has been described. Two of these (the ‘Preventive care checklist for adults with developmental disabilities’ and the ‘OK health check’) were developed through a (Delphi) consensus procedure (30, 31). As in our study, the participants in those studies were experts on medical care for people with ID. Our experts agreed on the inclusion of falls and mobility. These two items are not included in the ‘Preventive care checklist for adults with developmental disabilities’ (31). In the latter, osteoporosis and thyroid disease are included, whereas they were excluded from our final list, as well as from the ‘OK health check’. Items on sexual health, falls and gastro-oesophageal reflux disease are not part of the ‘OK health check’ (30).

Two other health assessment instruments (the 'Health toolkit' and 'Let's get healthy together') were constructed through focus group discussions (32, 33). The participants in the focus group discussions were people with ID and/or their caregivers. As expected, the set of medical items included (section A, Table 1) in our study is more detailed than the set that proposed in the focus group studies (20). In our study, the experts mentioned that they expected that practice nurses could give support. This is confirmed by a study that showed that health assessments for people with ID provided by practice nurses produced health care improvements and were more optimal than standard care, being both cheaper and more effective(7).

The European assessment system called the EASY-Care standard is a comprehensive instrument that can be used in primary and community settings for the geriatric population (34). Although the domains found in our study, e.g. finances, differ with the EASY-Care there are also similarities (seeing-hearing-communication, mobility, prevention, mental health and wellbeing). An eye-catching difference between the consensus items found in our study and 'subjects/items' questioned in the EASY-Care standard is the domain of high-prevalence diseases. GPs have reported a lack of knowledge about specific diseases in patients with ID (35).

Implications for future research and practice

Items that should be part of a health assessment instrument have been selected in this study. The results of this study imply the need for a newly developed health assessment instrument. This is the first step. The experts (GPs and ID physicians) prefer that patients and carers complete the health assessment questionnaire, at least in part, at home. It is not sufficient to simply pass on the items on which consensus was reached to the patient and carer and ask them to 'Tell me more about........(vision, constipation,etc).. The next step will be to formulate clearly formulated questions that encompass these items. This implies that each question should be understood in a consistent way and should provide unambiguous answers that inform the GP additionally regarding the specific item. Malpass et al. showed that lack of attention to this aspect leads to ambiguous questions and consequently to questionable validity (36). Another important step will be to further refine this health assessment instrument made after GPs have used the tool in daily practice. This will be the subject of further study.

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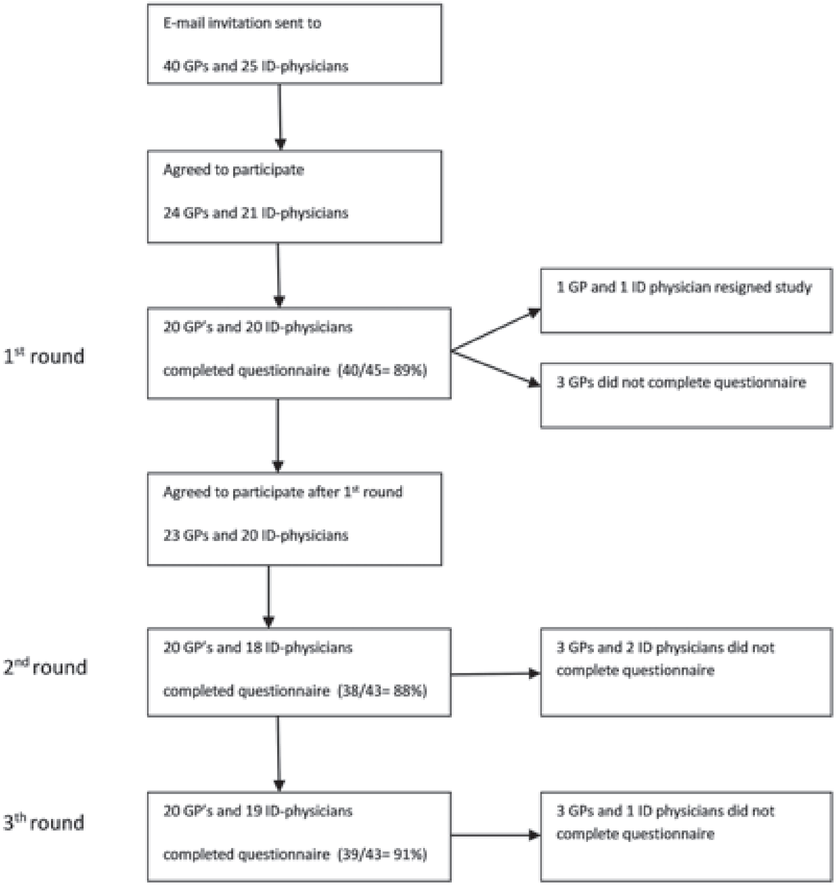
Supplementary material



Supplementary Figure S1. GP and ID physician participation throughout the rounds in the Delphi study (2016)

Table A1. Items selected in 1st round on which 75% agreement was reached

Subject	GP (% yes)	ID Physician (% yes)
Vision	100	100
Hearing	100	100
GERD	100	100
Choking	95	95
Defecation problems	100	100
Constipation	95	90
Weight gain/loss	100	95
Difficulty urinating	80	90
(Recurrent) urinary tract infections	85	85
Sexuality	75	80
Contraceptives	90	100
Mobility	90	95
Falls	95	90
Artralgia	80	50
Chest pain	75	60
Sleep in sitting position	75	75
Respiratory tract problems	75	90
Epilepsy	95	95
Functional decline	90	100
Sleep	90	100
Dental care	100	95
Behaviour	100	100
Behavioural changes	95	100
Breastcancer screening	75	95
Immunisations	90	90
Colon cancer screening	75	95
Smoking	100	100
Alcohol consumption	100	100
Drug use	100	100
Healthy diet	95	95
Sports/	100	100
Outside activities	90	95
Support network	80	80
Use of devices /aids	85	90
ADL functioning	95	85
Communication(problems)	95	95
Living circumstances	75	80
Familiy history	85	90
Level of ID	80	100
Etiology of ID	75	100
Actual medication use	95	100
Medication review	85	90
Self medication	90	100
Overall assessment of the health	80	95

light grey: 100% in 1 expert group
dark grey: 100% in both expert groups

Table A2. Changes in percentage agreement on items in 1st and 2nd round

Subject	GP 1st round (%)	GP 2nd round (%)	IDphysician 1st round (%)	IDphysician 2nd round (%)	Decision
Fecal incontinenence	70	70	60	78	out
Urine incontinence	70	95	80	83	in
Polyuria	60	35	60	50	out
Phimosis	55	5	55	22	out
Menstrual problems	70	85	95	94	in
Discharge from penis	65	15	45	22	out
Sexual education	65	60	65	56	out
Locomotion	50	45	65	83	out
Muscle problems	65	30	40	33	out
Osteoporosis*	55	55	65	100	out
Low Vit D*	60	65	65	89	out
Coronairy problems	65	95	75	100	in
Shortage of breath	70	80	75	72	in
Allergies*	60	80	85	89	in
Memory problems	70	90	80	83	in
Pain	70	85	80	100	in
Diabetes	65	65	65	56	out
Psychiatric problems*	70	100	90	100	in
Pap smear	65	65	95	78	out
Work (payed)*	55	25	60	28	out
Work (unpayed)*	55	25	45	28	out
Daycare*	70	60	75	78	out
Social contacts	55	60	80	78	out
Relation (having a partner)	65	75	70	78	in
Medical specialists involved	55	55	95	100	out
Relevant agencies involved	55	55	80	94	out
Other health care professionals involved	60	80	90	100	in
Legal guardian	65	90	95	100	in
General concerns	70	65	90	89	out
(Sexual) abuse	70	70	70	72	out
Mental competence	70	65	65	22	out
Psychotropic drug use	65	80	85	83	in

light grey: 100% in 1 expert group
middle grey: > 75% GP expert group: inclusion
dark grey: 100% in both expert groups
*additional qualitative information provided

6

Constructing a health assessment questionnaire for people with intellectual disabilities:

A cognitive interview study

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Abstract

Background Health assessment instruments can help to raise awareness among general practitioners of specific health problems in people with intellectual disabilities (PID). PID and their caregivers acknowledge the value of health assessments.

Aim We developed a health assessment instrument. An essential step is to test the wording of questions with respect to comprehensibility and clarity for PID and their caregivers.

Design and Setting The qualitative study, where we used the cognitive interview technique (CI), was conducted among people with ID and their caregivers.

Method We interviewed 14 participants with ID in 5 subsequent rounds. After each round, the questionnaire was adjusted until saturation was reached.

Results In total, 363 identified problems led to 316 changes to the questionnaire. Most problems (102) concerned the comprehension of the question with regard to wording or technical terms, followed by problems in the 'missing answer categories' and 'inaccurate instruction' section.

Conclusion PID prefer to take an active role in communication with their GP. This comprehensible health assessment questionnaire can help them to fulfil this role. The questionnaire can be filled in at home, which saves time spent in the GP practice. CI is a usable and valuable procedure in questionnaire development for this vulnerable group. The reduction in the number of problems identified in the successive rounds showed that the use of CI improved the health assessment questionnaire for PID.

1. Introduction

Although the life expectancy of people with ID is increasing, life expectancy at birth of people with ID is still 20 years lower than in people in the general population (1). There are problems with accessing health care and receiving appropriate diagnostics and treatments. Consequently, these problems cause unnecessary morbidity and premature deaths (2, 3). A wide range of health problems are described for people with ID (4, 5). GPs experience difficulties in providing medical care to this vulnerable group of patients, partially caused by a lack of knowledge about specific diseases in patients with ID (6). A qualitative study showed several barriers in health information exchange described by GPs in the care for people with ID, e.g. patients with ID often do not notice or discuss unusual health signs, or do not show proactive responses to abnormal symptoms (7).

Walmsley stated that an annual health check could probably be the single most important improvement in the primary health care of people with ID in the twenty-first century (8). Health assessment instruments can help to create awareness of specific health problems (9). Studies have shown that health assessments result in detection of new diseases, improved health promotion and increased participation in preventive activities (10-15). People with ID, their caregivers, and health professionals acknowledge the value of health assessments (10, 16-19). Other studies have shown that health assessments are cost-effective (14, 20, 21). In a focus group study by our research group, GPs pointed out that in order to deliver good care to this target population, they need tools, education and support (22). A health assessment instrument with input from the person with ID and their caregivers can support GPs. However, the available health assessment instruments show deficiencies concerning development, clinimetrics, content and effectiveness (23). Our purpose is to develop a new health assessment tool according to scientific principles, based on the currently available scientific literature.

Most of the time, health assessment instruments consist of a questionnaire to be completed by the patient (to be reviewed by the GP), supplemented with questions that the GP should ask, suggestions about physical and additional examinations and an action plan (23). In a Delphi study, we previously determined which items the health assessment instrument should contain according to experts (GPs and

ID physicians) (24). However, to be applicable to the target group, determining the exact verbal formulation is the next step. Therefore, the current study focuses on the formulation of the questions, because questions in surveys are frequently ambiguous or often have more than one meaning (25). In patients with ID, the exact formulation of questions, in plain language concerning health, is even more important than in other patients (26). The aim of this study is therefore to further develop the health assessment questionnaire with respect to comprehensibility and clarity for the target population, by using a cognitive interviewing technique and directly involving the target group of persons with ID and their caregivers. Also, we wanted to investigate whether the use of the cognitive interview (CI) technique is feasible in this special population.

2. Methods

2.1 Study design

We performed a qualitative study evaluating the items of the questionnaire with the cognitive interviewing (CI) technique in persons with ID and their caregivers. CI is an often used method to critically evaluate the transfer of information in survey questionnaires (25). In short, this method leads respondents through the items of a questionnaire asking them to paraphrase items, discuss thoughts, feelings, and ideas that come to mind, and suggest alternative wording. The purpose of the procedure is to obtain a set of questionnaire items that are unambiguous and easily understandable for the target population. According to the CI technique, there are two issues per question: what does the question mean for the participant and does the participant have problems with the question, for example with the wording, the reference period, or the sensitivity of the question. Concerning meaning, the participants will be asked to think aloud when reading and answering the question. Concerning problems, specific probe questions will be asked. Probe questions are pro-actively established by the researcher/interviewer and reviewed by the research team, for example: “What do the words ‘congenital heart defect’ mean to you?” The questions will help to delve into problems that we suspect may exist. Moreover, problems spontaneously expressed by participants (called ‘emergent probes’) are also discussed (25). These emerging probe questions help us to unravel unexpected problems in the questionnaire. We used the Question Appraisal System (QAS-99) developed by

Willis, which can help to develop questionnaires, develop probe questions and analyse the results (25).

2.2 Participants

Participants were recruited through the academic collaborative association 'Stronger on your own Feet'. In this association, 9 organisations, all providing care to people with ID, work together in research with the Radboud University Medical Center (Radboud UMC), Nijmegen, the Netherlands. We selected adults (18+ yrs.) with ID and their caregivers. We purposively sampled adults with all levels of ID. The caregiver that accompanied the person with ID could be a family member or a professional caregiver. If the participant had a mild intellectual disability, and was able to read and communicate, it was up to the participant whether to invite a caregiver. After telephone contact, the potential participant and his/her caregiver received an invitation letter (in easy to read language) about the research question, the goal of the project, the researcher (ID physician, EBvG), and practical information. The place and time at which the interview took place was determined according to the preferences of the participant. Before starting the interview, the informed consent form (in easy to read language) was signed. Ethical approval was awarded by the local ethical committee of Radboud UMC (File number 2016-3038).

2.3 Proactive health assessment questionnaire for people w1ith ID in primary care

The basis of this health assessment questionnaire consists of all of the items that were proposed in our Delphi study (24). The items were categorised into different topic groups. For example, for the topic group 'neurology', the items were 'epilepsy' and 'dementia'. Each item had been transformed into a question by our research team. According to Fowler, a good question produces answers that are reliable and valid measures of something that we want to describe (27). A good question is easy to read, accompanied by clear instructions, does not use difficult technical terms, and has no missing answer categories, etc. (25) These suggestions and rules for designing good survey questionnaires were taken into account (25, 28, 29).

ID physicians are medical physicians who have undertaken a 3-year vocational training course. In 2000, the Dutch Minister of Health recognised medical care for people with ID as a new medical specialisation. The 3-year postgraduate training for physicians takes place at the Erasmus University in Rotterdam, as part of the institute for training GPs.

2.4 Procedure and analysis

The procedure consisted of the repeated application of the following two stages. Stage 1: the researcher (EBvG) completed the questionnaire, applying the CI technique, together with the PID and their caregiver. The whole cognitive interview was audio-taped, and transcribed verbatim. In addition, notes were made. After 1 hour, the interview stopped, unless the participant gave explicit permission to continue. The transcription was uploaded in ATLAS.ti (version 7) to support qualitative data analysis. Two researchers (EBvG and HvSLdV, both experienced ID physicians (see box)), familiarised themselves with the data and applied the coding independently. Codes were derived from the QAS-99 (Table 1) (25). Differences in opinions concerning the coding were solved through discussion. Stage 2: after a set of 3 interviews, the researchers collected and discussed the suggestions from stage 1, decided upon the changes and continued with the next set of 3 interviews, with other participants, using the ‘updated’ questionnaire. We continued this iterative process until saturation was reached, meaning that no new major comments by new participants interviewed emerged from the data. The final questionnaire was developed in accordance with the outcome of the interviews.

3. Results

3.1 Participants

In total, we included 14 participants: 8 men and 6 women. Of those, 5 had a mild intellectual disability, 2 mild/moderate, 4 moderate, and 3 had a severe intellectual disability. The age varied between 15 and 73 years (mean age 39.4). A caregiver accompanied two-thirds of them (Table 2).

We started the health assessment questionnaire adaptation process by separately interviewing two assistant researchers with (mild) intellectual disabilities working in our department (Table 2, No. 1 and 2). They are experienced in giving feedback on written language (in Dutch).

Table 1 Coding according to Question Appraisal system (QAS) (25)

1	Reading
1a	Ambiguity of what to read
1b	Missing information
1c	Uncertainty of how to read
2	Instructions
2a	Conflicting or inaccurate instructions
2b	Complicated instructions
3	Questions
3a	Wording of the question
3b	Technical term used
3c	Vague - multiple ways to interpret the question
3d	Reference period in the question
4	Assumptions
4a	Inappropriate assumptions
4b	Assumes constant behaviour
4c	Double barrelled question
5	Knowledge/Memory
5a	Knowledge asked for does not exist
5b	Attitude may not exist
5c	Recall failure
5d	Computation problem
6	Sensitive
6a	Sensitive content
6b	Sensitive wording
6c	Socially acceptable
7	Answers
7a	Open-ended question
7b	Mismatch between question and response categories
7c	Technical terms in response categories
7d	Vague response categories
7e	Overlapping response categories
7f	Missing response categories
7g	Illogical order of response categories
8	Other problems

Table 2 Interviewed participants with intellectual disabilities

number	gender	Age (in years)	Level of ID* * information received in interview	accompanied by
1	F	35	Mild	-
2	M	62	Mild	-
3	M	73	Mild/moderate	professional caregiver
4	M	30	Mild	professional caregiver
5	F	35	Mild	-
6	F	39	Mild/moderate	-
7	M	25	Severe	parents
8	F	56	Moderate	professional caregiver
9	M	28	Severe	mother
10	M	15	Severe	mother
11	M	31	Moderate	mother
12	F	29	Mild	-
13	M	22	Moderate	professional caregiver
14	F	72	Moderate	professional caregiver

3.2 Problems identified in the questionnaire

In total, 363 problems were identified during 14 interviews conducted in 5 rounds (Table 3). These problems led to 316 adjustments in the questionnaire. Most problems were seen in the components ‘reading’, ‘instructions’, ‘question’, and ‘answer’, while the components ‘assumption’, ‘knowledge’ and ‘sensitive’ were coded infrequently. We did not find any problems in the component ‘other problems’ (Table 3). The number of problems mentioned during the interviews diminished gradually, with the exception of round 4.

Overall experiences with this health assessment questionnaire

The final question in the interview was whether the participant and/or the caregiver had any other remarks about the health assessment questionnaire. The overall reactions were positive. They enjoyed being part of this development process, emphasised the importance of this questionnaire, thought that it could be helpful for the GP, and the questions were not too difficult as one of the participants and his caregiver explained: ***I:*** *Did you find the questions difficult?* ***P:*** *No.* ***I:*** *I think that P actually understands many of the questions.* ***C.*** *Yes, that is true. [His] ears are very good (☺) and he understands a lot.(4th round, participant no. 11; M, 31 y)*

Table 3: Number of problems identified, and leading to adjustments of the questionnaire

Questionnaire version:	1	2	3	4	5	All versions
Number of interviews:	2	3	3	3	3	14
Number of identified problems	117	79	67	84	16	363
Number of problems leading to adjustments:	109	72	53	72	10	316
Separately for each component						
Reading	29	15	2	10	0	56
Instructions	19	15	16	16	1	67
Questions	34	17	17	28	6	102
Assumptions	1	2	3	4	0	10
Knowledge/memory	5	3	1	0	0	9
Sensitive	0	2	1	0	0	3
Answers	21	18	13	14	3	69
Other problems	0	0	0	0	0	0

Reading

In the 5 rounds, a total of 56 problems were identified in the component ‘reading’. Most problems occurred in the section ‘uncertainty of how to read’ (1c, Table 1), which means difficulty with reading, among other things. The most valued suggestions were to use a bigger font size, to use **bold**, and to adjust the blue colour used into a more distinguished blue colour for the answers (Table 4). In the section ‘missing information’ (1b, Table 1), the lack of pictograms was mentioned.

Instructions

Sixty-seven problems were identified within the component ‘instructions’, especially in the section ‘inaccurate instruction’ (Table 3 and Supplementary Table A1). Most often the participants asked for examples belonging to certain words. According to the participants, the words themselves were clear but the examples (‘instructions’) gave them insight into how to answer (Table 4). A completely different ‘inaccurate instruction’ considered questions for which more answers were allowed, but where the explicit instruction ‘multiple answers possible’ was lacking (Table 5).

Table 4 Examples of text adaptation based on the various components

Reading	Original text All the questions have a black color. The answers have a blue color. Adaptation: All the questions have a black color. The answers have a blue color.	How to read (1C) Quote (fourth round): *I: All the questions have a black color. The answers have a blue color.* *C: Yes, well if you can't see well, you cannot see those light blue letters. Those can definitely be made a bit larger.* *I: Yes, that is indeed true. And is blue then also not the right color?* *C. Well, I find it very light. And if you cannot see the contrast that well, then you will not see it, I think.* *I: Okay, maybe it should be red then. But a larger font, for sure.* *C. I think so. I'm older, I find these letters really small.*
Instruction	Original question: Do you have trouble peeing? Adapted final question: (For example: pain when peeing, straining when peeing, peeing many times in the night, etc.)	Inaccurate instruction (2a) Quote (first round): I: *What does "problems with peeing" mean to you?* P: *Uh oh.* *I: Is that a question that people can answer easily? What do you think of when you read problems with peeing?* *P: No idea. I don't have any problems with it, so I can't say much about it* *I: Should I again mention some examples here?* *P: Yes, I would do that.*
Assumption	Original question: Do you wear glasses? ☐ NO (continue with question 2) ☐ YES If YES: When was the last time that you were at the eye doctor, optician/glasses shop, or doctor to have your eyes checked? Adapted final question: Do you wear glasses? ☐ NO ☐ YES When was the last time that you were at the eye doctor, optician/glasses shop, or doctor (GP) to have your eyes checked?	Inappropriate assumption (4a) Quote (third round): *C. For example, in the question: "Do you wear glasses?" The answer is no. [You would then have to continue with question 2] But he has been examined once, and it was clear that he does have trouble seeing.* *I: He does not wear glasses, but there is a problem. So that deserves adjustment in the question, because now you cannot answer the question well.* *C: No, because it is also possible that he does not wear glasses.* *I: Because?* *C. They don't stay in its place ..... He turns his head in the wheelchair and then his glasses come off.*
Knowledge	Original question and answer: When was the last time that you were at the eye doctor, optician/glasses shop, or doctor to have your eyes checked? Date: Adapted final answer: ☐ I have been there o Date: .... o I don't remember the date	Recall (5c) Quote (third round): *I: Okay. [The date] Is that difficult or easy?* *P: The clients would not know the date anyways.*

Sensitive	Original text - Adapted final text: The doctor (GP) wants to help you stay healthy. The doctor (GP) would like you to not get any diseases from unsafe sex or to get pregnant if that's not what you want. The next 3 questions are about this.	Sensitive content (6a) Quote (third round): P: *Maybe a little explanation about why you are asking the question. I think some people would like that. Because it just comes suddenly in between.* I: *So maybe we should put an extra introductory sentence in between, because after this, there is another question about birth control and STDs.* P: *Yes, I would do that.* I: *This question is needed because it is important for your health, even though you might find it a bit of a silly question.* Note: P=participant, I=interviewer, C=caregiver

Table 5: Example of question adaptation process through the rounds

First round	Question: Where do you pee? ☐ Usually on the toilet ☐ Usually in the diaper ☐ Usually in my pants	Missing answer categories (7f) Quote: I: *Where do you pee? Usually on the toilet, usually in a diaper, usually in my pants.* P: *Toilet.* I: *Toilet. Should we add more categories to this? Did I miss anything?* P: *Maybe a urinal bottle. Depends.* I: *Oh yes, urinal bottle.* P: *Other than that, I don't really know.* I: *Are there also people who have catheters?* P: *Maybe there are.* I: *So maybe it should be in there then too?* P: *Yes.*
Second round	Adapted question: Where do you pee? ☐ Usually on the toilet ☐ Usually in the diaper ☐ In a urinal bottle ☐ Usually in my pants ☐ I have a catheter	Technical terms (3b) Quote: I: *Where do you usually pee?* P: *On the toilet.* I: *Toilet. Then we have added a lot of answers here.* P: *What is a urinal bottle?* I: *Urinal is a bottle to pee in. Should I put a bottle behind it?* P: *I think that this is clearer.*
Third round	Adapted question: Where do you pee? ☐ Usually on the toilet ☐ Usually in the diaper ☐ In a urinal bottle (a bottle to pee in) ☐ Usually in my pants ☐ I have a catheter (a tube with a peeing bag stuck to it)	Instructions (2a) Quote: I: *Where do you pee? (reads out answer categories).* P: *This is what I have (catheter).* C: *Yes, you have that one too. And you have also diaper-pants on, right?* P: *I also have diapers, because I sometimes have something.* I: *That it accidentally happens anyways.* P: *Then I cannot just wear regular pants, no.* I: *So here you would actually like to fill in more things, right?* P: *Yes.* ……. I: *So here you would actually want to choose more options, I did not write here that you could. With most questions, I added, you may select more answers. But I did not find out about this yet until now. But now you are telling me, that you do more than one of these things. You pee on the toilet, you have diaper pants, and you have a catheter.* C: *Yes, three.* P: *Yes, Yes.*

Fourth round	**Adapted question:** Where do you pee? (You can select more than one answer) Answer categories remain the same as in the third round	**Wording (3a)** **Quote:** *I: There are a number of categories, urinal bottle and catheter, these are troublesome words, so we have given explanations of them. Do you think they are easy to understand?* *P: Yes, I'm just wondering if you should turn it around. Considering the target audience.* *I: So, start with a bottle. And then behind it urinal bottle. Or tube with a peeing bag stuck to it and then catheter* *P: Yes*
Fifth round	**Adapted question:** Where do you pee? (You can select more than one answer) ☐ Usually on the toilet ☐ Usually in the diaper ☐ A bottle to pee in (urinal bottle) ☐ Usually in my pants ☐ A tube with a peeing bag stuck to it (catheter)	No comments anymore Note: P=participant, I=interviewer, C=caregiver

Questions

Most problems (102) were found in this component. Of those, the section 'technical terms' was most often cited. For example, the question 'Where do you pee?' had the following answer categories (after the first round):usually on the toilet, usually in the diaper, usually in my pants, in an *urinal bottle,* or I have a *catheter* (Table 5). The words urinal bottle and catheter needed further explanation. In the case of 'urinal' the clarification 'a bottle to pee in' was well understood. The explanation of 'catheter' was achieved with the addition of 'a tube with peeing bag stuck to it'. In the section 'wording of the question', participants asked us to not start the question or answer with a difficult word. Being confronted with a difficult word at the beginning of the sentence will prevent respondents from reading the question further. The 'reference period' mentioned in the question could pose problems as well. Words such as lately, the past months, and the last year should only be used when strictly necessary.

Assumptions

The component 'assumption', with sections as 'inappropriate assumptions' or 'double-barrelled question', was only coded 10 times. Not wearing glasses (Table 4) does not mean that there is no vision problem, as our first question suggested in the way in which it was asked.

Knowledge/memory

The component ‘knowledge/memory’ was coded 9 times. Difficulties with recalling a date were most often mentioned (Table 4). Which immunisations the participants had received in the past were also difficult to recall. The participants understood the question, but the information was too difficult to recall.

Sensitive

This component was coded 3 times. The participants agreed that sensitive questions about sex, smoking, drugs or alcohol use needed to be asked. They advised us to introduce these questions with some words about the importance of these questions in relation to their health, and the need to be honest when answering (Table 4).

Answers

Although an open-ended answer option was available, participants often mentioned the ‘missing response category’. Of the 69 problems found in this component, the ‘missing answer’ section was coded most often (Table A1). In the example mentioned in Table 4, the participants missed the response categories urinal and urinary catheter. For the GP, it is important to know that a patient has a urinary catheter. Those who have a urinary catheter are more prone to urinary tract infections.

PROSPER–ID

The Dutch proactive comprehensive health assessment instrument named PROSPER-ID[1]* has been translated into English by a certified translator (see supplementary material. This English version was reviewed after which it was back translated into Dutch. The back translation was then checked for discrepancies by our research team members, (EBvG, PL) after which a few adjustments to the English version were made by the certified translator (30). Cross-cultural validation will be needed in order to use the PROSPER-ID in other countries.

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[1] * **Pro**active **S**ysthematic **P**articipation **E**vidence based p**R**imary care- **I**ntellectual-**D**isabilities

4. Discussion and conclusion

4.1 Discussion

4.1.1Summary

In this study, we improved the comprehensibility and clarity of a health assessment questionnaire with the help of cognitive interviews with PID, with or without their caregivers. In addition, we showed that the cognitive interview technique can be applied and is useful in this population. Most remarks were made in the 'question' component, especially in the sections 'technical terms' and 'wording of a question'. 'Instructions', i.e. providing examples of the information the health assessment questionnaire is looking for, were also reported to be an important component. In all rounds, there were remarks on the 'answer' section, most often in the section 'missing answer categories' (Table A1). In the first round, the two assistant researchers with mild intellectual disabilities who were experienced in giving feedback on written language made the most remarks by far, as can be seen in Table 3. They proved to be a valuable addition to our research department. The gradual reduction in the number of problems identified by new participants in the successive versions of the questionnaire showed that cognitive interviewing proved to be useful for improving the questionnaire in many different ways. The cognitive interview technique proved to be feasible in this highly complex population. The participants enjoyed being part of this development process and stressed the importance of this questionnaire. The cognitive interview technique was therefore well accepted.

4.1.2 Strengths and limitations

Conducting cognitive interviews to improve the content of a survey questionnaire is a technique that has been used in the general population (31-33). The strengths of this study are the following: first, this technique was used in the population of PID, which is not common; as far as we know, this is the first study using this technique in such a complex population. Second, the interviews and analysis of the qualitative data were performed by two researchers experienced in working with PID. We have noticed that this technique can be applied well in this target population. Third, participants were able to answer the questions with a visual analogue scale with smiley faces, and could point out which 'smiley' reflected their situation. Fourth, we gathered data in a cyclical process and reached saturation. Fifth, we included people with different levels of ID, ages, and genders. The study limitations are the following: first, one participant with severe ID was under the age of 18, so his mother answered the questions. There was no difference between this interview and the other interviews, so we decided to include this participant. In people with severe ID, who could not speak for themselves, the questionnaire was completed by a proxy. When necessary, the questions were adjusted in order to make this possible, although some questions (e.g. Do you have pain?) are difficult for a proxy to answer. We tried to use unbiased phrasing in the probe questions, but this was sometimes difficult when trying to use easy language. For example, some people with moderate intellectual disabilities were not able to explain in detail (as a probe question) what the word pneumonia meant to them, however they were able to point out which housemates suffer from pneumonia often. By doing so, they showed us that they 'understood' the concept of pneumonia. Finally, if we had used audiotapes or videotapes for the analysis, we would have been able to include all non-verbal communication (hesitations, sighing or nodding) in our analysis. However, our interviewer frequently observed non-verbal communication and whenever this occurred, she tried to verbalise what she saw. By doing so, non-verbal expression became part of the verbatim transcript. We advise to use videotaping in future CI studies in this population, to allow better review by others and to be able to review data later for subtle non-verbal clues, which were not picked-up during the interview. We found that people with mild intellectual disabilities could complete the questionnaire on their own, people with moderate ID could answer most of the questions on their own but needed the help of a caregiver to read the questionnaire aloud, while people with severe ID required a proxy to complete the questionnaire.

4.1.3 Comparison with existing literature

Malpass et al. used the CI technique to test the Patient Health Questionnaire (PHQ-9) (32). They showed that the items in the PHQ-9 were interpreted in a range of ways. This demonstrates the importance of this CI step in questionnaire development. In the general population, Watt et al. studied a newly developed patient-reported outcome measure for thyroid patients with the help of the CI technique (33). They also found that most problems were within the comprehension component. Tourangeau proposed a four-stage cognitive model (comprehension, retrieval, judgement, response) to improve survey questionnaires (34). Willis has made a practical translation of this model with his QAS, the model we used (25). Jenli et al. described how Tourangeau's model of survey response can be adapted to facilitate research with PID (35). We have followed some of the adaptations mentioned in this paper: preparing participants (i.e. easy to read information letter, practice questions, emphasize that this is not an exam), enabling participants to choose the interview site and time, ordering related questions, and simplifying explanations. However, we did not minimise 'interference' with the caregiver, nor did we only use open-ended questions. Jen-li et al. pointed out that the Likert scale was too abstract for some of the participants. This is in line with adjustments made in the Stay Well and Healthy – Health Risk Appraisal (SWH-HRA), a health assessment instrument for PID (36). The "SWH-HRA" was adjusted after a pre-pilot phase with simplifications of the vocabulary and adding visual analogue faces. Qualitative interviews after these adjustments of the "SWH-HRA" showed that participants experienced less difficulty in responding. This is in line with our findings. The SWH-HRA is the only health assessment instrument developed for PID that pays attention to the comprehensibility of a health assessment instrument (36).

4.2 Conclusion

CI is a usable and valuable procedure in questionnaire development for this vulnerable group. The reduction in the number of problems identified in the successive rounds showed that the use of CI improved the health assessment questionnaire.

4.3 Implications for future research and practice

PID prefer to take an active role in the communication with their GP (26, 37, 38). A health assessment questionnaire with comprehensible questions can help them to play this active role. GPs have stated that they need a health assessment questionnaire to fill the gap in health care for PID (24). Now, we have a scientifically developed questionnaire which can be used for further testing for feasibility and later on for effectiveness in general practice. We also found that the participation of PID in developing survey questions with the cognitive interview technique was remarkably successful. Participation of PID in questionnaire development should be mandatory.

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Supplementary material

Table A1 Number of problems identified through the cognitive interview specified

Questionnaire version:	1		2		3		4		5		All
Number of interviews:	2		3		3		3		3		14
Number of identified problems	117		79		67		84		16		363
Number of problems leading to adjustments:	109		72		53		72		10		316
Separately for each component											
Reading	29		15		2		10		0		56
1a Ambiguity of what to read		a		a 2		a		a		a	
1b Missing information		b		b		b 1		b		b	
1c Uncertainty of how to read		c 29		c 3		c 1		c 10		c	
Instructions	19		15		16		16		1		67
2a Conflicting or inaccurate instructions		a 12		a 12		a 14		a 13		a 1	
2b Complicated instructions		b 7		b 3		b 2		b 3		b	
Questions	34		17		17		28		6		102
3a Wording of the question		a 10		a 3		a 3		a 10		a 1	
3b Technical term used		b 16		b 8		b 10		b 11		b 3	
3c Vague - multiple ways to interpret the question		c 8		c 4		c 1		c 3		c 1	
3d Reference period in the question		d		d 2		d 3		d 4		d 1	
Assumptions	1		2		3		4		0		10
4a Inappropriate assumptions		a		a		a 3		a		a	
4b Assumes constant behaviour		b		b 2		b		b 1		b	
4c Double barrelled question		c 1		c		c		c 3		c	
Knowledge/memory	5		3		1		0		0		9
5a Knowledge asked for does not exist		a 2		a 2		a		a		a	
5b Attitude may not exist		b		b		b		b		b	
5c recall failure		c 3		c 1		c 1		c		c	
5d computation problem		d		d		d		d		d	
Sensitive	0		2		1		0		0		3
6a Sensitive content		a		a 2		a 1		a		a	
6b sensitive wording		b		b		b		b		b	
6c Socially acceptable		c		c		c		c		c	
Answers	21		18		13		14		3		69
7a Open ended question		a 1		a 1		a		a		a	
7b Mismatch between question and response categories		b		b		b		b 2		b	
7c Technical terms in response categories		c 3		c 1		c 2		c 1		c	
7d Vague response categories		d 1		d		d 2		d 3		d	
7e Overlapping response categories		e		e		e		e		e	
7f Missing response categories		f 14		f 16		f 9		f 8		f 3	
7g Illogical order of response categories		g 2		g		g		g		g	
Other problems	0	8	0	8	0	8	0	8	0	8	0

7

General discussion

General discussion

People with intellectual disabilities (ID) experience health inequities. They have a considerably lower life expectancy: they generally die twenty years earlier than the unaffected population from treatable diseases (1, 2). They have a pattern of morbidity that differs from the general population, they have problems recognising signs of abnormality in their body, and when they do recognise these signs they have problems describing them to health professionals. On the other side: health care professionals lack knowledge about the specific morbidity patterns of people with ID, have difficulties in communication with people with ID and probably over-prescribe medication. There is evidence that planned health assessments are effective in reducing morbidity, however, and in increasing the uptake of preventive health activities. The aim of this thesis was therefore to develop a Dutch proactive comprehensive health assessment instrument for people with ID in order to facilitate GPs, supporting the communication with patients with ID and thereby improve medical care for these vulnerable patients in primary care. In this final chapter we will reflect on the results found in the different studies in this thesis and consider the implications of our findings from the perspective of the researcher, the patient with ID, the GP, the ID physician, and the health system.

The Case of Mr P. (continued)

The question in the Introduction was: "Could a pro-active comprehensive health assessment, conducted in primary care by a GP, have prevented the deplorable condition of Mr P.?" As an ID physician, I investigated and explored the possible somatic causes of his challenging behaviour. Although, during his first visit, it was impossible to communicate with Mr P., he wàs able to speak. *[53] He was wearing hearing aids, but nobody had checked the batteries lately. *[5] His ears were plugged with cerumen. *[l-5] He was using medication for glaucoma, but nobody had checked his vision in the last few years. *[1] He was taking Promethazine pills. Promethazine acts as an antihistamine, but is also used as a sedative or sleep aid, with disorientation as a known side effect. *[62] There was no information about why he had a suprapubic catheter. *[15] Urinary tract infections *[16] are more common in people with suprapubic catheters and there is an association between urinary tract infections and delirium in the elderly (3). He had a huge left-sided inguinal hernia. Mr P. pointed to his right knee*[23], which was swollen, warm and red. Mr P.

was very unsteady on his feet. Attention to fall accidents was needed. *22 Several of these somatic problems could be reflected in his challenging behaviour. Working with his GP, the somatic problems were treated. A few months later Mr P. visited our outpatient clinic again. We had a nice conversation. He was able to answer questions and seemed happy. The batteries in his hearing aid were checked. His ears were cleared of earwax. He was wearing hip protection underwear. His blood and urine had been examined. A medication review had taken place. The Promethazine had been stopped. He received a low dose (1 mg) of haldol, to treat the delirium. The change was remarkable. In retrospect, accumulating unnoticed ailments had led to severely disturbed behaviour.

(*number corresponds with a question in our health assessment questionnaire)

Reflection

When Mr P. visited our outpatient clinic a health assessment instrument in Dutch for people with ID was not available. The case description of Mr P. demonstrated that nine out of ten (somatic) problems could have been detected with our newly developed questionnaire. The questionnaire doesn't ask about the last problem, the inguinal hernia, but it could have been detected through the physical examination that is part of the instrument. Although only a single case is presented here, the outcome is in line with studies about applying health assessment instruments in the ID population: new health needs are found and attention is paid to prevention. This is only one example of outcomes resulting from the application of the health assessment instrument developed in our research.

In the following section we will go deeper into, and reflect on, several insights and findings that emerged during our project:

1. An assessment of the quality of existing health assessment instruments for people with ID used in primary care.
2. The necessity for more clear and rigorous study designs in the field of ID medicine.
3. The participation of people with ID in research.
4. The development of our health assessment instrument (PROSPER-ID).

The assessment of the quality of health assessment instruments

Pro-active comprehensive health assessments for people with ID have been shown to promote a higher quality of primary care: health needs are detected earlier, and more attention is paid to health promotion and prevention (4-7). In **Chapters 1** and **2** we discussed the diverse problems (e.g. communication problems, morbidity patterns) that hinder the provision of good medical care for people with ID. As you cannot expect primary care physicians to be experts in taking care of this highly complex minority group, health assessments should be guided by scientifically developed health assessment instruments. In our review study (**Chapter 3)** we identified the health assessment instruments for people with ID that were used in primary care and assessed their quality in four domains (*development*, *clinimetric properties* (i.e. validity, reliability, feasibility, acceptability)*, content* (i.e. ID-related health problems, prevention and health promotion topics) and *effectiveness)*. The choice of these domains was based on the recommendations of De Vet and Streiner (8, 9). We found 20 different health assessment instruments. The results with regard to the quality of health assessment instruments somewhat disappointed us. Limited information was found about the *development* of the instruments; the scientific development was well described for only two instruments. Limited information was also found on their *clinimetric properties*. We will come to that later. The *content* of the instruments was rather diverse. Only three subjects (oral health/dental care, visual impairment, hearing impairment) were found in most of the instruments; some highly prevalent diseases were often missing. An internationally accepted content list was not available. Fifteen out of twenty instruments paid attention to prevention and health promotion topics. Physical examination, medication review and action plans were part of only half the instruments. Although the papers included agreed that health assessment instruments were effective, the *effectiveness* of only three instruments (comprehensive health assessment programme (CHAP), the ASK health diary, and the Scottish health check) had been assessed in a randomised controlled trial.

According to our quality domains, two instruments, “Stay well and healthy - Health risk appraisal (SWH-HRA)”and the “CHAP” appeared to be of the highest quality, but they didn’t score positively in all domains. Neither instrument included a description of their *development*, but they scored highly on *content*. *Effectiveness* was only assessed for the “CHAP”. The validity, and the reliability had been tested for several subscales of the “SWH-HRA”. Feasibility was tested for the “SWH-HRA”, and the acceptability was tested for the “CHAP”.

We decided a priori to judge the quality of the available instruments with broad quality indicators, because we were not aware of any validated instrument being available for this specific task. Superficially, one could consider a health assessment instrument as something equal to a health measurement instrument for outcomes, for example the SF-36, and consequently apply the same quality indicators. Validity and reliability are important measures for the quality of outcome measurement instruments, in the domain of clinimetrics (10), but health assessment instruments do not really measure a construct: they are more like checklists. The quality criteria in the domain of clinimetrics proposed for health measurement instruments are therefore not generally applicable to health assessment instruments. The problem is most salient in the domain of validity and reliability. The validity and reliability were tested in two (“SWH-HRA”, “the OK health check”) out of 20 instruments. The “SWH-HRA” has incorporated existing health measurement scales. Correlation statistics were used for test–retest reliability, and for criterion validity assessment which compared selected SWH-HRA subscales to comparable measures used by the advanced practice nurse intervention (the ‘gold standard’). In the “OK health check” validity was tested by comparing “the OK health check” with the outcomes of a blank form on which the patients could describe their health needs. This captures a relevant aspect of validity, namely face validity. As a result of these problems in assessing validity, we considered feasibility and acceptability to be more important. These issues could and should be tested when designing new health assessment instruments and they should take precedence over the validity. Nevertheless, only two instruments tested feasibility and only three instruments tested acceptability. Overall, we concluded that there is much room for improvement in the application of more rigorous methods for the development of high-quality health assessment instruments for people with ID. More specifically we think that studies should focus on development, content, feasibility, acceptability and effectiveness when judging the quality of checklists.

The necessity for more clear and rigorous designs in the field of ID medicine

Research in the field of ID medicine is young compared to research in other medical fields. Naaldenberg et al. noted in their paper on health promotion for persons with ID that research experiences, methodological weaknesses, and inconsistencies make it difficult to compare and contrast the results of different studies in this field (11). The study designs of the papers included in our systematic review did not seem sufficiently robust at first sight, and therefore, as we included papers of various designs, we used Naaldenberg et al.'s method to assess their methodological quality (11). This method includes the following criteria: (1) clear description of aim(s) and research question(s); (2) description and discussion of rationale for sample size chosen; (3) description and discussion of research population; (4) description and discussion of attrition rate; (5) description and discussion of measurement instruments; (6) discussion of study limitations; (7) description of intervention development; and (8) description of intervention content. Some criteria were not applicable to all studies. Each criterion could score two, one or zero point(s), or was not applicable. The designs of the included studies were very different, and sometimes not described very clearly. In most studies the aims were described well, but other information (e.g. rationale of the sample size chosen, attrition rate, intervention development) was missing. Information about the inclusion or exclusion criteria for participants often missed; convenience samples were very frequently used. We consider it important that clear and internationally accepted designs are used in this young ID research field.

We made an effort in the different studies in our project to improve the quality of research in ID medicine by using rigorous study designs which we described clearly in our method sections. The limitations of our studies are described in the various discussion paragraphs of the chapters in this thesis. In our review study (**Chapter 3)** we applied the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for systematic reviews (12). Our search strategy was developed in accordance with these guidelines, with the help of a librarian, and described in the paper. We searched four different databases, including EMBASE, the inclusion and exclusion of studies and data extraction was performed by two reviewers independently, the methodological quality of the studies was assessed, the references of the included articles were checked, and we developed a data extraction form for this study. Furthermore, we calculated kappa as a measure of inter-observer agreement and found good inter-observer agreement for inclusion and exclusion (9).

In our focus group study (**Chapter 4**) we applied the consolidated criteria for reporting qualitative research (COREQ) guidelines (13). A purposive sampling strategy was used to ensure heterogeneity in the characteristics of the participating GPs, such as age, sex, type of general practice and experience with the care of people with ID. Data collection continued until saturation was reached. Two researchers applied open coding independently. Data analysis was performed using the framework analysis approach. This type of analysis can be easily applied in the medical field, and is suitable for meeting specific information needs and providing outcomes or recommendations (14).

We performed our Delphi study (**Chapter 5**) according to the methodological criteria cited in the review by Diamond et al. (15). In accordance with these criteria respondents took part anonymously in three sequential online questionnaire rounds. After each round, the respondents received feedback enabling them to reconsider their views based on the report of the overall results including the views of the other members of the group. Before we started, we defined the criteria for agreement (> 75%) on the uptake of an item, specified the planned number of rounds and established criteria for dropping items in each round.

In **Chapter 6** we applied the cognitive interview technique. It is strongly recommended that a questionnaire be evaluated before starting to use it in the field, to improve its quality (16). Cognitive interviewing is a tool for improving questionnaires (17). We applied this cognitive interview technique **(Chapter 6)** according to the method described by Willis in order to improve our health assessment questionnaire (17).

In conclusion, we made an effort to improve the quality of our ID research by using clear designs.

The participation of people with ID in research

The active involvement of patients in general health research has become more and more commonplace. The active involvement of people with ID in health research is not as common yet, although there is now more emphasis on this topic (18). The mantra of the disability movement: *'Nothing about us without us'* also points in the direction of the participation of people with ID in research. Recently, consensus was reached by an international group of researchers and people with

ID, about how to design and conduct inclusive ID research (19). Patients with ID participate in the design of the study in ‘real’ inclusive research. In our study this was not the case, but patients with ID did participate in our cognitive interview (CI) study.

Although CI is used infrequently, it is a strongly recommended research method to improve the content of a survey questionnaire(16, 17, 20-23). We used the technique in **Chapter 6**. As far as we know this has never been done before in the ID population. The aim of the method was to obtain a questionnaire with questions that are easy to understand and unambiguous. The essence of the method is to ask respondents to think aloud when trying to answer the questions in the questionnaire, and to respond to probing questions. Probing is asking follow-up questions when you do not fully understand a response, when answers are vague or ambiguous or when you want to obtain more specific or in-depth information. The cognitive interview technique proved to be feasible in this complex population of patients with ID. The cognitive interview step clearly improved our questionnaire. More than 360 problems were identified, leading to 316 changes in the questionnaire. The participating ID patients really enjoyed being part of the study and emphasised the importance of their participation. There is room for improvement, however. People with ID have problems with communication and so they often used non-verbal communication (e.g. nodding, pointing, etc.) during our interviews. For example, when reacting to a question on heartburn (Sometimes, some food from your stomach comes back up into your mouth. This sometimes has a sour taste. Does this ever happen to you?) a participant acted like he was vomiting. His (not altogether correct) understanding is completely missed in the transcript, as he used no words here. The interviewer sometimes tried to overcome this limitation by verbalising the non-verbal communication so as to capture this information in the transcript. In future CI research with this population we will consider the use of videotaping, so as not to miss any verbal or non-verbal communication and make the interviewing interventions and decisions by the interviewer during the interview even more transparent for others. We suggest that the participation of people with ID in ID questionnaire development should be mandatory.

The development of our health assessment instrument (PROSPER-ID).

The aim of this thesis was to develop a Dutch proactive comprehensive health assessment instrument for people with ID to be used in primary care, in order to reduce health inequities. We thought about translating an existing instrument but we could not find a health assessment instrument that met all our quality criteria (**Chapter 3)**, so, we continued with a Delphi study (**Chapter 5)** in the development of a new instrument to determine the content, or more specifically which items should be part of the health assessment instrument. We developed the first set of items (82 'general' items and 14 items concerning physical and additional examinations) based on information extracted from the health assessment instruments that we assessed as the best in our systematic review ("SWH-HRA" and "the CHAP"), and based on information provided by our focus group study with 23 GPs (**Chapter 4**). As described in **Chapter 1** the health care provision for people with ID in the Netherlands is unique. No other country has a specialist in ID medicine: the ID physician. We invited 24 GP experts (GPs experienced in providing care to patients with ID) and 21 ID physicians to our Delphi panel. The experts, in particular ID physicians, suggested 10 new items and proposed a rearrangement of the items on physical and additional examinations. Consensus (i.e. more than 75% of the GPs said yes to the uptake of an item) was reached on 64 'general' items related to highly prevalent diseases, public health and health promotion topics, and on 18 physical and additional examination items. This item selection was a first step in the development of our instrument, which we named PROSPER-ID. PROSPER-ID stands for; **Pro**active, **S**ystematic, **P**articipation, **E**vidence-based, p**R**imary care - **I**ntellectual-**D**isabilities. The case of Mr P. shows that we proactively and systematically have to search for medical problems in people with ID. We hope that people with ID may prosper in primary care with the aid of this instrument.

Can all the (medical) problems and health inequities of people with ID be solved using PROSPER-ID? The answer is no. People with ID face many of the same health inequities as people with low health status and limited communication skills (e.g. migrants and homeless people). They often have a lower socio-economic status, which increases the risk of chronic diseases and premature death (24), but there are also differences compared to this 'low health skill' group: people with ID do not adequately notice unusual and abnormal symptoms, they have a different prevalence of diseases, early aging and multimorbidity (whether or not related to specific syndromes) (see **Chapter 1** and **Chapter 2)** (5). We expect that PROSPER-ID can address a number of these problems, however, before wider introduction the acceptability, feasibility and the (cost-)effectiveness of PPROSPER-ID has to be proven in the real-life setting.

PROSPER-ID is found in Dutch and in English in the appendix. PROSPER-ID has been translated into English by a certified translator. This English version was reviewed, and then back-translated into Dutch. The back translation was then checked for discrepancies by our research team members, (EBvG, PL) after which a few adjustments to the English version were made by the certified translator. Cross-cultural validation is needed in order to use the PROSPER-ID in other countries (25).

Implications of our findings

What are the implications of our findings from the perspective of the researcher, the patient with ID, the GP, the ID physician, and the Dutch health system? We will discuss these in the underlying sections.

Researcher's perspective

The scientific development of a health assessment instrument is a first step to improving the health disparity of people with ID. The next, probably more challenging, steps will be testing the implementation and the evaluation of effectiveness of applying the health assessment instrument for people with ID in primary care.

What can we learn from the Anglo-Saxon countries is this respect? Between 2008 - 2015 the uptake of health checks differed across and within nations: there was 41% uptake in the UK with regional differences: 64% in Northern Ireland (UK) and 26% in Oxfordshire (UK); 22% in Ontario (Canada) (26-28). Several barriers to implementation were noted: uncertainty over who was eligible, limited awareness of the benefits of annual health checks for people with ID, organisational problems, the absence of a paid health facilitator, the time necessary to complete the health assessment, and the perceived lack of willingness by GPs to perform a health assessment (27-30). The barriers described here show great similarities with the barriers found in our focus group study (**Chapter 4)** and have to be taken into account when implementing PROSPER-ID. In accordance with the application of clear designs in our previous studies, we suggest that we should use the knowledge developed in the field of implementation research for the implementation. In the studies described above, this knowledge was not sufficiently used.

It will be a challenge to understand the factors that affect implementation, as proactive comprehensive health assessment for people with ID is a complex intervention. The only study, as far as we know, that describes the process of implementation of health checks for people with ID in two different primary care settings is Durbin et al. (31). She used the staged change process of the national implementation research network (NIRN) in this study. The NIRN studies the implementation process, focusing on four stages which follow each other. Tools have been developed to guide the implementation of a complex intervention : the NIRN; the Normalisation Process Theory (NPT); and the Consolidated Framework for Implementation Research (CFIR). The CFIR was developed by Damschroder after studying different implementation theories (32). The CFIR contains five domains: intervention characteristics, outer setting, inner setting, characteristics of the individuals involved and the process of implementation. Each domain is divided into smaller sections. For example, one of the sections in the domain of intervention characteristics is trialability, the ability to test the intervention (PROSPER-ID) on a small scale in the organisation (GP practice) (32). We have received funds to start such a pilot study with PROSPER-ID. The NPT describes four core constructs that play a role in the implementation of a complex intervention: coherence (i.e. sense making), cognitive participation (i.e. engagement), collective action and reflexive monitoring (i.e feedback mechanisms). Each of these constructs are divided into smaller components (33, 34). The NPT focuses on the participants of the complex intervention. Although the involvement and cooperation of the participants is of crucial importance, we consider the CFIR model more appropriate. The NIRN studies the process of implementation. The CFIR not only tries to find answers that match the characteristics of the individuals involved, but also for other areas, such as the setting in which the complex intervention takes place, the intervention characteristics, and the process of implementation.

We suggest starting the implementation before the evaluation of effectiveness of PROSPER-ID. We want to avoid an underestimation of the effect caused by an implementation problem (35). We feel this is supported by the literature which has already shown that comprehensive health assessments are effective. A cluster (per GP practice) randomised control trial (RCT) could be conducted to show the effectiveness of PROSPER-ID. The results of such a study should be compared with the results of the CHAP and the "Scottish health check programme for adults with learning disabilities" which both tested effectively in a (cluster) RCT (6, 36, 37). This also applies to the cost effectiveness of applying proactive health assessments for people with ID. The "Scottish health check programme for adults with learning disabilities" demonstrated that the intervention was both more effective and cheaper than standard care (36).

There is no information yet available on the long-term effects of health assessment for people with ID. A promising possibility is to collect longitudinal data from regular health assessments embedded in a system that already collects patient data routinely. The availability of longitudinal data will enable us to respond to deficiencies in the care for people with ID, and could help us in developing specific health promotion programs.

Patients with ID perspective

People with ID tend to live longer in the community rather than in residential care facilities, and they should live life in the same way as anyone else as much as possible. Active participation in the community is supported by the ratification of the Convention on the Rights of Persons with Disabilities (CRPD) in 2016 by the Dutch government. An elaboration of this is the promotion of an active role for people with ID in communication with their GPs (38-40). A health assessment questionnaire with comprehensible questions can help them to play this active role, with the ultimate goal of reducing health inequities for persons with ID.

We have to find ways to reach out to people with ID, and to their caregivers, to provide them with information about the PROSPER-ID. In the UK Walmsly found that there was limited awareness of the health assessments and their potential benefits amongst carers and adults with ID (28). In Australia people with ID and their caregivers were approached through the staff of a service care provider who were provided with information about the comprehensive health assessment programme (CHAP). As a consequence patients with ID, and their caregivers, contacted their GPs themselves. The willingness of the GPs to participate after this request from their patient was high (29). Most patients with ID valued the use of health assessment instruments positively after participation (27, 41-46). We are in a good position to reach people with ID because we collaborate in the academic collaborative centre ‘Stronger on your own feet’ with nine care organisations for people with ID. Patients with ID who receive care through these organisations can easily be reached. Because not all patients with ID receive care through these service care providers, other ways to approach the patients must also be considered. Patients with ID can also be reached through the ‘Vereniging Gehandicapten Nederland’ (VGN is a branch organization of healthcare providers in the Netherlands), their magazine Markant, ‘Kennisplein gehandicaptenzorg’, as well as ‘Iederin’, a network organisation for people with ID and chronic illness which stimulates the active participation of their members in society.

One of the themes that emerged in the study of health assessments was the challenge of the ability of patients with ID to effectively respond to the questions in the questionnaire (30). In our cognitive interview study (**Chapter 6)** we showed that although there is a great diversity in the group of people with ID, patients with different levels of ID were able to complete the questionnaire, with more or less help. We found that people with mild intellectual disabilities could fill in the PROSPER-ID on their own. People with moderate ID could answer most of the questions on their own but needed the help of a caregiver to read the questionnaire aloud. In people with severe ID the questionnaire had to be filled in by a proxy. Further research is needed to confirm this first impression.

General practitioner perspective

The aim of our focus group study (**Chapter 4)** was to explore GP opinions about applying a health assessment instrument for people with ID in daily practice. GPs stressed that specific tools, support and education are needed. We will go further into these topics now.

GPs were willing to use a health-assessment instrument, so they told us in our focus group study, if the tool was scientifically tested, and if its use would lead to significant health gains (**Chapter 4**). Other studies have shown that the implementation of a pro-active health assessment instrument for people with ID in primary care, although proven to be effective, was received with scepticism by GPs (28-30). An important factor determining the thinking of GPs about screening is that general health checks in adult populations generally show no reduction of morbidity or mortality (47). GPs must therefore become acquainted with the greater effectiveness of health assessments for people with ID. With the scientific development of PROSPER-ID, applicable with patients of all ID levels, we have made a first step.

An important element of implementation in general practice is the support provided by persons, resources, and technical applications. In both our focus group study (**Chapter 4)** and our Delphi study (**Chapter 5)** the practice nurse (POH: praktijk ondersteuner huisarts) was mentioned as a possible assistant to help the GP with health checks in patients with ID. Practice nurses are experienced in providing proactive health care because they commonly use chronic disease management models for cardiovascular risk, diabetes mellitus and COPD. A study in Scotland shows that practice nurses are capable of carrying out health assessments for people with ID (36). McDonald advises that training practice nurses could improve the benefits of health checks because they are inclined to make adjustments to the instrument, which may reduce potential benefits of the health assessment (48). This advised training is in line with the recommendations of the experts in our Delphi study (**Chapter 5**).

Another source of support mentioned by GPs is the ID physician. Some GPs wanted the ID physician to take over care for people with ID, which would be impossible given the low number of ID physicians (230) available in the Netherlands (49). Others suggested that the ID physician could help with the more difficult patients in the ID population. At the moment it is not clear whether GPs are aware of the possibility to refer patients to one of the 88 ID outpatient clinics in the Netherlands. We also assume that cooperation between GPs and ID physicians can improve.

Further support for GPs is necessary because of a shortage of time and increased workload. These barriers were noted in our focus group study **(Chapter 4)**. As a result of the reforms of the long-term care acts, GPs have experienced increased pressure on primary healthcare. Given the estimated number of patients with ID in a standard GP practice, 10-15 (50), this patient group will be, in part, responsible for this increased pressure. We expect that implementing a new instrument will not be welcomed with cheers in times of increased work pressure. Extra financial recourses are needed to do the work properly.

Finally, although all Dutch GPs use electronic patient files, registration levels of ID as a problem are low. GPs don't want to somatise, nor stigmatise patients with ID (**Chapter 2**). It is my personal belief that patients with ID will understand, and even be pleased if more attention is paid to their health through the registration of their intellectual disability in the medical files, and health assessments are carried out. Research endorses this (33, 41-43, 45, 46). Their registration will be an important improvement for three reasons. Firstly, being aware of the intellectual disability of a patient will help the GP communicate with them in a different way, in simple language (51). Secondly, it provides an overview of the total number of patients in the GP practice and will give an impression of the workload. Thirdly, the registration of ID patients as a group will make systematic assessments more easily applicable. A further problem is how to incorporate the findings from the health assessments into the electronic medical files.

Education will help in the recognition of people with ID and reduce the feeling of incompetence. GPs need to be taught about the specific medical issues of people with ID, and the role that the PROSPER-ID can play in that respect. We have already made a start with this. At a national level, our review study (**Chapter 3)** and our Delphi study **(Chapter 5)** were presented at a national conference for Dutch GPs. The focus group study (**Chapter 4)** was abbreviated and translated into Dutch and published in the national GP journal 'Huisarts en Wetenschap'. An NHG (Nederlands Huisarts Genootschap) course '(light) intellectual disability' has been developed and is available for those GPs who are interested. At a regional level, we have provided a course for GPs in the region of Nijmegen. Attention is paid to this topic in the GP internship-training program at the Radboud University Medical Centre, however, this does not reach all GPs, so more education will be necessary.

ID physician perspective

To date, half the Dutch ID population lives in or receives care from residential care facilities. These facilities are situated in primary care. The professional caregivers working in residential care facilities mostly have no medical background (52-54). They could therefore easily miss symptoms and illnesses of the ID patients. Because PROSPER-ID has been developed for use in primary care, it would make sense for ID physicians, or the ID nurse practitioners, to apply it in residential care facilities. It is expected that ID physicians are, because of their specialisation, more aware of the highly prevalent diseases mentioned in PROSPER-ID. The added value is the systematic application of the instrument. It would be interesting to include the ID practice in a cluster RCT together with the GP practice. The results of such a study might give an indication of how to adjust PROSPER-ID for these two specific care practices.

Health system perspective

By ratifying the Convention on the Rights of Persons with Disabilities, and recognising ID physicians as a new medical specialisation, uniquely worldwide, the Dutch government shows that people with ID do matter. Despite this, people with ID experience health inequities. As mentioned in the introduction, some of the health inequities cannot be solved, but health assessments for people with ID in primary care are able to improve the health status of people with ID. Before PROSPER-ID can be applied in the Netherlands, we still see a number of obstacles. In this section we will discuss our concerns from the health system perspective.

In the Netherlands, no exact record is kept of the number of people with ID; the estimated number of ID patients is between 112,000 and 231,000 (0.7-1.4% of the population) (55, 56). Privacy laws mean that it is not possible to connect the different digital systems for an overview of the total ID population. This will hinder the provision of good medical care and the practice of research in the ID population. The provision of a pro-active comprehensive health assessment for all people with ID is therefore hampered. This would not have been a problem if ID patients were adequately registered in the primary care practices.

If the health status of people with ID improves by applying health assessments, one would expect their life expectancy to increase. Today, the life expectancy at birth of people with ID is 20 years lower than that of people in the general population (1). Mortality studies can provide insight into the health of diverse populations. The long-term effects of PROSPER-ID could be made clear by using this data. A recent review of issues in recording the causes of death of people with ID on medical certificates of cause of death (MCCD) concluded that there are concerns about the accuracy of MCCD in identifying the cause of death in the ID population (57). The first step is to make it clear on the MCCD that the death is that of someone with an intellectual disability. We have no reason to believe that the accuracy of the MCCD in the Netherlands differs from those found in this review. Attention will therefore have to be paid to the correct completion of the MCCD.

In Anglo-Saxon countries health assessments for people with ID are stimulated by government regulations. GPs are paid for providing health assessments. In our focus group study (**Chapter 3**) Dutch GPs mentioned the absence of payment for this specific extra task as a barrier to applying health assessments. Dutch health insurance companies therefore need to include this health assessment in their remuneration. We imagine that the health assessments could be financed in the same way as cardiovascular risk management screening and diabetes care in primary care, in view of the similarities.

Medical education is needed for those who work with people with ID, including professional caregivers, practice nurses, medical students, GP internship students, GPs. The government can play a role by ensuring that this topic should be taught at all levels of (medical) education.

Conclusion

'Towards reducing health inequities' is the subtitle of this thesis. Many studies describe the existing health disparity gap of people with ID. Proactive health assessments for people with ID are a way to reduce these health inequities. Because of the complex health problems of people with ID, who are different from those in the general population, a scientifically developed health assessment instrument should guide health assessments. We developed such a health assessment instrument (PROSPER-ID) with the help of people with different levels of ID, with or without their caregivers. The first step has been taken with the scientific development of PROSPER-ID. The next steps will be to test the feasibility, the actual implementation, and (cost)-effectiveness of PROSPER-ID. In the long term we really hope that the application of PROSPER-ID will contribute to reducing the health inequities of people with ID.

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8

English summary

Nederlandse samenvatting

Makkelijk te lezen samenvatting

Summary

Chapter 1

People with intellectual disabilities (ID) experience health inequities. They have a considerably lower life expectancy, as they generally die 20 years earlier than the unaffected population from treatable diseases. They experience twice as many health problems compared to the general population, receive more medication, take part less in public health screening (e.g. bowel and breast cancer screening) and health promotion programmes. They are more exposed to health risk factors, such as being overweight. They have problems recognising signs of abnormality in their body, and when they do recognise these signs, they have problems describing them to health professionals. Their health needs are often not recognised. They have a pattern of morbidity that differs from the general population. Health care professionals often lack knowledge about the specific morbidity patterns of people with ID. General practitioners (GPs) acknowledge difficulties with providing medical care to people with ID, due to time constraints and a shortage of knowledge of specific diseases that people with ID suffer from.

The number of people with ID in the Netherlands is estimated at 112.000-231.000. Exact figures are unknown. Half of this population lives in residential care facilities, the other half lives in the community. Nowadays, the society is more individualistic and complicated. More people with ID ask for help from health care organisations. The healthcare costs have risen enormously. This has led to changes in health care laws and financial constraints. A consequence is that less people with ID are allowed to live in residential health care facilities. On the other hand, the citizenship paradigm plays a role; people with ID want to live a life as anyone else in the community.

In the Netherlands, medical care to people with ID is provided by GPs and ID physicians. Until recently, ID physicians worked in residential care facilities, and GPs worked in the community. This situation has changed. GPs started to provide medical care in residential care facilities. ID physicians started to work in ID outpatient clinics to which GPs can refer people with ID who live in the community. Overall, GPs started providing more care to people with ID, because more people with ID are living in the community, plus the medical care they provide in residential care facilities.

Proactive health assessments for people with ID can support GPs in providing good medical care. Proactive health assessment instruments often contain three elements: highly prevalent diseases, public health screening and health promotion. A systematic literature review about the impact of health assessments showed they provide new diagnoses and set individual health goals.

We expect that proactive health assessments for people could lead to the following improvements:

1. Health problems not reported by patients with ID will be detected earlier
2. Unnecessary complications can be prevented
3. Unnecessary medication use can be reduced
4. More attention to prevention and health promotion will be provided
5. Patients and health professionals will be more satisfied with the medical care delivered
6. Cooperation between GPs and ID physicians will be stimulated

Proactive health assessments for people with ID will stimulate a higher quality of primary care for this vulnerable population.

The research question in this thesis is: Can we develop a Dutch proactive comprehensive health assessment instrument in order to accommodate GPs, support communication with the patient with ID and thereby improve medical care for people with ID in primary care?

In order to develop a Dutch proactive comprehensive health assessment instrument, we studied the following research questions:

1. Which proactive comprehensive health assessment instruments are available and what is the quality of those health assessment instruments?
2. What are the opinions of Dutch GPs about applying a health assessment instrument for people with ID in daily practice?
3. Which items should be part of a health assessment instrument for people with ID that is to be used in primary care?

4. How comprehensible and clear is the proactive health assessment instrument questionnaire for people with ID (and their caregivers)?

Chapter 2

In **chapter 2**, we discuss three patient cases, which gives us insight into the difficulties in medical care provision for people with ID. A 22-year-old man, severely intellectually disabled, presented with an unsteady gait. He had recently been diagnosed with Cohen syndrome. Since he was unable to express himself, it took some time to discover that he had additional symptoms, e.g., frequent infections. Eventually, all his complaints fit with his syndrome. A 54-year-old woman, severely to moderately intellectually disabled, presented with new behaviours (i.e. loss of appetite, weakness in her legs and excessive thirst). Although she was able to speak, she was unable to explain what was wrong with her. Since we knew of the aetiology of her disability, Prader Willi syndrome, we were more aware of the possibility of diabetes mellitus. A 56-year-old man, mildly intellectually disabled, presented with hearing voices for which he received antipsychotic medication. After a conversation in simple language, we discovered that he heard humming sounds rather than voices. He was ultimately diagnosed with tinnitus rather than psychosis. It takes time to discover the health issues that affect patients with ID. This is due to communication problems, the inability to understand bodily functions, symptoms and diseases, multi-morbidity, the atypical presentation of disease at times and the different prevalence rates for certain diseases when compared with the general population.

Chapter 3

The aim of the review, described in **chapter 3**, was to find the available health assessment instruments for people with ID used in primary care and to evaluate their quality. Therefore, we conducted an electronic literature search between January 2000 and May 2016. We collected data from the 29 included peer-reviewed articles on the following four domains; *development*, *clinimetric properties* (i.e. validity, reliability, feasibility and acceptability), *content* (i.e. ID-related health problems and prevention and health promotion topics) and *effectiveness* of the instruments. We were able to distinguish 20 different health assessment instruments. Limited information was found on the *development* of the instruments as well as their *clinimetric properties*. The *content* of the instruments was rather diverse. The included papers agreed that health assessment instruments are effective. However, only three instruments evaluated *effectiveness* in a randomised controlled trial. Patients with ID, carers and GPs generally appreciated the health assessment instruments. Two instruments, “Stay well and healthy - Health risk appraisal (SWH-HRA)”and the ”comprehensive health assessment programme (CHAP)”, appeared to have the highest quality. These instruments can be used to construct a health assessment instrument for people with ID that meets scientific standards.

Chapter 4

The aim of the qualitative study, described in **chapter 4,** was to explore the considerations of GPs about applying a health assessment for people with ID. Before the focus group study was conducted among GPs, an interview guide was developed. All discussions were audio recorded and transcribed. Two researchers independently applied open coding and identified a thematic framework. After four focus groups, saturation was reached. Three main themes evolved: health assessments in relation to the responsibilities of GPs, the usefulness and necessity of health assessments and barriers to using health assessments on people with ID. A health assessment instrument for people with ID can help GPs to focus on certain issues that are not so common in the general population. GPs are motivated to use such a tool if it is scientifically tested and results in significant health gains. However, GPs identify barriers at the level of the GP, patient and organisation. In conclusion, we could say that most GPs in our focus groups consider providing medical care to people with ID their responsibility and indicate that a health assessment instrument could be a valuable tool. In order to deliver good care, they need education and support. Many barriers need to be overcome before a health assessment instrument can be implemented.

Chapter 5

The aim of the study, which is presented in **chapter 5**, was to determine which items should be part of a health assessment instrument for people with ID to be used in primary care. This Delphi consensus study was conducted among 24 GPs experts and 21 ID physicians. We performed three anonymous sequential online questionnaire rounds. We started with 82 ‘general’ items and 14 items concerning physical and additional examinations derived from the international literature and a focus group study among Dutch GPs. We definitely included items if more than 75% of the GPs agreed on their inclusion. The participation rate in all rounds was above 88%. The expert groups proposed 10 new items. Consensus was reached on 64 ‘general’ items related to highly prevalent diseases, public health and health promotion. Consensus was also reached on 18 physical and additional examination items. The overall agreement among the GPs and ID physicians was good. Because the experts prefer that patients complete the health assessment questionnaire at home, questions that cover these items must be formulated clearly.

Chapter 6

The aim of the study described in **chapter 6** was to test the wording of questions with respect to comprehensibility and clarity for people with ID and their caregivers. In this qualitative study, we used the cognitive interview (CI) technique. We interviewed 14 participants with ID in five subsequent rounds. After each round, the questionnaire was adjusted until saturation was reached. In total, 363 identified problems led to 316 changes to the questionnaire. Most problems concerned the comprehension of the question with regard to wording or technical terms, followed by problems in the ‘missing answer categories’ and ‘inaccurate instruction’ section. People with ID prefer to take an active role in communication with their GPs. This comprehensible health assessment questionnaire can help them to fulfil this role. The questionnaire can be filled in at home, which decreases the time spent in the practice of the GP. The CI technique is a usable and valuable procedure in questionnaire development for this vulnerable group. The reduction in the number of problems identified in the successive rounds showed that the use of the CI technique improved this health assessment questionnaire.

Chapter 7

In **chapter 7**, we reflected on several insights and findings that have emerged during our project and described the implications of the implementation of our health assessment instrument, which we have named PROSPER-ID.

We assessed the quality of the found health assessment instruments in four domains (*development*, *clinimetric properties* (i.e. validity, reliability, feasibility and acceptability), *content* (i.e. ID-related health problems and prevention and health promotion topics) and *effectiveness*). The choice of these domains was based on the recommendations of De Vet and Streiner, as there is not a validated instrument available for this specific task. Superficially, one could consider a health assessment instrument as something equal to a health measurement instrument for outcomes, for example the SF-36, and consequently apply the same quality indicators. Validity and reliability are important measures for the quality of outcome measurement instruments, but health assessment instruments do not really measure a construct; they are more like checklists. As a result of the problems in assessing validity, we considered feasibility and acceptability to be more important in order to check the quality of the health assessment instrument. Therefore, when designing new health assessment instruments, they should take precedence over the validity. Nevertheless, in our review study, only two instruments tested feasibility and only three instruments tested acceptability.

Research in the field of ID medicine is young compared to research in other medical fields. The study designs of the papers included in our systematic review did not seem sufficiently robust at first sight. We assessed their methodological quality. We made an effort in the different studies in our project to improve the quality by using rigorous study designs. We applied the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines for systematic reviews (**chapter 3**), the consolidated criteria for reporting qualitative research (COREQ) guidelines (**chapter 4**), the methodological criteria for Delphi studies cited in the review by Diamond et al (**chapter 5**) and the CI technique (**Chapter 6**) according to the method described by Willis in order to improve our health assessment questionnaire.

The mantra of the disability movement *'Nothing about us without us'* points in the direction of the participation of people with ID in research. In 'real' inclusive research, patients with ID participate in the design of the study. In our study, this was not the case, but patients with ID did participate in our CI study. The CI technique proved to be feasible in this complex population of patients with ID. We suggest that the participation of people with ID in ID questionnaire development should be mandatory.

The aim of this thesis was to develop a Dutch proactive comprehensive health assessment instrument for people with ID to be used in primary care, in order to reduce health inequities. We thought about translating an existing instrument, but we could not find a health assessment instrument that met all our quality criteria. After several study steps, we developed the PROSPER-ID. PROSPER-ID stands for **Pro**active, **S**ystematic, **P**articipation, **E**vidence-based, p**R**imary care - **I**ntellectual-**D**isabilities. We hope that people with ID may prosper in primary care with the aid of this instrument.

From a researchers perspective, the next steps will probably be more challenging, testing the implementation and the evaluation of the effectiveness of applying the health assessment instrument for people with ID in primary care. We suggest the use implementation framework tools to better understand the factors that affect implementation, as the proactive comprehensive health assessment for people with ID is a complex intervention.

A health assessment questionnaire with comprehensible questions can help people with ID play an active role in the communication with their GPs. Literature shows us that it will be necessary to create awareness of the potential benefits of health assessments among people with ID. We have to find ways to reach out to people with ID, and to their caregivers, to provide them with information about the PROSPER-ID and its expected benefits.

GPs stressed that specific tools, support and education are needed in order to deliver medical care to people with ID. GPs have to get acquainted with the benefits of health assessments for people with ID, as general health checks in the adult population generally show no reduction of morbidity or mortality. An important element of its implementation in general practice is the support provided by people, resources and technical applications. We have to find solutions that solve these issues. We expect that people with ID living in residential care facilities will benefit by applying proactive health assessments. The added value will probably be the systematic application of the health assessment.

At this time, there is no information available on the long-term effects of health assessments for people with ID. To investigate the long-term effects, we recommend a few adjustments to the health system, such as registration of people with ID to invite them for a proactive health assessment, insight into the causes of death of people with ID by accurate medical certificates for cause of death, financial compensation by insurance companies for GPs performing proactive health assessments and good medical education of health care professionals working with people with ID.

'Towards reducing health inequities' is the subtitle in this thesis. The development of the PROSPER-ID is the first step. We hope that the PROSPER-ID will contribute to reducing health inequities of people with ID.

Samenvatting

Hoofdstuk 1

Mensen met een verstandelijke beperking (VB) zijn minder gezond. Zij overlijden twintig jaar eerder, vaak aan behandelbare aandoeningen, dan mensen in de algemene populatie. Zij hebben, gemiddeld, twee keer zoveel gezondheidsproblemen als mensen in de algemene populatie, krijgen veel meer medicatie voorgeschreven, nemen minder deel aan bevolkingsonderzoek (bijvoorbeeld naar darmkanker, borstkanker en baarmoederhalskanker) en programma's voor gezondheidsbevordering. Zij staan meer bloot aan gezondheidsrisicofactoren, zoals overgewicht. Door gebrek aan ziekte inzicht en lichaamsbesef, en problemen in de communicatie is het voor mensen met VB vaak moeilijk hun klachten te verwoorden. Hun behoeften op gezondheidsgebied worden vaak niet herkend. Dit wordt mede veroorzaakt doordat het vóórkomen van bepaalde ziektes (bijvoorbeeld epilepsie, botontkalking, problemen met zien en horen) bij mensen met VB hoger ligt dan in de algemene populatie. Gezondheidsprofessionals zijn zich vaak niet bewust van die verschillen. Huisartsen geven aan dat zij problemen ervaren in de medische zorg aan mensen met VB, met name door een gebrek aan tijd en door een gebrek aan kennis m.b.t. specifieke aandoeningen.

We weten niet precies hoeveel mensen met VB er in Nederland wonen. Men schat tussen de 112.000 en 231.000. Ongeveer de helft van deze mensen woont in instellingen, de andere helft woont in de gemeenschap. De maatschappij wordt steeds individualistischer en gecompliceerder. Meer mensen met VB doen daarom een beroep op de gezondheidszorg. De kosten voor de zorg aan mensen met VB liepen tot enkele jaren geleden hoog op. Dit heeft geleid tot verandering van de wetgeving en daarmee financiële bezuinigingen, met als gevolg dat steeds minder mensen met VB in een instelling (kunnen) gaan wonen. Daarnaast speelt het burgerschapsparadigma een rol. Mensen met VB willen een leven in de maatschappij net als ieder ander.

De medische zorg voor mensen met VB wordt geleverd door huisartsen en artsen voor verstandelijke gehandicapten. AVG's werkten voorheen met name in instellingen en huisartsen in de gemeenschap. De afgelopen jaren is hier verandering in gekomen. Huisartsen leveren algemeen medische zorg in instellingen en AVG’s zijn meer medisch zorg gaan leveren in AVG poli’s aan mensen met een verstandelijke beperking uit de gemeenschap. Huisartsen kunnen patiënten met VB verwijzen naar een van de 88 AVG poli's. Huisartsen zijn meer zorg gaan geven aan mensen met VB omdat er enerzijds meer mensen in de gemeenschap blijven wonen en omdat ze anderzijds vaker algemeen medische zorg aan mensen in een instelling verzorgen.

Pro-actief gezondheidsonderzoek bij mensen met VB (PGO-VB) kan huisartsen ondersteunen in hun medische zorg aan mensen met VB. PGO-VB instrumenten zijn vaak opgebouwd uit 3 elementen: veel voorkomende ziektes, leeftijd- en geslachtspecifieke screeningen en gezondheidsbevordering. Een systematisch literatuuroverzicht over de impact van pro-actief gezondheidsonderzoek, laat zien deze nieuwe diagnoses aan het licht brengen en dat individuele gezondheidsdoelen beter in kaart worden gebracht.

Wij verwachten dat pro-actief gezondheidsonderzoek voor mensen met VB tot de volgende verbeteringen kan leiden:

1. Gezondheidsproblemen die niet door mensen met VB aangedragen worden, worden eerder ontdekt
2. Onnodige complicaties worden voorkomen
3. Onnodige medicatie voorschriften worden verminderd
4. Er zal meer aandacht aan preventie en gezondheidsbevordering zijn
5. Patiënten en gezondheidsprofessionals zullen meer tevreden zijn met de geleverde medische zorg
6. De samenwerking tussen huisartsen en artsen voor verstandelijk gehandicapten (AVG’s) zal gestimuleerd worden

De onderzoeksvraag in dit proefschrift is:

Kunnen we een Nederlands pro-actief gezondheidsonderzoeksinstrument ontwikkelen dat huisartsen ondersteunt in de communicatie met mensen met VB, met als doel de verbetering van de medische zorg voor mensen met VB in de eerste lijn.

Om een Nederlands pro-actief gezondheidsonderzoeksinstrument te ontwikkelen hebben we antwoorden op de volgende onderzoek deelvragen gezocht:

1. Welke pro-actief gezondheidsonderzoeksinstrumenten zijn beschikbaar en wat is de kwaliteit van deze instrumenten?
2. Wat is de mening van Nederlandse huisartsen over het toepassen van pro-actief gezondheidsonderzoek bij mensen met VB in de dagelijkse praktijk?
3. Welke onderwerpen moeten deel uitmaken van een pro-actief gezondheidsonderzoeksinstrument?
4. Zijn de vragen in pro-actief gezondheidsonderzoeksinstrument vragenlijst duidelijk en helder voor mensen met VB (en hun zorgverleners)?

Hoofdstuk 2

In hoofdstuk 2 bespreken we aan de hand van een aantal casus de bijzonderheden met betrekking tot de medische zorg aan mensen met VB. Een 22 jarige, ernstig verstandelijk, beperkte man kwam op het spreekuur met onder andere loop problemen. Recent was bij hem de diagnose Cohen syndroom gesteld. Hij kon zelf niet vertellen waarom hij moeilijker ging lopen. Het duurde even voordat we erachter kwamen dat de problemen die speelden, oa de loopproblemen en veelvuldige infecties, voortkwamen uit het Cohen syndroom. Een 54 jarige ernstig verstandelijk gehandicapte vrouw liet nieuw gedrag zien; zij had geen zin in eten, stond wankel op haar benen en had veel dorst. Zij kon wel spreken, maar kon ons niet vertellen wat ze mankeerde. Zij was bekend met het Prader Willi syndroom (PWS). Dit bracht ons op de gedachte dat er mogelijk sprake was van suikerziekte. Dit komt namelijk vaker voor bij mensen met PWS. Een 56 jarige licht verstandelijk beperkte man kwam vanwege het horen van ‘stemmen’, waarvoor hij antipsychotica kreeg. Na een gesprek in eenvoudige taal kwamen we erachter dat hij last had van oorsuizen in plaats van een psychose. Het kost tijd om te ontdekken met welke gezondheidsproblemen mensen met VB te maken hebben. Dit heeft te maken met communicatieproblemen, de moeite die ze hebben met begrijpen hoe hun lichaam functioneert, symptomen te duiden en te denken aan bepaalde ziektes, de atypische presentatie van ziektes, het vaak tegelijk voorkomen van verschillende ziektes en de mate waarin bepaalde ziektes voorkomen in vergelijking met de algemene populatie

Hoofdstuk 3.

Het doel van de literatuurstudie, gepresenteerd in **hoofdstuk 3**, is om alle in de 1^{e} lijn beschikbare pro-actief gezondheidsonderzoeksinstrument instrumenten voor mensen met VB te vinden en die te beoordelen op hun kwaliteit. We voerden een elektronische zoekactie uit in de literatuur, gepubliceerd tussen januari 2000 en mei 2016. Dit leverde 29 artikelen op waarin een PGO-VB instrument werd beschreven. Elk instrument werd beoordeeld op basis van de volgende kwaliteitscriteria: *ontwikkeling, klinimetrische waarde* (validiteit, betrouwbaarheid, toepasbaarheid, acceptatie), *inhoud en effectiviteit*. We vonden 20 verschillende PGO-VB instrumenten. De informatie over de ontwikkeling en de klinimetrische waarde van de instrumenten was beperkt. De inhoud van de instrumenten liep erg uiteen. Van 3 instrumenten is de effectiviteit onderzocht in een gerandomiseerd onderzoek. In de interventiegroep werden (significant) meer nieuwe ziektes ontdekt en was er meer aandacht voor leeftijds- en geslachtsspecifieke screening en gezondheidsbevordering. Patiënten met VB, hun verzorgers en huisartsen waren over het algemeen tevreden met de PGO-VB instrumenten. Twee instrumenten, de “Stay well and healthy - Health risk appraisal (SWH-HRA)” en de ”comprehensive health assessment programme (CHAP)” werden als beste beoordeeld. Deze instrumenten zijn geschikt als basis voor de wetenschappelijke ontwikkeling van een nieuw PGO-VB instrument.

Hoofdstuk 4

Huisartsen verlenen steeds vaker zorg aan mensen met een verstandelijke beperking. Het doel van de kwalitatieve studie, die we beschrijven in **hoofdstuk 4,** is te ontdekken welke overwegingen huisartsen hadden bij pro-actief gezondheidsonderzoek(instrumenten) voor mensen met VB. In een focusgroep exploreerden we met steeds vijf of zes Nederlandse huisartsen de zorg aan mensen met een verstandelijke beperking. De discussies werden letterlijk uitgeschreven en naderhand kwalitatief geanalyseerd. Uit vier bijeenkomsten met in totaal 23 huisartsen kwam naar voren dat huisartsen zich verantwoordelijk voelen voor de zorg aan mensen met een verstandelijke beperking, maar daarbij wel scholing en ondersteuning nodig hebben. Zij zien het nut van een PGO-VB, maar signaleren ook professionele en organisatorische barrières. Een PGO-VB is nuttig om de minder gangbare gezondheidsproblemen van patiënten met een verstandelijke beperking te signaleren, maar er is geen wetenschappelijk onderbouwd en gevalideerd instrument beschikbaar. Ook moeten de nodige praktische belemmeringen uit de weg geruimd worden.

Hoofdstuk 5

In **hoofdstuk 5** bespreken we een Delphi studie. De onderzoeksvraag in de studie luidt: Uit welke onderwerpen moet een Nederlands PGO-VB bestaan? Experts bestaande uit huisartsen met ervaring met mensen met VB en artsen voor verstandelijk gehandicapten (AVG's) namen deel aan deze studie. De voorgelegde onderwerpen waren verzameld uit internationale literatuur en aangedragen door huisartsen tijdens de focusgroep studie. Het onderwerp werd opgenomen in het PGO-VB indien meer dan 75% van de huisarts experts koos voor opname. Gedurende 3 vragenrondes was het deelnamepercentage boven de 88%. Er werden 82 onderwerpen voorgelegd aan de experts. Zij voegden daar nog tien nieuwe onderwerpen aan toe. In totaal was er consensus over 64 onderwerpen verdeeld over diverse onderwerpgroepen die opgenomen moeten worden. Huisartsen gaven aan dat zij graag ondersteund worden tijdens dit PGO-VB. Deels door het PGO-VB thuis door de patiënt (en verzorger) in te laten vullen en deels door assistentie van een praktijk ondersteuner (POH). De huidige kanteling in de zorg met een prominentere rol voor de 1^{e} lijn en de gemeentes zal vragen om geneeskunde-op-maat. Het PGO-VB kan onopgemerkte medische problemen bij mensen met VB voor het voetlicht brengen en aanzetten tot individuele toegesneden tijdige behandeling.

Hoofdstuk 6

Op basis van de uitkomst van de Delphi studie hebben we een pro-actieve gezondheidsvragenlijst ontwikkeld. In de kwalitatieve studie, die we beschrijven in **hoofdstuk 6**, gebruikten we de cognitief interview techniek. Deze techniek wordt aanbevolen om vragenlijsten te testen op begrip en duidelijkheid. We interviewden mensen met VB en hun verzorgers met behulp van deze techniek. In totaal interviewden we 14 deelnemers met VB (met hun eventuele verzorgers) in 5 verschillende rondes. Na elke ronde werd de vragenlijst aangepast totdat saturatie was bereikt. Dit betekent dat er geen nieuwe grote problemen meer naar voren kwamen. We vonden 363 problemen die geleid hebben tot 316 aanpassingen in de vragenlijst. De meeste problemen hadden betrekking op moeilijke woorden en zinsconstructies, gevolgd door ontbrekende antwoorden in de multiple choice categorieën en ontbrekende instructies bij de vragen. Mensen met VB willen graag actief deelnemen in de communicatie met hun huisarts. De uitgebreide pro-actieve gezondheidsvragenlijst stelt hun in staat deze actieve rol te nemen. De vragenlijst kan thuis ingevuld worden, dit scheelt tijd in de huisartspraktijk.

De cognitieve interview techniek is een bruikbare en waardevolle methode in vragenlijst ontwikkeling bij deze kwetsbare groep mensen. De afname van het aantal problemen in de opeenvolgende rondes laat zien dat de cognitieve interview techniek de vragenlijst heeft verbeterd.

Hoofdstuk 7

In **hoofdstuk 7** reflecteren we op de inzichten en bevindingen die zijn voortgekomen uit ons onderzoek en beschrijven we de implicaties met betrekking tot de implementatie van ons pro-actief gezondheidsonderzoekinstrument. We noemen het instrument PGO-VB.

We hebben de kwaliteit van de gevonden pro-actief gezondheidsonderzoek-instrumenten onderzocht op 4 domeinen (*de ontwikkeling*, *de klinimetrische waarden* (zoals validiteit, betrouwbaarheid, toepasbaarheid, acceptatie), *de inhoud* (zoals hoog prevalente gezondheidsproblemen, preventie and gezondheidsbevordering onderwerpen) en *effectiviteit)*. De keuze van deze domeinen was gebaseerd op de aanbevelingen van andere onderzoekers. Er was geen ander gevalideerd instrument beschikbaar voor deze specifieke taak. Oppervlakkig zou men kunnen denken dat gezondheidsonderzoekinstrumenten gelijk zijn aan gezondheidsmeetinstrumenten, zoals bijvoorbeeld de SF36, en daarom met dezelfde kwaliteitsindicatoren beoordeeld kunnen worden. Validiteit en Betrouwbaarheid zijn belangrijke waarden bij gezondheidsmeetinstrumenten. Echter, een pro-actief gezondheidsonderzoekinstrument is meer een checklijst dan een meetinstrument. De toepasbaarheid en de acceptatie van pro-actief gezondheidsonderzoekinstrument vinden we daarom belangrijker waarden dan de validiteit. Desalniettemin vonden we in onze review studie maar 2 instrumenten getest op toepasbaarheid en drie instrumenten getest op acceptatie.

Onderzoek in het veld van verstandelijke beperking is relatief jong in vergelijking met onderzoek in andere medische gebieden. De studiedesigns van de artikelen die we geïncludeerd hebben in ons systematische review zagen er niet zo robuust uit op het eerste gezicht. We hebben hun methodologische kwaliteit in kaart gebracht. Om een goede methodologische kwaliteit na te streven hebben we in de studies in ons project gewerkt volgens strikte studiedesigns: In de review studie (**hoofdstuk 3**) pasten we de PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) richtlijn toe, in focusgroepstudie (**hoofdstuk 4)** gebruikten we de COREQ (consolidated criteria for reporting qualitative research) richtlijn, in de Delphi studie (**hoofdstuk 5)** pasten we de methodologische criteria toe die geadviseerd werden in een review van Diamond en in de cognitieve interview studie (**hoofdstuk 6)** hielden we ons aan de methode die Willis beschreef t.b.v. verbetering van vragenlijsten.

Het mantra van de beweging van mensen met een beperking: '*Nothing about us without us'* stimuleert ons om mensen met VB te laten deelnemen in onderzoek. In 'echt' inclusief onderzoek nemen mensen met VB ook deel aan het ontwerp van de studie. Dit was bij onze studie niet het geval. Mensen met VB namen wel deel aan onze cognitieve interview studie. De cognitieve interview techniek bleek bruikbaar te zijn in deze complexe patiënten populatie. We stellen dan ook voor dat mensen met VB betrokken zullen worden bij toekomstig VB vragenlijst ontwikkeling.

Het doel van ons onderzoek was de ontwikkeling van een Nederlands 1^{e} lijns pro-actief gezondheidsonderzoeksinstrument. Aanvankelijk dachten we een bestaand instrument te kunnen vertalen, maar we vonden geen instrument dat voldeed aan onze kwaliteitscriteria. Na verschillende studies ontwikkelden we de PGO-VB (Pro-actief GezondheidsOnderzoek-Verstandelijk Beperking). We hopen dat de inzet van PGO-VB zal leiden tot vermindering van gezondheidsproblemen van mensen met VB.

Vanuit het perspectief van de onderzoeker zullen de volgende onderzoeksstappen uitdagend zijn. We moeten de implementatie onderzoeken en de effectiviteit testen in de dagelijkse praktijk. Er bestaan richtlijnen en instrumenten die ons kunnen helpen de implementatie gedegen te bestuderen. Daar willen we graag gebruik van maken, want een pro-actief gezondheidsonderzoeksinstrument voor mensen met VB is een complexe interventie.

De gezondheidsonderzoeksvragenlijst met begrijpelijke vragen stelt mensen met VB in staat een actieve rol te spelen in de communicatie met de huisarts. Uit de literatuur komt naar voren dat mensen met VB zich wel bewust moeten worden van de potentiële voordelen van pro-actief gezondheidsonderzoek. We moeten wegen vinden om mensen met VB, en hun verzorgers, te bereiken om hen hiervan op de hoogte te stellen.

Huisartsen gaven aan dat zij baat kunnen hebben bij instrumenten, ondersteuning en scholing met betrekking tot de zorg voor mensen met VB. Algemene gezondheidschecks in de algemene volwassen populatie leiden niet tot het verlagen van de morbiditeit en mortaliteit. Huisartsen moeten daarom op de hoogte gesteld worden van de voordelen die een pro-actief gezondheidsonderzoek voor mensen met VB heeft. Als we het pro-actief gezondheidsonderzoek voor mensen met VB willen implementeren in de huisartspraktijk dan is personele, financiële en technische ondersteuning noodzakelijk. We zullen hier aan tegemoet moeten komen. We verwachten dat mensen met VB die in een instelling wonen ook baat zullen hebben bij het toepassen van pro-actief gezondheidsonderzoek. De toegevoegde waarde zal bestaan uit het systematisch uitvoeren van dit gezondheidsonderzoek.

Er is geen informatie beschikbaar over de lange termijn effecten van pro-actief gezondheidsonderzoek voor mensen met VB. Om deze lange termijn effecten te kunnen bestuderen stellen we een aantal aanpassingen in het gezondheidssysteem voor: registratie van mensen met VB zodat ze uitgenodigd kunnen worden voor het pro-actief gezondheidsonderzoek, accuraat invullen van de overlijdensverklaringen voor mensen met VB, financiële compensatie door zorgverzekeraars aan huisartsen om pro-actief gezondheidsonderzoek uit te kunnen voeren, medische scholing aan (gezondheids)professionals werkzaam met mensen met VB.

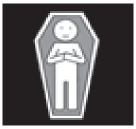
Op weg naar het verminderen van gezondheidsongelijkheden is de subtitel van dit proefschrift. De ontwikkeling van het PGO-VB is de eerste stap. We hopen dat het PGO-VB uiteindelijk zal bijdragen aan het verminderen van gezondheidsongelijkheden.

Makkelijk te lezen samenvatting

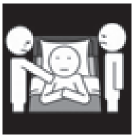
Het maken van een gezondheidsvragenlijst voor mensen met een verstandelijke beperkingen (VB)

Inleiding

- Dit onderzoek gaat over mensen met VB

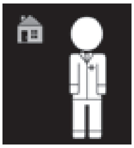


- Mensen met VB overlijden 20 jaar eerder dan andere mensen

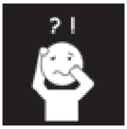


- Mensen met VB zijn twee keer zoveel ziek als andere mensen

- Mensen met VB krijgen vier keer zoveel pillen als andere mensen



- Mensen met VB gaan vaker naar de huisarts

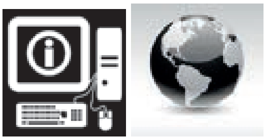
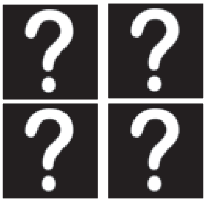


- De huisarts vindt het soms lastig om goede zorg te geven.
- Veel ziektes bij mensen met VB komen minder vaak voor bij andere mensen

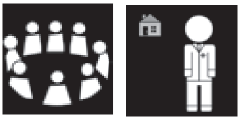
- Een gezondheidsvragenlijst kan de ziektes van mensen met VB helpen vinden

- In Nederland hebben wij geen gezondheidsvragenlijst voor mensen met VB

Literatuurstudie

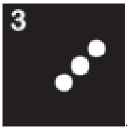
		- We gingen op zoek naar alle gezondheidsvragenlijsten voor mensen met VB - We noemen dit een literatuurstudie
		- We vonden 20 verschillende gezondheidsvragenlijsten
		- Bij elke gezondheidsvragenlijst stelden we 4 vragen 1. Hoe is de vragenlijst gemaakt? 2. Is de vragenlijst goed getest? 3. Wat staat er allemaal in de vragenlijst? 4. Worden er meer ziektes ontdekt als de vragenlijst gebruikt wordt?
	1e vraag: Hoe is de vragenlijst gemaakt?	Antwoord: - Van vier vragenlijsten weten we hoe ze gemaakt zijn
	**2e vraag:** Is de vragenlijst goed getest?	Antwoorden: - Twee vragenlijsten zijn getest of ze goed en betrouwbaar zijn - Bij twee vragenlijsten is getest of de patiënten ze goed vonden - Bij twee vragenlijsten is getest of ze goed toepasbaar zijn in de praktijk
	**3e vraag:** Wat staat er allemaal in de vragenlijst?	Antwoorden: - De vragen in de vragenlijst waren erg verschillend - Sommige vragenlijsten waren lang en andere kort - Bijna alle vragenlijsten stelden vragen over zien, horen en tandartscontrole
	**4e vraag:** Worden er meer ziektes ontdekt als de vragenlijst gebruikt wordt?	Antwoorden: - Drie vragenlijsten zijn goed onderzocht - Bij twee vragenlijsten ontdekten ze meer ziektes en andere punten. Bijvoorbeeld beter op het gewicht letten
		- Twee vragenlijsten, de CHAP en de SWH-HRA, waren beter dan alle andere

Focusgroepstudie



- Samen met groepen huisartsen gingen we praten over de medische zorg aan mensen met VB
- We noemen dat een focusgroepstudie

- Onderzoeksvraag: Wat vinden de huisartsen van een gezondheidsvragenlijst voor mensen met VB?



- Drie onderwerpen vonden de huisartsen belangrijk

1. Huisartsen voelden zich verantwoordelijk voor patiënten met VB in hun praktijk

2. Een gezondheidsvragenlijst voor mensen met VB kan helpen. De vragenlijst moet dan wel goed gemaakt zijn en voordeel opleveren voor mensen met VB

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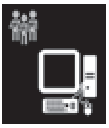
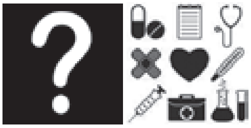
3. Huisartsen zagen nog wel wat moeilijkheden op de weg om de gezondheidsvragenlijst te gaan gebruiken

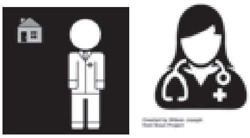
Delphi studie



- Met de computer, via de email, stuurden we vragen naar dokters
- Dit noemen we een Delphi studie



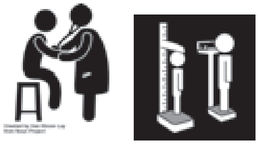
- We vroegen welke onderwerpen over gezondheid en ziekte bij mensen met VB, in de gezondheidsvragenlijst moesten komen
- Als drie van de vier dokters het een goed onderwerp vonden, dan kwam het in de gezondheidsvragenlijst



- Huisartsen en artsen voor verstandelijk gehandicapten deden mee aan dit onderzoek

- De dokters kozen 64 onderwerpen

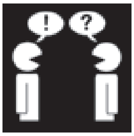
- Die onderwerpen gaan bijvoorbeeld over zien, horen, vallen en epilepsie/toevallen



- Lichamelijk onderzoek is belangrijk,
- De dokters kozen 18 onderwerpen. Bijvoorbeeld wegen en meten

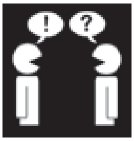
- De dokters hadden ook een advies
  De gezondheidsvragenlijst kan de patiënt alvast thuis samen met iemand invullen.
  Dit scheelt tijd in de huisartspraktijk

Cognitieve interview studie



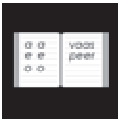
- We gingen praten met mensen met VB en hun verzorgers over de gezondheidsvragenlijst
- Dit noemen we een cognitieve interview studie


- Samen met mensen met VB wilden we de vragenlijst verbeteren
- We willen dat iedereen de vragen begrijpt en goed kan beantwoorden




- 2-3 mensen met VB deden er mee per ronde
- Er waren 5 rondes
- In totaal hebben we met 14 mensen met VB gepraat

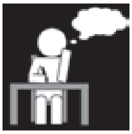
- Zij hadden 363 tips
- In de 5^{e} ronde waren er nog maar weinig tips over. Toen zijn we gestopt.
- We hebben op 316 punten de vragenlijst verbeterd



- De meeste tips gingen over moeilijke woorden en zinnen


- De gezondheidsvragenlijst is nu klaar.
- We hebben de vragenlijst ook nog in het Engels vertaald

Discussie

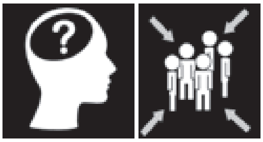


- Wat hebben we geleerd van dit onderzoek?
- Dit bespreek je in het discussie hoofdstuk

vraag:
Is de vragenlijst goed getest?

- Deze vraag stelden we in de literatuur studie
- Testen van gezondheidsvragenlijsten is moeilijk
- 2 dingen moet je in ieder geval onderzoeken:
  - ✓ Hoe je de vragenlijst moet gebruiken in de huisartspraktijk
  - ✓ Vinden mensen met VB het gezondheidsonderzoek fijn en goed

- Er zijn regels voor goed onderzoek doen
- Ook bij onderzoek over/met mensen met VB moet je je aan deze regels houden
- De uitkomsten zijn dan betrouwbaarder
- In ons onderzoek hebben we ons goed aan de regels gehouden

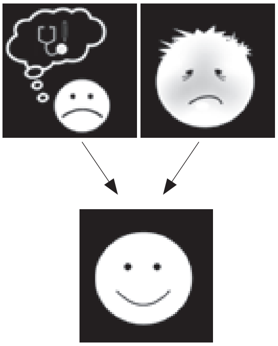


- Samenwerken in onderzoek is belangrijk
- Mensen met VB kunnen heel goed mee doen in onderzoek
- Mensen met VB hebben in ons onderzoek geholpen de vragenlijst te verbeteren
- Dit is nog nooit eerder gedaan

- De gezondheidsvragenlijst is nu klaar
- We noemen hem PGO-VB. Dit betekent Pro-actief GezondheidsOnderzoek – Verstandelijke Beperking
- In het Engels heet de lijst PROSPER-ID

klaar?

- We zijn nog NIET klaar met het onderzoek
- We gaan onderzoeken hoe we de vragenlijst moeten gebruiken in de huisartspraktijk
- We gaan onderzoeken of mensen met VB het gezondheidsonderzoek fijn en goed vinden
- We gaan onderzoeken of we ook meer ziektes bij mensen met VB ontdekken als we PGO-VB gaan gebruiken



- We hopen dat door het gebruik van de PGO-VB mensen met VB minder vaak ziek zijn

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Met dank aan :

Anneke van der Cruijsen en Henk Jansen voor het kritisch meelezen van dit hoofdstuk

De picto’s komen van de website: http://www.sclera.be/nl/picto/overview of zijn gemaakt door Lorenza Stella, Gan Khoon Lay, Wilson Joseph, Michael Thompson, Mateus Dias Gomes, Eric Benoit, Okan Benn, Evan Shuster van het Noun project.

9

Dankwoord

List of publications

Curriculum Vitae (English, Nederlands)

Radboud Institute of Health Sciences portfolio

Dankwoord

Het begon in 2011. Ik reed naar Nijmegen om te solliciteren op de AVG plek die vrijgekomen was op poli Zeldzaam in het Radboudumc. Tijdens het ontzettend leuke gesprek werd gevraagd of ik eventueel naast mijn werk op poli Zeldzaam ook zin had om promotieonderzoek te doen. Wat een prachtige kans werd me hier geboden. Het duurde even voordat ik echt aan de slag kon als promovendus; in september 2013 startte mijn avontuurlijke reis. Met heel veel plezier heb ik de afgelopen jaren leren onderzoek doen. Een roman schrijver schrijft zijn boek nooit alleen, er is een heel scala aan mensen betrokken voordat het boek in de boekhandel ligt. Ook een proefschrift schrijven doe je niet alleen. Vele mensen hebben me geholpen op deze avontuurlijke reis. Deze laatste pagina's van mijn proefschrift wil ik gebruiken om hen te bedanken.

Prof. dr. Henny M.J. van Schrojenstein Lantman – de Valk. Jaren geleden was ik op bezoek bij Pepijn en Paulus en luisterde naar een lezing die jij, Henny, daar gaf. Die lezing maakte indruk. Als AVG in opleiding nam ik me voor om jou als voorbeeld te nemen. Hoe bijzonder dat je het zag zitten om mijn promotor te worden. Dank je wel Henny dat je van zo dichtbij deze voorbeeldfunctie voor me hebt willen vervullen. Dank voor de opbouwende en leuke gesprekken die we hadden en je continue aanmoediging. Dank voor de heerlijke lunches in Limbricht, toen we samen de cognitieve interviews codeerden. Ik had me geen betere promotor kunnen wensen.

Dr. Peter L.B.J. Lucassen. Een paar maanden na de start van mijn promotieonderzoek had ik samen met Henny een eerste gesprek met jou. Je wilde je eerst een oordeel vormen over de promovendus voordat je een toezegging deed om co-promotor, dagelijks begeleider, te worden. Ik weet niet Peter wat je heeft doen besluiten om deze toezegging te doen, maar wat ben ik blij dat jij mijn co-promotor bent geweest. Onze samenwerking liep als een trein. Je reageerde altijd ontzettend snel op mijn stukken concept tekst. Regelmatig heb jij de tekst zo herschreven dat er precies stond wat ik bedoelde te zeggen. Duizend maal dank.

Prof. dr. (Pim) W.J.J. Assendelft, Dr. Tim C. Olde Hartman. Ik ben een bevoorrecht mens met 2 promotoren en 2 co-promotoren in mijn begeleidingscommissie. Dank je wel, Pim. Als 2e promotor, zat je vaak eerst aandachtig te luisteren naar de discussie tijdens de begeleidingsgroep overleggen om vervolgens ineens kernachtig het geheel samen te vatten en sturing te geven aan de te nemen vervolgstappen. Elk overleg werd zo een sprong vooruit. En Tim. Wat een enthousiaste, dynamische, slimme, sneldenkende begeleider ben jij. Als er iemand weet hoe je positieve feedback moet geven dan ben jij het wel. Deze feedback gaf me vleugels en inspiratie om door te gaan.

Prof. dr. B. G. M. van Engelen, Prof. dr. H. Vermeulen en Prof. dr. M.Y Berger. Hartelijk dank voor uw bereidwilligheid om in mijn manuscriptcommissie plaats te nemen en mijn proefschrift op waarde te schatten.

Dr. A.A.E.M. van Alfen - van der Velden, Dr. D.A.M. Maes - Festen, Prof. dr. J.W.A. Smit. Als leden van de corona wil ik u bedanken voor de tijd die u genomen hebt om mijn proefschrift te lezen en vragen te bedenken. Ik zie uit naar een mooie discussie.

Drs. Rob E.C.S. Hoogma, Julianne A. Meijers, MSc, Dr. Geraline L. Leusink, MBA. Als Raad van bestuur van Siza, en directeur van de medische dienst, gaven jullie mij de gelegenheid om naast mijn werk als arts voor verstandelijk gehandicapten dit promotie traject te doorlopen. Ik prijs mij zeer gelukkig met zo'n werkgever die gericht is op de ontwikkeling van haar medewerkers. Eigenlijk kan het ook niet anders bij een organisatie die denkt in mogelijkheden en het verleggen van grenzen van haar cliënten èn medewerkers.

Deelnemers aan de onderzoeken. Goed onderzoek staat of valt met de bereidwilligheid van participanten om deel te nemen aan het onderzoek. Daarom wil ik de mensen met een verstandelijke beperking en hun begeleiders/verzorgers/familieleden heel erg bedanken voor hun deelname aan de cognitieve interview studie. Wat heb ik genoten van de interviews en jullie kritische, en soms grappige, opmerkingen over de vragenlijst. Bij het analyseren en coderen van de interviews zat ik geregeld met een grote glimlach op mijn gezicht. Lex van Son stond me van a-z terzijde tijdens de review studie. Wat een klus hebben we samen geklaard Lex. Dank! Toen ik jou, Marianne Dees, vroeg om moderator te zijn bij mijn focusgroepen reageerde je zeer enthousiast. Het was goed samenwerken. Dank ook aan huisartsen en artsen voor verstandelijk gehandicapten die, in hun spaarzame vrije tijd, deel genomen hebben aan mijn focusgroep en Delphi studie. Een deelname percentage van boven de 88% over 3 rondes in een Delphi studie onderstreept jullie grote betrokkenheid.

Drs. Arjen K. van Gijssel, Drs. Marja Meinsma - van der Tuin, kinderrevalidatiearts. Toen ik jullie vroeg om paranimf te zijn, zeiden jullie beiden direct ja. Ik prijs mij gelukkig dat ik straks daar niet in mijn eentje sta, maar geflankeerd word door mijn broer en beste vriendin/collega. Arjen, je volgde mijn promotie avonturen op de voet. Ik weet dat ik nooit tevergeefs een beroep op je zal doen. Marja, wat spijtig dat we zover uit elkaar wonen, maar onze (lange!) telefoongesprekken maken veel goed. Vanaf het moment dat we elkaar tijdens de co-schappen tegenkwamen vonden we in elkaar een klankbord.

Anneke van der Cruijsen, Henk Jansen. Wat is het van onschatbare waarde om jullie als collega's te hebben. Elke keer helpen jullie ons eraan te herinneren dat alles wat we doen goed te begrijpen moet zijn voor mensen met VB. Zo hebben we samen kritisch gekeken naar mijn makkelijk te lezen samenvatting. Dank jullie wel voor de opmerkingen, aanvullingen en verbeteringen.

AVG collega's. Wim Kok, Gé Jacobs, Aimé Okouere, Brigit Spierenburg-Meelen en Loes van Keimpema, dank jullie wel voor jullie bereidwilligheid om steeds meer patiënten en taken van mij over te nemen. Gedurende mijn promotietraject en met de uitbreiding van de AVG praktijk in het Radboudumc bleef uiteindelijk alleen de dinsdag over als gezamenlijke werkdag. Ik hoop dat we de positieve flow waar we nu in zitten kunnen vasthouden en samen verder kunnen bouwen aan kwalitatief hoogwaardige AVG zorg voor onze Siza patiënten en mensen met VB in de omgeving van Arnhem.

Siza collega's. Rianne Molenhuis, Carla Harmelink, Klasien van Soest, Mirjam Krielen, collega's van het eerste uur. Ik leerde jullie kennen toen met mijn opleiding tot AVG bij Siza begon. Dank voor jullie belangstelling, aanmoediging en vertrouwen dat ik ook dit project tot een goed einde zou brengen. Laten we vooral blijven 'bij-beppen' tijdens gezellige etentjes.

GMVB collega's. Mathilde Mastebroek, Noortje Kuiken, Tessa Frankena, Marloes Heutmekers, Kristel Vlot, Tonny Coppus, Francine Driessen Mareeuw, Maarten Cuypers, Monique Koks-Leensen, Geraline Leusink, Jenneken Naaldenberg, Anja van Lieshout-Hol. Francine, dank je wel voor je hulp bij het coderen van de focusgroepen. Als GMVB collega's zetten we samen het onderzoek bij deze bijzondere doelgroep op de kaart. De bereidwilligheid om elkaar te helpen, te stimuleren, de gezellige lunches en uitjes zorgen ervoor dat ik elke dag weer met plezier aan het werk ga. De saamhorigheid in ons team is bijzonder groot, menigeen kan daar jaloers op zijn.

Nordic Walking meisjes. Anneke Zandstra, Annelies van Gennip, Elsbeth Tanja, Jose Steenvoorden, Marloes de Ruiter-Jorna, Marita van de Berg, Maaike Wigboldus, Renate van Montfoort, Margie Schmits. Hard werken zonder ontspanning en lichamelijke inspanning is onmogelijk en onwenselijk. Gelukkig wonen we in een bosrijke omgeving waar het wandelend goed toeven is. Dank voor alle leuke gesprekken die goed samengaan met het nordic walken. En ons jaarlijkse Fjoertoer uitje is het hoogtepunt van het jaar.

VYW kwadrant dames. Esther Verdonk-Fels, Rineke van Eijk en Urika Grutterink. Dank jullie wel voor jullie morele support en gebed tijdens deze promotie periode. Het is goed om samen op ontdekkingsreis te zijn naar onze talenten, bijdrage en plek op deze aardbol.

Familie. Dank je wel Rachel Wols voor de prachtige omslag van mijn proefschrift.

Van jongs af aan heb ik een gedrevenheid gehad om alles ‘zewwes/zelf’ te doen. Mijn ouders hebben me daarin gestimuleerd en gecoacht. Mijn vader heeft nooit de mogelijkheid gehad om te studeren, al had hij een studie vast glansrijk doorlopen. Hij zou een geschikt huisarts zijn geweest. Het is heel verdrietig dat we vorig jaar zeer onverwacht en plotseling afscheid van hem hebben moeten nemen. Wat zag hij uit naar deze promotieplechtigheid en wat zou hij trots zijn geweest. Daarom draag ik dit proefschrift ook aan hem, Geert van Gijssel, op. Mam, fijn dat jij er straks wel bij kunt zijn. Dank voor je luisterend oor en je altijd aanwezige betrokkenheid.

Tim, Eva, Mirthe en Job. Jullie zijn allemaal uitgevlogen en bezig jullie eigen leven vorm te geven. Jullie hebben het mij gemakkelijk gemaakt. Doordat het, nou ja op een paar kleine dipjes na, goed ging met jullie was ik in de gelegenheid me volledig te storten op dit promotieonderzoek. Ik ben er trots op jullie moeder te zijn en zie met vertrouwen en nieuwsgierigheid de toekomst tegemoet.

Evert Jan, jij bent de liefde van mijn leven al 34 jaar lang. Op onze huwelijksdag 1 mei 1987 begon jouw baan als promovendus. Nooit gedacht dat ik ooit nog eens, zoveel jaar later, zou promoveren. Maar een ding weet ik zeker, zonder jouw hulp bij alles, was het ook nooit zover gekomen.

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Curriculum Vitae

Esther van Gijssel was born in Zwolle on 22 June 1965. She is the eldest of three children. After completing her secondary education at ‘Het Meander College’ in Zwolle in 1983, she started her medical education at the University of Groningen. She married Evert Jan Bakker in 1987. Since then, she bears the double name Bakker-van Gijssel. The year 1991 was a very special year; she finished her medical degree and became the mother of Tim. In 1992, the family moved to Mali, Western Africa. Esther started an outpatient clinic for children in the hospital at Niono. In 3 years’ time, she saw 3000 children. One of these children, a tiny little baby, was Eva, who was adopted into the family in 1992. In 1995, the family, by now also including Mirthe who was born in 1993, moved back to the Netherlands.

Esther started to work as a well-baby clinic doctor at ‘Stichting Thuiszorg Midden Gelderland’. In 1997, she completed the well-baby clinic doctor application course at the PAOG (post academic medical education) of the Catholic University of Nijmegen (now Radboud University Medical Center). Together with three well-baby doctor colleagues they applied for and received financial support to do research in a national study called LOOZ (Landelijk Obstipatie Onderzoek Zuigelingen; National Research Constipation Infants) focusing on normal defecation patterns and signs of constipation in infants. In 2004, after her youngest son Job (1996) had begun primary school, she started to specialise as an Intellectual Disability (ID) physician at Erasmus University in Rotterdam. The ID physician Wim Kok, working at Siza in Arnhem, was her supervisor during her specialisation. After her graduation in 2007, Siza invited her to stay as an ID physician. She became head of Siza’s medical department. ‘De Schreuderhuizen’ (now Elver) asked her to become the ID physician of their children’s department. In the same year, she became president of the NVAVG (Dutch association of ID physicians) Arnhem-Nijmegen regional ID physicians group. She was president for 6 years. Two years later, she became president of the Dutch association of ID physicians, the NVAVG. In 2011, she started to work as a teacher at Radboud University Medical Center and as an ID physician in the multidisciplinary outpatient clinic Unique, where she works together with a clinical geneticist. In that same period, she wrote the research proposal for her PhD thesis. In 2013, she started part-time, with her PhD project. She continued to work as an ID physician at Siza and took over the work in the outpatient clinic ‘AVG Praktijk” from her PhD supervisor. In 2016, she became an executive member of the IASSIDD (Health SIRG (International Association for the Scientific Study of Intellectual and Developmental Disabilities, Health special interest research group) and of the Dutch Association of Childhood Disabilities. Since 2017, she has been part of the ‘We do see you’ team. The Dutch Minister of Health asked this team to investigate the possibilities of better help for people with severe ID and their families. After finishing her PhD thesis, Esther continues to work as an ID physician and researcher.

Levensloop

Esther van Gijssel is op 22 juni 1965 in Zwolle geboren als oudste in een gezin met drie kinderen. Zij behaalde in 1983 haar VWO diploma aan het Meander college in Zwolle. In datzelfde jaar begon ze haar studie geneeskunde aan de Rijksuniversiteit in Groningen. Ze trouwde tijdens haar studie in 1987 met Evert Jan Bakker en draagt sindsdien de dubbele naam Esther Bakker-van Gijssel. Het jaar 1991 was voor haar een speciaal jaar. Zij werd moeder van Tim en behaalde haar artsexamen. Vlak na haar artsexamen verhuisde het gezin naar Mali, West Afrika. In het ziekenhuis in Niono zette zij een polikliniek voor kinderen op. Gedurende de drie jaar dat zij verbonden was aan deze kliniek zag zij meer dan 3000 kinderen. Een van deze kinderen was Eva. Ze verwelkomden haar in 1992, als baby van amper een paar weken, in het gezin. In 1995 verhuisde het gezin, inclusief Mirthe (1993), terug naar Nederland.

Na terugkomst in Nederland ging Esther werken als consultatiebureau (CB) arts bij de Stichting Thuiszorg Midden Gelderland (STMG) en rondde ze in 1997 de applicatiecursus voor CB artsen aan het PAOG (post academisch onderwijs geneeskunde) van de Katholieke Universiteit Nijmegen (thans Radboudumc) af. Ze werd betrokken bij LOOZ (landelijk obstipatieonderzoek zuigelingen), een grootschalig onderzoek in Nederland met als doel te bepalen wat een ‘normaal’ ontlastingpatroon bij zuigelingen is en of tekenen van obstipatie vroegtijdig te herkennen zijn. In 2004, nadat haar jongste zoon Job (1996) op de basisschool gesetteld was, startte zij met de fulltime AVG opleiding aan het Erasmus MC in Rotterdam. Wim Kok, AVG (arts verstandelijk gehandicapten) bij Siza in Arnhem, was gedurende die drie jaar haar opleider. Na het afronden van de AVG opleiding in 2007 kreeg zij een aanstelling als AVG bij Siza en kreeg zij als zodanig de kindergroepen van de Schreuderhuizen (thans Elver) onder haar hoede. Ook werd zij 1^{e} geneeskundige en BOPZ-arts bij Siza. In datzelfde jaar werd ze lid van de deskundigheidsbevorderingscommissie van de NVAVG (Nederlandse Vereniging van Artsen voor Verstandelijk Gehandicapten). In 2009 werd zij voorzitter van de NVAVG regiovergadering Arnhem- Nijmegen, een functie die zij ruim 6 jaar vervulde. Twee jaar later nam zij plaats in het landelijk bestuur van de NVAVG, waar zij van november 2010 t/m april 2013 voorzitter was.

In 2011 begonnen haar parttime werkzaamheden in het Radboudumc, eerst als AVG-docent en later ook als AVG verbonden aan de polikliniek Zeldzaam, een multidisciplinaire poli samen met de klinisch geneticus. In diezelfde periode begon het nadenken over en het schrijven van een onderzoeksvoorstel voor promotieonderzoek. In september 2013 ging zij parttime van start met haar PhD project, nam zij het werk in de AVG praktijk in het Radboudumc over van haar promotor en bleef ze als AVG verbonden aan Siza. In 2016 werd zij lid van het bestuur van de onderzoeksgroep ‘gezondheid’ van het IASSIDD (International Association for the Scientific Study of Intellectual and Developmental Disabilities). Daarnaast werd zij lid van het bestuur van de Dutch association of childhood Disabilities. Sinds 2017 maakt zij deel uit van de door het ministerie van VWS ingestelde onafhankelijke werkgroep 'wij zien je wel'. Deze werkgroep beoogt voorzieningen te treffen die het leven van zeer ernstig verstandelijk gehandicapte mensen en hun families vergemakkelijken.

Na het afronden van haar proefschrift blijft Esther het werk van onderzoeker en praktiserend AVG combineren.

Institute for Health Sciences
Radboudumc

PHD PORTFOLIO

Name PhD candidate: Esther Bakker-van Gijssel, AVG ***Department: Primary and community care*** ***Graduate School: Radboud Institute for Health Sciences***	**PhD period:** ***1-9-2013– 1-6-2018*** ***Promotor(s): Prof. dr.H van Schrojenstein Lantman- de Valk, Prof. dr. W.J.J Assendelft*** ***Co-promotor(s): Dr. P. Lucassen, Dr .T. OldeHartman***

	Year(s)	ECTS
TRAINING ACTIVITIES		
a) Courses & Workshops		
- End-Note Workshop, Radboud medical library	2013	0.2
- RIHS Introduction course for PhD students	2013	1.1
- BROK course: Basic course legislation and organization for clinical researchers	2013	1.5
- Pubmed for users, Radboud medical library	2013	0.1
- CaRe course: Qualitative Research Methods in Health Care (Introduction)	2013	0.6
- Courses Developing a Cochrane Systematic Review of interventions (Dutch Cochrane centre, Julius centre UMC Utrecht)	2014	0.6
- Course ER&T, qualitative research : focusgroups (Erasmus MC Rotterdam)	2014	0.7
- Course Statistics for PhD students, (Radboud university)	2015	2.0
- Scientific integrity for PhD students	2015	0.5
- Academic writing for PhD candidates	2015	3.0
- Basic qualification teaching	2017	0.2
- Clinimetrics (wintercourse) EPIDM: clinimetrics of health measurement instruments	2017	1.75
- Art of presenting science	2017	1.5
- Advanced conversation	2017	1.5
- BROK re-registration	2017	0.2
b) Seminars & lectures		
- Health care for People with ID in the Netherlands Erasmus MC Rotterdam, aios AVG dag, (oral)	2013	0,35
- Proactief risicomanagement voor mensen met verstandelijke beperkingen. NVAVG regiovergadering(oral)	2014	0,35
- Proactief risico management voor mensen met verstandelijke beperkingen (VB) een systematische review NHG wetenschapsdag (poster presentation) RUGroningen	2014	0,35
- Eerstelijnszorg voor mensen met verstandelijke Beperkingen (oral) VGN slotbijeenkomst,	2014	0,35
- Preventief geneeskundig onderzoek bij mensen met VB Studiedag AVG's (oral) 's Heerenloo Amersfoort,	2014	0,35
- Zorg voor mensen met verstandelijke beperkingen in de eerste lijn - *Kwestie van samenwerken* huisartsen gemeente Renkum op uitnodiging van de wethouder (oral)	2015	0,35
- Pro actief gezondheidsonderzoek (PGO) bij mensen met een verstandelijke beperking 's (oral) Heerenloo, expertisecentrum	2015	0,35
- Patiënten met een verstandelijke beperking in de huisartsenpraktijk (oral) WDH Nijmegen,	2016	0,35
- Mensen met een verstandelijke beperking (oral) Opleidingsdag aios klinisch genetica, Utrecht	2016	0,35
- Van praktijk probleem naar onderzoek (workshop) Wetenschapsdag AVG opleiding, Radboudumc Nijmegen	2016	0,50
- Meningen van huisartsen met betrekking tot een pro-actief gezondheidsonderzoeksinstrument voor mensen met VB- focusgroepstudie (oral), regiovergadering NVAVG	2016	0,35
- Pro actief gezondheidsonderzoek voor mensen met verstandelijke beperkingen in de huisartspraktijk, Lunch bespreking Siza, Arnhem (oral)	2018	0,25
- Pro actief gezondheidsonderzoek voor mensen met verstandelijke beperkingen in de huisartspraktijk, MEDT zorg, Arnhem (oral)	2018	0,25

c) Symposia & congresses		
- ‘Ervaringen van een AVG’ (oral) nascholingsdag ESN (erfelijke stofwisselingsziekten Nederland)	2013	0,25
- Health care for People with ID in the Netherlands (oral) IASSIDD congress,	2013	0,75
- Preventive health screening for people with intellectual disabilities-a systematic review (oral) European IASSIDD congress, Vienna	2014	0,75
- Een zeldzame diagnose, en dan… (oral) gezamenlijke studiedag NVAVG en Vlaamse artsen werkzaam in de zorg voor mensen met een verstandelijke beperking	2016	0,50
- Samenwerken met de 1e lijn (workshop) symposium “Colour the future” Rotterdam,	2014	0,75
- De (meer)waarde van preventief gezondheidsonderzoek bij mensen met verstandelijke beperkingen in de 1e lijn (workshop), congres nationaal programma gehandicapten	2015	0,75
- Preventive health screening for people with intellectual disabilities (roundtable discussion) European IASSIDD congress, Vienna,	2014	0,75
- Personalized healthcare in context: experiences with health research with people with ID (round table discussion) symposium research in Individuals with ID, Radboudumc Nijmegen	2015	0,50
- IASSIDD Melbourne, Australia: Health assessment instruments for people with intellectual disabilities: A systematic review (oral)	2016	0,75
- IASSIDD Melbourne, Australia: Opinions of GPs regarding health assessment instruments for people with intellectual disabilities: A qualitative study (oral)	2016	0,50
- Refereerbijeenkomst ELG: Pro actief gezondheidsonderzoek voor mensen met een verstandelijke beperking in de huisartsenpraktijk (oral)	2016	0,25
- PhD retreat RIHS: Health assessment instruments for people with intellectual disabilities in primary care	2016	0,75
- Proactief gezondheidsonderzoek **voor mensen met een verstandelijke beperking (PGO-VB) NHG wetenschapsdag, Utrecht (oral)**	2017	0,50
- Let’s talk about seks, 51e kinderartsenweek Radboudumc, 15 maart 2017 (oral)	2017	0,50
- Implementation and uptake of primary healthcare guidelines to improve the health of adults with intellectual and developmental disabilities Health SIRG conference IASSIDD, Belfast (workshop)	2017	0,75
- Proactive health assessment instrument for people with intellectual disabilities (ID) **Health SIRG IASSIDD Belfast (Rewarded posterpresentation)**	2017	0,50
- Uptake and implementation of the health check to improve the health of adults with IDD -*setting the research agenda*- Health SIRG conference IASSIDD, Belfast (workshop)	2017	0,50
- Lid expertpanel; Voorschrijven van psychofarmaca; niet alleen een zaak voor de dokter Assen, 26 september 2017	2017	0,25
- Mogen we risico’s nemen? Moeten we risico’s mijden? Nieuw Wehl, Symposium Ethiek georganiseerd door Zozijn, Siza, Elver, Passarelle (oral)	2017	0,35
d) Other		
- Health care for People with ID in the Netherlands IASSID congress, organization of a site visits to Dutch service providers for people with ID	2013	2
- Wetenschapsdag AVG opleiding, Radboudumc Nijmegen (dagvoorzitter)	2016	0,50
- Medewerking Richtlijn signalering somatische klachten bij mensen met verstandelijke beperkingen in opdracht van V&VN, uitgevoerd door Trimbos instituut	2013	1
- Gastredacteur Themanummer **ntvg,** Geneeskunde voor mensen met een verstandelijke beperking, nummer 47, november 2014	2014	2
- Publicatie ntvg (klinische les): Neem de tijd. Zorg voor mensen met verstandelijke beperkingen in de eerste lijn	2014	0,75
- MOOC **(Massive Open Online Course) High support needs-spasticity, in cooperation with** The University of Queensland, Brisbane, Australia	2015	0,50
- Publicatie ntvg(commentaar): Psychofarmaca voor mensen met een verstandelijke beperking in de eerste lijn	2015	0,75
- Publicatie ntvg (in het kort): "Fitness bij mensen met een verstandelijke beperking, helpt dat?”	2016	0,75
- Research visit Queensland Centre for Intellectual and Developmental Disability QCIDD, Mater Research Institute – University of Queensland, Brisbane, Australia	2017	0,50
- Executive member Health SIRG IASSIDD: organisatie conferentie 19,20,21 juni2017 : Bridging the gap: from evidence to improved health for persons with intellectual and developmental disabilities	2017 2017	2
- Track director Access to health care/Primary care guidelines **Health SIRG IASSIDD Belfast**	2017	0,50
- **Medewerking aan Casusboek LVB en verslaving**	2017	0,25
- **Reviewing Scientific papers for multiple journals**	2014 - present	0,8

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TEACHING ACTIVITIES		
e) Lecturing		
- Docent geneeskunde studenten/biomedische wetenschappen, ELG/GMVB, Radboudumc	2011-heden	0,50
- Research methodology for health and Science, YRM-30306,WUR: Health assessments for people with ID in primary care	2016	0,25
f) Supervision of internships / other		
- Supervisie 3e aios AVG poli zeldzaam	2014-2017	1
- Supervisie co-assistenten stage op zorginstelling voor mensen met VB	2013-heden	1
- Beoordeling aios Klinische genetica op poli Zeldzaam	2011-heden	1
- Stage begeleider wetenschapsstudent geneeskunde (masterscriptie)	2017	1
TOTAL		**47.00**

Radboud University Nijmegen Medical Centre

Appendices

PROSPER–ID*

26-3-2018
Radboud university medical center
E.J. Bakker-van Gijssel

*Proactive Systematic Participation Evidence based pRimary care- Intellectual-Disabilities

Soon, you will answer a list of questions. It is okay if someone (family, caregiver, etc.) helps you with this.

- The questions are all about your health.
- We know that people with intellectual disabilities sometimes find it difficult to explain to others about their health.
- We have come up with 62 different questions. That is quite a lot.
- If you are tired of answering questions, you can put the questions away for a while. Only continue with the questions once you feel rested again.
- There are no good or bad answers. It is about what you find important or where you have problems.

The completed list of questions helps your doctor (GP) to better understand what is NOT going well with your health. They can then help you to feel better again.

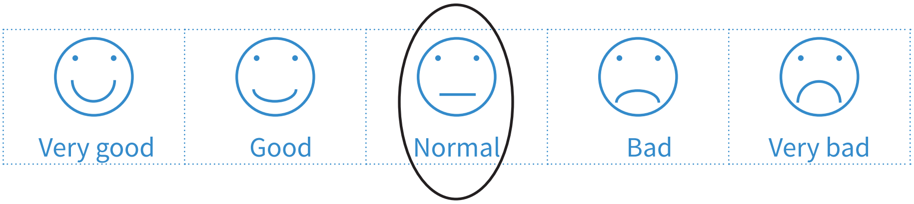
All the questions have a **black color**. The answers have a **blue color**.

Here is an example:

• Have you ever had an epileptic seizure?	☐ YES ☐ NO
• Tick the box of your choice. Like this:	☑ YES ☐ NO
• And then continue with the next question	

Another example:

- How well can you see, in your opinion? (If you wear glasses, with your glasses, otherwise without)
- Put a circle around your choice. Like this:



Very good | Good | [✓ Normal] | Bad | Very bad

Last example:

- Can you tell why not?

  Write your answer here:

A1. Seeing and hearing

Seeing

1. Do you wear glasses?
   - ☐ No
   - ☐ Yes

   When was the last time that you were at the eye doctor, optician/glasses shop, or GP to have your eyes checked?
   - ☐ I have never been there
   - ☐ I have not been there in a long time
   - ☐ I have been there
     - O date: ………….
     - O I don’t remember the date
   - ☐ Don’t know

2. In your opinion, how well can you see (with your glasses, if you wear any, or without them if you don’t)?

😀	🙂	😐	🙁	☹
Very good	Good	Normal	Bad	Very bad

3. Have you started seeing worse in the past year?
   - ☐ No (continue with question 4)
   - ☐ Yes (a little)
   - ☐ Don’t know

   If YES:

   Do you see worse when you look at a photobook or iPad or newspaper (up close)?
   - ☐ Yes
   - ☐ No

   Do you see worse when you look at the TV (far away)?
   - ☐ Yes
   - ☐ No

Hearing

4. When was the last time that you had a hearing test at the ear, nose, and throat doctor, ear doctor/hearing aid shop or GP?
   - ☐ I have never been there
   - ☐ Have not been in a long time
   - ☐ I have been there
     - ○ date: …………..
     - ○ I don't remember the date
   - ☐ I don't know

5. Do you have a hearing aid?
   - ☐ No (continue with question 7)
   - ☐ Yes
6. Do you wear the hearing aid every day?
   - ☐ Yes
   - ☐ No

   If NO: Can you explain why not?

   Write your answer here: …………

7. In your opinion, how well can you hear (with your hearing aid, if you wear one, or without it if you don't)?

Very good	Good	Normal	Bad	Very bad

A2. Stomach and Bowels

8. Sometimes, some food from your stomach comes back up into your mouth. This sometimes has a sour taste.
   Does this ever happen to you?
   - ☐ No
   - ☐ Yes

9. Do you have trouble swallowing?
   - ☐ No
   - ☐ Yes

10. Do you often choke when you are drinking or eating?
    - ☐ No
    - ☐ Yes
    - ☐ Very rarely

    If YES: When this happens, do you start coughing or do you have trouble breathing or do you have trouble speaking after choking/swallowing?
    - ☐ No
    - ☐ Yes

11. How often do you need to poop?
    - ☐ More than 2 times per day
    - ☐ 1-2 times per day
    - ☐ 1 time every 2 days
    - ☐ 1-2 times per week
    - ☐ It changes, sometimes often, sometimes not very often
    - ☐ Other, namely (Write your answer here):

12. Do you have trouble pooping?
    (For example: not being able to poop for a while, pressing hard, pain when pooping, blood in poop, hard poop, very thin poop, etc.)
    - ☐ No (continue with question 13)
    - ☐ Yes
    - ☐ Sometimes

If YES or SOMETIMES:
Write down the problem here: ....

13. Has your weight changed in the last 3 months?
    - ☐ Yes
    - ☐ No (continue with question 14)
    - ☐ I don’t know (did not weigh myself) (continue with question 14)

If YES: Have you gained weight (become heavier) or lost weight (become lighter)?

- ☐ Gained weight
- ☐ Lost weight
- ☐ My weight changes; I get heavier, then lighter again

How many kilograms do you think you weigh? …………….. kg

A3. Peeing and sex

14. Do you have trouble peeing?
(For example: pain when peeing, straining when peeing, peeing many times in the night, etc.)
☐ No (continue with question 15)
☐ Yes

If YES:
Write down the problem here:

15. Where do you pee? (You can select more than one answer)
☐ Usually on the toilet
☐ Usually in the diaper
☐ A bottle to pee in (urinal bottle)
☐ Usually in my pants
☐ A tube with a peeing bag stuck to it (catheter)

16. Have you recently had a bladder infection?
(When you have a bladder infection, you have to pee often, peeing hurts, sometimes there will be blood in the pee, and sometimes you get pills from the doctor to help you get better)
☐ No
☐ Sometimes
☐ Often

17. Question for women: How are your periods?
(You can select more than one answer)
☐ I'm in menopause, so no more periods
☐ Good: no problems
☐ Pain in belly
☐ A lot of blood loss
☐ Very little blood loss
☐ Other, namely (Write your answer here):

The doctor (GP) wants to help you stay healthy.
The doctor (GP) would like you to not get any diseases from unsafe sex or to get pregnant if that’s not what you want.
The next 3 questions are about this.

18. Have you ever had sex?
(By sex, we mean making love to a man or woman)
☐ No (continue with question 19)
☐ Yes

19. Do you use contraceptives/birth control?
(so that the woman does not get a baby in her belly)

(You can select more than one answer)
☐ No (continue with question 20)
☐ Birth control pills
☐ IUD
☐ Contraceptive injection
☐ Condoms
☐ Sterilization (then you are “helped”)
☐ Other, namely (Write your answer here):

20. Are you ever afraid of getting an infectious disease through sex (an STD)?

☐	☐	☐	☐	☐
Never	Sometimes	Regularly	Often	All the time

A4. Moving

21. Is it easy for you to move?

☐ Yes, easy
☐ No, (a little) difficult

If (a little) difficult: What is difficult to do?
Write your answer here:

22. Did you fall in the past month?

☐ No (continue with question 23)
☐ Yes

If YES: How many times did you fall in the past month?
………. times

23. Do you have pain in your joints or in your back?
(joints are, for example, your knee, ankle, wrist, shoulder, finger, hip)

☐ No (continue with question 24)
☐ Yes
☐ Sometimes
☐ I don't know

If YES: Which joint hurts?
Write your answer here:

A5. Heart and lungs

24. Do you have a heart problem that you were born with?
(For example: hole in the heart, heart valve defect, etc.)

☐ No (continue with question 25)
☐ Yes
☐ I don't know

If YES: Which one?

Write your answer here:

25. Do you think that you have problems with your heart?

(You can select more than one answer)

☐ No (continue with question 26)
☐ Heart palpitations (this is when your heart starts pounding very hard, fast, and weirdly)
☐ Blue color (for example, on your lips, fingers, toes)
☐ Getting tired very quickly during sports and exercise
☐ Chest tightness or chest pain
☐ Stuffy when I lay flat in bed (I like to sleep sitting upright)
☐ Other, namely (Write your answer here)

26. Do you have problems with your breathing?

☐ No (continue with question 27)
☐ Yes
☐ Sometimes

If YES or SOMETIMES: What do you suffer from?
(You can select more than one answer)

☐ Coughing
☐ Stuffiness/not getting air
☐ Wheezing
☐ Other, namely (Write your answer here):

27. Do you have one or more lung infections every year?

☐ No
☐ Yes

28. People who suffer from sneezing, stuffiness, itching, hay fever may be allergic.
Do you suffer from any of these things?

☐ No
☐ Yes, sometimes

A6. Epilepsy, sleep, pain

29. Do you ever have a seizure/epileptic seizure?
    - ☐ No (continue with question 30)
    - ☐ Yes
    - ☐ I have had it in the past

    If YES: Have the epileptic seizures lately....
    - ☐ Become worse
    - ☐ Become less frequent
    - ☐ Remained the same

30. Are you still able to do everything that you used to do? (For example: writing, taking the bus on your own, shopping for groceries by yourself, working, walking, being alert, etc.)
    - ☐ No
    - ☐ Yes (continue with question 31)

    If NO: Can you describe the change?
    Write your answer here:

31. Do other people in your surroundings notice that you can do less than before? (If you're not sure, ask someone)
    - ☐ No (continue with question 32)
    - ☐ I don't know (continue with question 32)
    - ☐ Yes

    If YES: What is it that they notice about you?
    Write your answer here:

32. How well can you usually remember things?
    (For example, is it easy for you to learn new things)

Very good	Good	Normal	Bad	Very bad

33. Do you notice any changes with remembering things?
    - ☐ No (continue with question 34)
    - ☐ Yes

    If YES: Do you forget things:
    - ☐ More often
    - ☐ Less often

34. Are you taking any medicine to be able to sleep well?
    - ☐ No
    - ☐ Yes

    How are you sleeping?

☺	🙂	😐	🙁	☹
Very good	Good	Normal	Bad	Very bad

Or

It Changes

One day/period	and	the other day/period
🙂		🙁
Good		Bad

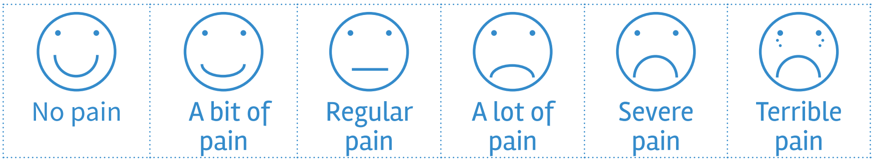
If you have filled in BAD or VERY BAD. Are you having trouble with:
(You can select more than one answer)
- ☐ Falling asleep
- ☐ Sleeping through the night/waking up during the night
- ☐ Waking up early
- ☐ Sleep apnea (very loud snoring and sometimes even not breathing while sleeping)

35. Do you have pain?

(Here, we mean pain that is MORE THAN a little headache)

☐ No (continue with question 36)
☐ Yes
☐ I don’t know

If YES: How much?



Where does it hurt? (For example, in your knee, belly, back, shoulder, fingers, leg, etc.)

Write your answer here:

36. Have you been to the dentist in the past year (cleaning and checking your teeth)?

☐ No
☐ Yes (continue with question 37)

If NO: Can you tell us why not?

☐ I don’t have any of my own teeth anymore
☐ I have artificial teeth.
☐ It is too stressful
☐ I’m afraid of the dentist
☐ Other, namely: (Write your answer here):

B. Behavior

37. Has your behaviour (anger, pounding, sad, emotional) changed in recent times? (For example: have you not been feeling very comfortable in your own skin lately?)

☐ No (continue with question 38)
☐ Yes

If YES, has your behavior gotten
☐ Better
☐ Worse

If it has BECOME WORSE,
write here what has become worse:

38. Examples of psychiatric illnesses/mental disorders are:

- anxiety
- AD(H)D (= very active/chaotic behavior),
- psychosis (hearing voices/getting commands)
- depression (very sad feeling)
- schizophrenia
- autism

Have you ever been diagnosed with a psychiatric illness?
☐ No (continue with question 39)
☐ Yes
☐ I don’t know (continue with question 39)

If YES: What was that illness?
Write your answer here:

C. Population study

39. For WOMEN only: Do you have any problems with your breasts?

☐ No (continue with question 40)
☐ Yes

If YES: What are those problems?
(You can select more than one answer)

☐ Pain
☐ Bumps/lumps
☐ Redness/irritation/itch
☐ Retracted nipple
☐ Other, namely: (Write your answer here):

40. For WOMEN only: Are you older than 50 years?

☐ No (continue with question 41)
☐ Yes

Every two years, all women between the ages of 50-75 get an invitation for a breast cancer screening/mammogram

If YES: Did you ever get an x-ray (mammogram) of your breasts?

☐ Yes (continue with question 41)
☐ No

If NO: Can you tell us why you did not go?

☐ It is too stressful
☐ I did not receive an invitation
☐ Other, namely: (Write your answer here):

41. Question for MEN and WOMEN

Are you older than 55 years?

☐ No (continue with question 42)
☐ Yes

Every two years, all men and women between the ages of 55-75 receive an invitation for a colon cancer screening.

Have you participated in this colon cancer screening?

☐ Yes (continue with question 42)
☐ No

If NO: Why have you not participated?

☐ It is too stressful
☐ I did not receive an invitation
☐ Other, namely: (Write your answer here):

42. Question for MEN and WOMEN:

Have you had immunizations/vaccinations/injections?
(See examples below)

☐ No
☐ Yes
☐ I don't know (continue with question 43)

If YES: Which one?
(You can select more than one answer)

☐ All vaccinations as a baby/toddler/preschooler/school child
☐ D(K)TP
☐ Tetanus
☐ Jaundice/Hepatitis B
☐ Flu Shot/Influenza
☐ HPV (cervical cancer)
☐ Other, namely (Write your answer here)
☐ I don't know

If NO: Why haven't you had any vaccinations?

☐ It is too stressful
☐ I'm afraid of injections
☐ I did not receive an invitation
☐ Other, namely: (Write your answer here):

D. Lifestyle

Try to answer honestly. It’s important for the doctor (GP) to know whether you smoke, drink alcohol, or use drugs.

43. Do you smoke or have you smoked before?
    - ☐ No, I have never smoked
    - ☐ I used to smoke
    - ☐ Sometimes 1 cigarette
    - ☐ Yes, I smoke

44. Do you drink alcohol such as beer, wine, hard alcohol (Bacardi, rum, whiskey) at least 1x per week?
    - ☐ No (continue with question 45)
    - ☐ I sometimes drink alcohol at a party (continue with question 45)
    - ☐ Yes

    If YES:
    How often do you drink beer, wine, or hard alcohol during the week?
    Answer: .... days per week
    How many glasses/bottles do you drink per day?
    Answer: .... glasses/bottles per day

45. Do you use or have you ever used drugs?
    (Drugs are, for example, weed, joints, cocaine, MDMA/ECSTASY pills, marijuana, etc.)
    - ☐ No (continue with question 46)
    - ☐ Yes

    If YES: Which drug?
    Write your answer here:

46. Moving and doing sports include hiking, cycling, swimming, horseback riding, and exercising at home.
Moving also includes, for example, vacuuming, washing windows, working in the garden.

Do you do sports and/or move?
☐ Often (more than 30 minutes every day)
☐ Regularly (every day, but less than 30 minutes)
☐ Sometimes (on 2-6 days per week)
☐ Very rarely (once per week)
☐ No

47. Vitamin D and exercise is important to make your bones strong. Your body makes vitamin D when you are outside.
How often do you go outside during the day?
☐ Every day
☐ A few times per week
☐ Once per week
☐ Never or almost never

48. It is important to eat and drink healthy. Select below what you eat:
☐ I only get fed through a tube (continue with question 49)

Fruit
☐ every day ☐ a couple times per week ☐ once per week
☐ never or almost never

Vegetables
☐ every day ☐ a couple times per week ☐ once per week
☐ never or almost never

Bread or cereals or porridge
☐ every day ☐ a couple times per week ☐ once per week
☐ never or almost never

Tea and/or coffee
☐ every day ☐ a couple times per week ☐ once per week
☐ never or almost never

Water
☐ every day ☐ a couple times per week ☐ once per week
☐ never or almost never

Milk, yoghurt, buttermilk
☐ every day ☐ a couple times per week ☐ once per week
☐ never or almost never

Coke, Fanta, Seven Up, soft drinks with bubbles
☐ every day ☐ a couple times per week ☐ once per week
☐ never or almost never

Fries, hamburger, pizza, crisps
☐ every day ☐ a couple times per week ☐ once per week
☐ never or almost never

Do you have any more comments about the food you eat? If so, write them here:

E1. Work, free time, and friends

49. With meaningful/nice daily activities we mean going to work, to day care, to school, or to do voluntary work.
Do you have nice daily activities?
☐ No
☐ Yes

50. Everyone needs friends and family.
Which people do you have to help you?
(You can select more than one answer)
☐ Parents (father, mother)
☐ In-laws (brothers-in-law, sisters-in-law)
☐ Brothers or sisters
☐ Husband or wife (spouse)
☐ Fiancé/partner/boyfriend/girlfriend
☐ Neighbor
☐ Friends
☐ Volunteers
☐ caregivers
☐ Other, namely: (Write your answer here):

☐ I have no one to help me

E2. Other

51. I use:

(You can select more than one answer)

☐ Hearing aid
☐ Glasses
☐ Walking stick
☐ Rollator/walker
☐ Wheelchair
☐ Mobility scooter
☐ No aid
☐ Other, namely (Write your answer here):

52. Do you need help throughout the day?

☐ No (continue with question 53)
☐ Yes

If YES: What do you need help with?

(You can select more than one answer)

☐ Everything

Or (tick box)

☐ Grocery shopping
☐ Taking a shower and getting dressed
☐ Eating
☐ Going to the toilet
☐ Cooking dinner
☐ Cleaning the house
☐ Washing clothes
☐ Making phone calls
☐ Travelling
☐ Making appointments
☐ Psychological support
☐ Other, namely (Write your answer here):

53. Communication (= telling) is very important. With communication, we mean making things clear by asking questions, understanding answers, and telling what you like and what you don't like. Most people communicate by talking, others use tools to "talk".

How do you make things clear?
(You can select more than one answer)

☐ Talking with words
☐ Voice synthesizer
☐ Signs (sign language)
☐ Using pictograms/cards with images
☐ Body language
☐ Use of objects (For example, showing swimsuit if you are going swimming)
☐ Other, namely (Write your answer here):

F1. Care providers

54. Your doctor (GP) is a care provider, just like your dentist. The same goes for doctors in the hospital, social workers, behavioral experts, physiotherapists, and counsellors.

Which (professional) care providers are important to you?

Counsellor	Name
(Personal) caregiver	
Outpatient counsellor	
Behavioral therapist/psychologist Remedial educationalist	
Doctor for people with intellectual disabilities (ID physician)	
Physiotherapist	
Dentist	
Social worker	
Occupational therapist	
Specialist from the hospital	1. 2. 3. 4.
Other, namely:	

F2. Personal questions

55. Where do you live?

- ☐ A home for people with disabilities (with 24-hour care)
- ☐ A home for people with disabilities (without 24-hour care)
  - o .... hours of care per day/per week
  - o I don't know the number of hours of care
- ☐ A house with my family
- ☐ I have my own house and I get outpatient care
  - o .... hours of care per day/per week
  - o I don't know the number of hours of care
- ☐ Other, namely (Write your answer here):

56. Sometimes you need help with making important decisions in areas such as health or finances. When it comes to health, the doctor (GP) needs to know who to consult with.

Who is helping you? (You can select more than one answer)

- ☐ Curator (deals with personal and financial matters)
- ☐ Mentor (deals with personal matters, such as health)
- ☐ Administrator (deals with financial matters)
- ☐ Legal representative
- ☐ Family
- ☐ I don't know

What is his/her name?

Write the name and phone number of this person here:

57. Sometimes people get a bit confused and can hurt themselves, others, or things. The law can then protect them against themselves. The judge will give them a legal status.
Do you have such a legal status? Please select one or more of the following options:
☐ Judicial authorization
☐ Detention in a specialized facility
☐ Article 60 (Often for people with severe intellectual disabilities who are not able to communicate whether they want something or not)
☐ No
☐ I don't know

58. I think my health is:

				
Extremely good	Quite good	Good	Okay	Bad

Over the past weeks, my health has:
☐ Improved
☐ Become worse
☐ Remained the same
☐ I don't know

59. Has your degree of intellectual disability ever been tested with, for example, an IQ test?
☐ No (continue with question 60)
☐ Yes
☐ I don't know

Can you tell me what level has been determined?

☐ Borderline (IQ 70-85, level of development 12-16 yrs.)
☐ Mild (IQ 50-70, developmental age: 7-12 yrs.)
☐ Moderate (IQ 35-50, developmental age: 4-6 yrs.)
☐ Severe (IQ 20-35, developmental age: 2-3 yrs.)
☐ Profound (IQ 0-20, developmental age: 0-1 yrs.)
☐ I don’t know

60. Is the cause of your intellectual disability known?
(Causes include, for example, Down syndrome, autism, oxygen deficiency at birth)

☐ No (continue with question 61)
☐ Yes
☐ I don’t know

If YES: What is the cause?
Write your answer here:

F3. Illnesses that occur in your family

61. Does anyone in your family have one of the following illnesses? (Family = parents, grandfather/grandmother, brother/sister, aunt/uncle)

Diabetes:
☐ No ☐ Yes ☐ I don’t know

Psychiatric/Mental illnesses:
(For example: (AD(H)D (= very active/chaotic behavior), psychosis (hearing voices), depression (very sad feeling)
☐ No ☐ Yes ☐ I don’t know

Cardiovascular diseases:
☐ No ☐ Yes ☐ I don’t know

Epilepsy:
☐ No ☐ Yes ☐ I don’t know

Breast cancer:
☐ No ☐ Yes ☐ I don’t know

Colon cancer:
☐ No ☐ Yes ☐ I don’t know

Intellectual disability:
☐ No ☐ Yes ☐ I don’t know

G Medication

62. Your doctor (GP) wants to know which medications you are using.
    If you have a current medication list from the pharmacy, you can also take this with you.
    For any medications that are not on this list, please write these here below.

    In addition to medications that have been prescribed by a doctor, you maybe also use other medicines that you bought on your own, such as homeopathic remedies, pain killers (paracetamol) or food supplements.
    For those medicines that you use and that are not on the pharmacy list, can you please fill in the scheme below?

Name Medicine	Quantity: number of mg or tablets	How many times per day	Do they work well?	Do you know what this medicine is for?

Do you also use psychotropic drugs?
(For example, risperidone, dipiperon, anti-depressants (e.g. citalopram) or Ritalin)

☐ No
☐ Yes
☐ I don’t know

If YES: What is the name of this medicine?
Write your answer here:

This was the last question. Thank you so much for completing this list of questions. Take this completed list with you to your doctor.

H. Own questions for the doctor

Below, you can write down any questions you have for your doctor.

1.

2.

3.

I. Physical and supplementary research by the general practitioner

(To be completed by the general practitioner)

1. General impression (consider the following points):
    a. appearance – physical characteristics;
    b. age estimation;
    c. self-care;
    d. contact – eye contact;
    e. attitude
    f. possibly behavior towards others;
    g. presentation of complaints;
    h. Other, namely:

2. Awareness (circle):
    clear/focused confused inadequate unintelligible
    apathic/no contact

3. Communication (tick box):
    - ☐ talking: whole sentences
    - ☐ talking: loose words
    - ☐ voice synthesizer
    - ☐ sign language
    - ☐ use of pictograms/photos
    - ☐ through body language
    - ☐ Other, namely...
4. Dysmorphology (describe):

5. Impression of the hearing (use for example the whisper map)

6. Otoscopy
    AS AD

7. Length
   cm
8. Weight
   kg

9. BMI

10. Blood pressure
    mmHg

11. Pulse
    /min. regular/irregular evenly: yes/no

12. Heart auscultation
    S1S2: Souffles: Additional tones:

13. Physical examination with regard to the points that have emerged from the anamnestic questionnaire

14. Indication for additional blood tests?
    Yes No

15. Indication for additional urine analysis?
    Yes No

16. Referrals necessary? (circle or describe)

a. Vision test	Yes	No
b. Hearing test	Yes	No
c. Clinical genetics	Yes	No
d. Other, namely …..		

17. Reanimation policy discussed?
    Yes No

18. Treatment limitations discussed?

    Yes No n/a

19. Are any freedom-limiting measures being applied? (For example: locked doors, mandatory medication administration, mandatory food administration)

    Yes No

Action plan for the patient and counsellors

In response to the questionnaire and the physical examination, we have made the following agreements:

1.

This action is performed by:

2.

This action is performed by:

3.

This action is performed by:

4.

This action is performed by:

5.

This action is performed by:

Pro-actief gezondheidsonderzoek voor mensen met een verstandelijke beperking

PGO-VB

26-3-2018
Radboudumc
E.J. Bakker-van Gijssel

Zo meteen ga je een vragenlijst invullen. Het is prima als iemand (familie, begeleider etc.) jou daarbij helpt.

- De vragen gaan over jouw gezondheid en alles wat daarmee samenhangt.
- We weten dat mensen met een verstandelijke beperking het soms moeilijk vinden om te vertellen hoe het met hun gezondheid gaat.
- We hebben 62 verschillende vragen gemaakt. Dat is best veel.
- Als je moe bent om vragen te beantwoorden leg dan de vragenlijst even weg. Ga pas verder met invullen als je weer uitgerust bent.
- Er zijn geen goede of foute antwoorden. Het gaat erom wat jij belangrijk vindt of waar jij problemen hebt.

De ingevulde vragenlijst helpt huisartsen om beter te begrijpen wat er NIET goed gaat met jouw gezondheid. Zij kunnen je dan helpen om je weer beter te voelen.

Alle vragen hebben een zwarte kleur. De antwoorden zijn blauw van kleur.
We geven een voorbeeld:

- Heb je wel eens een epileptische aanval gehad?
  ☐ JA ☐ NEE
- Kruis je keus aan. Zo :
  ☑ JA ☐ NEE
- En ga dan verder met de volgende vraag

Nog een voorbeeld:

- Hoe goed kun je zien, vind jij? (als je een bril hebt met je bril en anders zonder)
- Zet een cirkel om je keuze. Zo:

Super goed	Goed	[✓ Gewoon]	Slecht	heel slecht

Laatste voorbeeld:

- Kun je vertellen waarom niet?
  Schrijf hier je antwoord op:

A1. Zien en Horen

Zien

1. Draag jij een bril?

☐ Nee
☐ Ja

Wanneer ben je voor het laatst voor controle van je ogen bij de oogarts, opticien/brillenwinkel of huisarts geweest?

☐ Nooit geweest
☐ Ben al lang niet meer geweest
☐ Ben wel geweest
  O datum:………….
  O ik weet de datum niet meer
☐ Weet niet

2. Hoe goed kun je zien, vind jij? (als je een bril hebt met je bril en anders zonder)

☺	🙂	😐	🙁	☹
Super goed	Goed	Gewoon	Slecht	heel slecht

3. Is het zien het laatste jaar slechter geworden?

☐ Nee (ga verder met vraag 4)
☐ Ja (een beetje)
☐ Weet niet

Indien JA :

Zie je slechter als je kijkt naar een fotoboek of Ipad of krant (dichtbij)

☐ Ja
☐ Nee

Zie je slechter als je kijkt naar de tv (veraf)

☐ Ja
☐ Nee

Horen

4. Wanneer had je voor het laatst een hoortest bij de KNO (keel neus en oor) arts, audioloog/winkel voor hoorapparaten of huisarts?
   - ☐ Nooit geweest
   - ☐ Ben al lang niet meer geweest
   - ☐ Ben wel geweest
     - ○ datum:…………..
     - ○ ik weet de datum niet meer
   - ☐ Weet niet

5. Heb je een hoorapparaat?
   - ☐ Nee (ga verder met vraag 7)
   - ☐ Ja

6. Draag je het hoorapparaat elke dag?
   - ☐ Ja
   - ☐ Nee

   Indien NEE: Kun je vertellen waarom niet?

   Schrijf hier je antwoord op:………..

7. Hoe goed kun je horen, vind je? (als je een hoortoestel hebt met je hoortoestel en anders zonder)

☺ Super goed	☺ Goed	😐 Gewoon	☹ Slecht	☹ heel slecht

A2. Maag en Darmen

8. Soms komt er een beetje eten omhoog vanuit je buik weer terug in je mond. Dit geeft soms een zure smaak.
Heb je dat wel eens?
☐ Nee
☐ Ja

9. Heb jij problemen met slikken ?
☐ Nee
☐ Ja

10. Verslik je je vaak als je drinkt of eet?
☐ Nee
☐ Ja
☐ Heel soms

Indien JA: Begin je dan te hoesten <u>of</u> heb je dan moeite met ademhalen <u>of</u> heb je moeite met praten na het (ver)slikken?
☐ Nee
☐ Ja

11. Hoe vaak moet jij poepen
☐ Meer dan 2 keer per dag
☐ 1-2 keer per dag
☐ 1 keer per 2 dagen
☐ 1-2 keer per week
☐ Wisselend, soms vaak, soms weinig
☐ Anders, nl. (Schrijf hier je antwoord op):

12. Heb je problemen met het poepen?
(bijvoorbeeld: lang niet kunnen poepen, hard persen, pijn bij poepen, bloed bij ontlasting, harde ontlasting, heel dunne ontlasting etc.)
☐ Nee (ga verder naar vraag 13)
☐ Ja
☐ Soms

Indien JA/soms:
Schrijf hier het probleem op:………

13. Is je gewicht veranderd in de laatste 3 maanden?
    - ☐ Ja
    - ☐ Nee (ga verder naar vraag 14)
    - ☐ Weet niet (niet gewogen) (ga verder naar vraag 14)

Indien JA: Ben je aangekomen (zwaarder geworden) of afgevallen (lichter geworden)?
- ☐ Aangekomen
- ☐ Afgevallen
- ☐ Ik schommel met mijn gewicht;dan weer zwaarder, dan weer lichter

Hoeveel kilo's denk je?:
……………..kg

A3. Plassen en seks

14. Heb je problemen met plassen?
(bijvoorbeeld: pijn bij plassen, persen tijdens het plassen, 's nachts veel plassen etc.)
☐ Nee (ga verder naar vraag 15)
☐ Ja

Indien JA:
Schrijf hier je probleem op:

15. Waar plas je? (meer antwoorden aankruisen mag)
☐ Meestal op de wc
☐ Meestal in de luier
☐ Een fles om in te plassen (urinaal)
☐ Meestal in mijn broek
☐ Een slangetje met een plaszak eraan(katheter)

16. Heb je kort geleden wel eens een blaasontsteking gehad?
(bij een blaasontsteking moet je vaak plassen, doet het plassen pijn, soms bloed in de plas, en krijg je van de dokter soms pillen om je beter te maken)
☐ Nee
☐ Soms
☐ Vaak

17. Vraag voor de dames: Hoe gaat het meestal met de menstruatie?
(meer antwoorden aankruisen mag)
☐ Ik ben in de overgang, dus geen menstruatie meer
☐ Goed: geen problemen
☐ Buikpijn
☐ Veel bloedverlies
☐ Heel weinig bloedverlies
☐ Anders, nl (Schrijf hier je antwoord op):

De huisarts wil je helpen gezond te blijven.
De huisarts wil graag dat je geen ziektes krijgt door onveilige seks of zwanger raakt terwijl je dat niet wilt.
Hier gaan de volgende 3 vragen over.

18. Heb je wel eens seks gehad?
(met seks bedoelen we vrijen met een man of vrouw)
☐ Nooit (ga verder naar vraag 19)
☐ Ja

19. Gebruik je voorbehoedsmiddel/anticonceptie?
(zodat de vrouw geen baby in de buik krijgt)

(meer antwoorden aankruisen mag)
☐ Nee (ga verder naar vraag 20)
☐ De pil
☐ Spiraaltje
☐ Prikpil
☐ Condooms
☐ Sterilisatie (dan ben je ‘geholpen’)
☐ Anders, nl(Schrijf hier je antwoord op):

20. Ben je wel eens bang voor een besmettelijke ziekte die je via seks kunt krijgen(een SOA)?

☐	☐	☐	☐	☐
Nooit	Soms	Regelmatig	Vaak	Altijd

A4. Bewegen

21. Beweeg je makkelijk?

☐ Ja, makkelijk
☐ Nee, (een beetje) moeilijk

Indien (een beetje) moeilijk: Wat gaat er moeilijk?
Schrijf hier je antwoord op:

22. Ben je de afgelopen maand gevallen?

☐ Nee (ga verder naar vraag 23)
☐ Ja

Indien JA: Hoe vaak ben je de afgelopen maand gevallen?
………. keer

23. Heb je pijn in je gewrichten of in je rug?
(gewrichten zijn bijvoorbeeld je knie, enkel, pols, schouder,vingers, heup)

☐ Nee (ga verder naar vraag 24)
☐ Ja
☐ Soms
☐ Weet niet

Indien JA: Welk gewricht of waar doet pijn?
Schrijf hier je antwoord op:

A5. Hart en longen

24. Heb jij een hartafwijking waar je mee geboren bent?
(bij voorbeeld: gaatje in het hart, hartklepafwijking etc.)
☐ Nee (ga verder naar vraag 25)
☐ Ja
☐ Weet niet
Indien JA: Welke?
Schrijf hier je antwoord op:

25. Denk je dat je problemen met je hart hebt?
(meer antwoorden aankruisen mag)
☐ Nee (ga verder naar vraag 26)
☐ Hartkloppingen (je hart gaat dan heel hard, snel en raar bonzen)
☐ Blauwe kleur (bijvoorbeeld van lippen, vingers, tenen)
☐ Snel moe met sporten en inspanningen
☐ Strak gevoel of pijn op de borst
☐ Benauwd wanneer ik plat in bed lig (ik slaap graag rechtop zittend)
☐ Anders nl(Schrijf hier je antwoord op):

26. Heb je problemen met ademhalen?
☐ Nee (ga verder naar vraag 27)
☐ Ja
☐ Soms

Indien JA/ Soms: Waar heb je last van?
(meer antwoorden aankruisen mag)
☐ Hoesten
☐ Benauwdheid /geen lucht krijgen
☐ Piepende ademhaling
☐ Anders nl (Schrijf hier je antwoord op):

27. Heb je elk jaar wel een of meer longontstekingen?
    - ☐ Nee
    - ☐ Ja

28. Mensen die last hebben van niezen, benauwdheid, jeuk, hooikoorts kunnen allergisch zijn.
    Heb jij daar last van?
    - ☐ Nee
    - ☐ Ja (soms)

A6. Epilepsie, slapen, pijn

29. Heb jij wel eens een toeval/epileptische aanval?
    ☐ Nee (ga verder naar vraag 30)
    ☐ Ja
    ☐ Vroeger wel gehad
    Indien JA: Zijn de epileptische aanvallen de laatste tijd….
    ☐ Erger geworden
    ☐ Minder geworden
    ☐ Gelijk gebleven

30. Kun je nu nog alles wat je vroeger deed? (bijvoorbeeld: schrijven, alleen met de bus reizen, zelf boodschappen doen, werken, lopen, alert zijn etc.)
    ☐ Nee
    ☐ Ja(ga verder naar vraag 31)

    Indien NEE: Kun je de verandering beschrijven?
    Schrijf hier je antwoord op:

31. Merken andere mensen in jouw omgeving dat je minder kan dan vroeger? (als je het niet zeker weet vraag het even na bij iemand)
    ☐ Nee (ga verder naar vraag32)
    ☐ Weet niet (ga verder naar vraag32)
    ☐ Ja

    Indien JA: wat merken ze dan aan jou?
    Schrijf hier je antwoord op :

32. Hoe goed kun jij meestal dingen onthouden?
(bijvoorbeeld: leer je dingen makkelijk aan)

Super goed	Goed	Normaal	Slecht	heel slecht

33. Merk je veranderingen bij het onthouden van dingen?
☐ Nee (ga verder naar vraag 34)
☐ Ja
Indien JA: Vergeet je steeds:
☐ Meer
☐ Minder

34. Slik je medicijnen om goed te kunnen slapen?
☐ Nee
☐ Ja

Hoe gaat het met slapen?

Super goed	Goed	Normaal	Slecht	heel slecht

Of

Wisselend

De ene dag/periode en de andere dag/periode

Goed Slecht

Als je SLECHT of HEEL SLECHT hebt ingevuld. Heb je dan problemen met :
(meer antwoorden mogelijk)

☐ Inslapen/ in slaap vallen
☐ Doorslapen/ ’s nachts wakker worden
☐ Vroeg wakker worden
☐ Slaap apnoe (erg snurken en soms even stoppen met ademhalen tijdens het slapen)

35. Heb je pijn?
(we bedoelen hier NIET een beetje hoofdpijn)

☐ Nee (ga verder naar vraag 36)
☐ Ja
☐ Weet niet

INDIEN JA: Hoeveel?

 Geen pijn	 Beetje pijn	 Regelmatig pijn	 Erge pijn	 Ernstige pijn	 Verschrikkelijke pijn

Waar zit de pijn? (bijvoorbeeld in je knie, buik, rug, schouder, vingers, been etc.)

Schrijf hier je antwoord op:

36. Ben je afgelopen jaar naar de tandarts geweest(schoonmaken en controle van de tanden)?

☐ Nee
☐ Ja (ga verder naar vraag 37)

INDIEN NEE : Kun je ons vertellen waarom niet?

☐ Ik heb geen eigen tanden meer
☐ Ik heb een kunstgebit
☐ Geeft te veel stress
☐ Ik ben bang voor de tandarts
☐ Anders nl. (Schrijf hier je antwoord op):

B. Gedrag

37. Is je gedrag (boosheid, bonken, verdrietig, emotioneel) veranderd in de afgelopen tijd? (bijvoorbeeld: zit je niet goed in je vel de afgelopen tijd?)

☐ Nee (ga verder naar vraag 38)
☐ Ja

INDIEN JA is je gedrag
☐ Beter
☐ Slechter geworden

INDIEN SLECHTER,
Schrijf hier op wat er slechter werd:

38. Voorbeelden van psychiatrische ziektes/geesteziektes zijn:

- angst
- AD(H) D (= héél druk/chaotisch gedrag),
- psychose (horen van stemmen/krijgen van opdrachten)
- depressie (zwaar verdrietig gevoel)
- schizofrenie
- autisme

Is er bij jou wel eens een psychiatrische ziekte vastgesteld?
☐ Nee (ga verder naar vraag 39)
☐ Ja
☐ Weet niet (ga verder naar vraag 39)

Indien JA: Wat was die ziekte?
Schrijf hier je antwoord op:

C. Bevolkingsonderzoek

39. Alleen voor VROUWEN: Heb je problemen met je borsten?

☐ Nee (ga verder naar vraag 40)
☐ Ja

Indien JA: Wat zijn die problemen?
(meer antwoorden aankruisen mag)

☐ Pijn
☐ Bobbels/knobbels
☐ Roodheid/irritatie/jeuk
☐ Ingetrokken tepel
☐ Anders nl. (Schrijf hier je antwoord op):

40. Alleen voor VROUWEN: Ben jij ouder dan 50 jaar?

☐ Nee (ga verder naar vraag 41)
☐ Ja

Alle vrouwen tussen de leeftijd van 50-75 jaar krijgen elke 2 jaar een uitnodiging voor een borstkanker screening/mammogram

Indien JA. Heb je een röntgenfoto(mammogram) van je borsten gehad?

☐ Ja (ga verder naar vraag 41)
☐ Nee

Indien NEE. Kun je ons vertellen waarom je niet bent gegaan?

☐ Geeft te veel stress
☐ Ik heb geen uitnodiging ontvangen
☐ Anders nl. (Schrijf hier je antwoord op):

41. Vraag voor MANNEN en VROUWEN
Ben jij ouder dan 55 jaar?
☐ Nee (ga verder naar vraag 42)
☐ Ja

Alle mannen en vrouwen tussen de 55-75 jaar ontvangen elke 2 jaar een uitnodiging voor onderzoek naar darmkanker.

Heb jij meegedaan aan het darmkanker onderzoek?
☐ Ja (ga verder naar vraag 42)
☐ Nee

Indien NEE. Waarom heb je dan niet meegedaan?
☐ Geeft te veel stress
☐ Ik heb geen uitnodiging ontvangen
☐ Anders nl. (Schrijf hier je antwoord op):

42. Vraag voor MANNEN en VROUWEN:
Heb jij inentingen/vaccinaties/prikken gehad?
(voorbeelden zie hieronder)
☐ Nee
☐ Ja
☐ Weet niet (ga verder naar vraag 43)

Indien JA. Welke?
(meer antwoorden aankruisen mag)
☐ Alle vaccinaties als baby/peuter/kleuter/schoolkind
☐ D(K)TP
☐ Tetanus
☐ Geelzucht/ Hepatitis B
☐ Griepprik/Influenza
☐ HPV (baarmoederhalskanker)
☐ Anders nl(Schrijf hier je antwoord op):

☐ WEET NIET

Indien NEE. Waarom heb je dan geen vaccinaties gehad?

☐ Geeft te veel stress
☐ Ik ben bang voor prikken
☐ Ik heb geen uitnodiging ontvangen
☐ Anders nl. (Schrijf hier je antwoord op):

D. Leefstijl

Probeer eerlijk te antwoorden, het is belangrijk voor de huisarts dat hij/zij weet dat je rookt, alcohol drinkt of drugs gebruikt.

43. Rook je of heb je gerookt?

☐ Nee, nooit gerookt
☐ Vroeger gerookt
☐ Soms 1 sigaretje
☐ Ja, ik rook

44. Drink je alcohol (bier, wijn, sterke drank (=bijvoorbeeld: bacardi, rum, whisky) minstens 1x per week?

☐ Nee (ga verder naar vraag 45)
☐ Ik drink heel soms op een feestje(ga verder naar vraag 45)
☐ Ja

Indien JA:
Hoe vaak drink je bier, wijn, sterke drank in de week?
Antwoord:………….dagen per week

Hoeveel glazen/flesjes drink je per dag?

Antwoord:………… glazen/flesjes per dag

45. Gebruik je, of heb je ooit drugs gebruikt?
(drugs is bijvoorbeeld wiet, jointje, cocaïne, MDMA/XTC(pilletjes), marihuana, etc)

☐ Nee (ga verder naar vraag 46)
☐ Ja

Indien JA: Welke drug?
Schrijf hier je antwoord op:

46. Onder bewegen en sporten verstaan we wandelen, fietsen, zwemmen, paardrijden en oefeningen thuis.
Bewegen is ook bijvoorbeeld stofzuigen, ramen wassen, in de tuin werken.

Doe je aan sport en/of bewegen?
☐ Vaak (elke dag meer dan 30 minuten)
☐ Regelmatig (elke dag maar minder dan 30 minuten
☐ Soms (op 2-6 dagen per week)
☐ Heel soms (één keer per week)
☐ Nee

47. Om sterke botten te krijgen is vitamine D en bewegen belangrijk. Je lichaam maakt vitamine D aan als je buiten bent.

Hoe vaak kom je, overdag, buiten?
☐ Elke dag
☐ Een paar keer per week
☐ Één keer per week
☐ (Bijna) nooit

48. Gezond eten en drinken is belangrijk. Kruis hieronder aan wat je eet:
☐ Ik krijg alleen sonde voeding (ga verder naar vraag 49)

Fruit
☐ elke dag ☐ een paar keer per week ☐ een keer per week
☐ (bijna) nooit

Groente
☐ elke dag ☐ een paar keer per week ☐ een keer per week
☐ (bijna) nooit

Brood of musli of pap
☐ elke dag ☐ een paar keer per week ☐ een keer per week
☐ (bijna) nooit

Thee en/of koffie
☐ elke dag ☐ een paar keer per week ☐ een keer per week
☐ (bijna) nooit

Water
☐ elke dag ☐ een paar keer per week ☐ een keer per week
☐ (bijna) nooit

Melk, yoghurt, karnemelk
☐ elke dag ☐ een paar keer per week ☐ een keer per week
☐ (bijna) nooit

Cola , fanta, seven up, frisdrank met bubbels
☐ elke dag ☐ een paar keer per week ☐ een keer per week
☐ (bijna) nooit

Friet, hamburger, pizza, chips
☐ elke dag ☐ een paar keer per week ☐ een keer per week
☐ (bijna) nooit

Heb je nog meer opmerkingen over het eten?
Schrijf die dan hier op:

E1. Werken, vrije tijd en vrienden

49. Met betekenisvolle/goede dagelijkse activiteiten bedoelen we naar het werk gaan, of naar dagbesteding, of naar school , of vrijwilligerswerk doen.

Heb jij een goede dagelijkse activiteiten?

☐ Nee
☐ Ja

50. Iedereen heeft vrienden en familie nodig.
Welke personen kunnen je helpen?
(meer antwoorden aankruisen mag)

☐ Ouders (vader, moeder)
☐ Schoonfamilie (zwagers, schoonzussen)
☐ Broers of zussen
☐ Man of vrouw (echtgenoot)
☐ Verloofde/partner/vriend/vriendin
☐ Buurman of buurvrouw
☐ Vrienden
☐ Vrijwilligers
☐ Begeleiding
☐ Anders nl. (Schrijf hier je antwoord op):

☐ Ik heb niemand om me te helpen

E2. Overig

51. Ik maak gebruik van:

(meer antwoorden aankruisen mag)

☐ Hoortoestel
☐ Bril
☐ Wandelstok
☐ Rollator/looprek
☐ Rolstoel
☐ Scootmobiel
☐ Geen hulpmiddel
☐ Anders, nl (Schrijf hier je antwoord op):

52. Heb je hulp nodig gedurende de dag?

☐ Nee (ga verder na vraag 53)
☐ Ja

Indien JA: Welke hulp heb je nodig?

(meer antwoorden aankruisen mag)

☐ Bij alles

Of (kruis aan)

☐ Boodschappen doen
☐ Douchen en aankleden
☐ Eten geven
☐ Naar de wc gaan
☐ Eten koken
☐ Huis schoonmaken
☐ Kleding wassen
☐ Telefoneren
☐ Vervoer
☐ Afspraken maken
☐ Psychische ondersteuning
☐ Anders, nl (Schrijf hier je antwoord op):

53. Communicatie (=vertellen) is erg belangrijk. Met communicatie bedoelen we dingen duidelijk maken, door vragen te stellen, antwoorden begrijpen, vertellen wat je leuk vindt en wat niet. De meeste mensen communiceren door te praten, anderen gebruiken hulpmiddelen om te "praten".

Hoe maak jij dingen duidelijk?
(meer antwoorden aankruisen mag)

☐ Praten met woorden
☐ Spraakcomputer
☐ Gebaren(taal)
☐ Gebruik van picto/plaatjes-kaarten
☐ Door lichaamstaal
☐ Gebruik van voorwerpen (bijvoorbeeld zwembroek laten zien als je gaat zwemmen)
☐ Anders, nl(Schrijf hieronder je antwoord op):

F1. Hulpverleners

54. Jouw huisarts in een hulpverlener, net als jouw tandarts. Maar ook dokters in het ziekenhuis, maatschappelijk werk, gedragsdeskundigen, fysiotherapeuten, begeleiders.

Welke (professionele)hulpverleners zijn belangrijk voor jou?

Hulpverlener	**Naam**
(Persoonlijk) begeleider	
Ambulant begeleider	
Gedragskundige/psycholoog/ Orthopedagoog	
AVG (arts voor verstandelijk gehandicapten)	
Fysiotherapeut	
Tandarts	
Maatschappelijk werker	
Ergotherpaeut	
Specialist ziekenhuis	1. 2. 3. 4.
Anders, nl:	

F2. Persoonlijke vragen

55. Waar woon je?

- ☐ Een huis voor mensen met een beperking (24 uurs zorg)
- ☐ Een huis voor mensen met een beperking (<u>géén</u> 24 uurszorg)
  - o ……... uren per dag/ per week zorg
  - o aantal uren zorg weet ik niet
- ☐ Een huis samen met mijn familie
- ☐ Ik heb mijn eigen huis en krijg ambulante begeleiding
  - o ……... uren per dag/ per week
  - o aantal uren weet ik niet
- ☐ Anders nl (Schrijf hieronder je antwoord op):

56. Soms heb je hulp nodig bij het nemen van belangrijke beslissingen op het gebied van bijvoorbeeld gezondheid of geldzaken. Als het gaat over gezondheid dan moet de huisarts weten met wie hij soms moet overleggen.

Wie helpt jou? (meer antwoorden aankruisen mag)

- ☐ Curator (gaat over persoonlijke èn geldzaken)
- ☐ Mentor (gaat over persoonlijke zaken, zoals gezondheid)
- ☐ Bewindvoerder (gaat over geldzaken)
- ☐ Wettelijk vertegenwoordiger
- ☐ Familie
- ☐ Weet niet

Wat is zijn/haar naam?

Schrijf hier de naam en telefoonnummer op:

57. Soms zijn mensen even de weg kwijt en kunnen ze zichzelf, anderen of spullen kwaad doen. De wet kan hen dan beschermen tegen zichzelf.

De rechter zal hen een wettelijke status geven.

Heb jij een?:

☐ RM ('rechtelijke machtiging')
☐ IBS ('in bewaring stelling')
☐ Artikel 60 (vaak bij mensen met een ernstige verstandelijke beperking die niet goed vertellen of ze iets wel of niet willen).
☐ Nee
☐ Weet niet

58. Ik vind mijn gezondheid zo:

				
Super goed	Heel goed	Goed	het gaat	Slecht

Mijn gezondheid is de afgelopen weken

☐ Beter geworden
☐ Slechter geworden
☐ Gelijk gebleven
☐ Weet niet

59. Is jouw mate van verstandelijke beperking ooit getest met bijvoorbeeld een IQ?

☐ Nee (ga verder naar vraag 60)
☐ Ja
☐ Weet niet

Kun je me vertellen welk niveau er bepaald is?

☐ Zwakbegaafd (IQ 70-85, ontwikkelingsniveau 12-16 jr)
☐ Licht (IQ 50-70, ontwikkelingsleeftijd: 7-12 jr)
☐ Matig (IQ 35-50, ontwikkelingsleeftijd: 4-6 jr)
☐ Ernstig (IQ 20-35, ontwikkelingsleeftijd: 2-3 jr)
☐ Zeer ernstig(IQ 0-20, ontwikkelingsleeftijd: 0-1jr)
☐ Weet niet

60. Is de oorzaak van jouw verstandelijke beperking bekend? (oorzaken zijn bijvoorbeeld Down syndroom,. autisme, zuurstof tekort bij de geboorte)

☐ Nee (ga verder naar vraag 61)
☐ Ja
☐ Weet niet

Indien JA. Wat is de oorzaak?

Schrijf hier je antwoord op:

F3. Ziektes die in je familie voorkomen

61. Heeft iemand in jouw familie een van de volgende ziektes?
(Familie = ouders, opa/oma, broer/zus, tante/oom)

Suikerziekte:
☐ Nee ☐ Ja ☐ Weet niet

Psychiatrische/Geestes ziektes:
(bijvoorbeeld:(AD(H) D (= héél druk/chaotisch gedrag), psychose (horen van stemmen), depressie (heel verdrietig gevoel)
☐ Nee ☐ Ja ☐ Weet niet

Hart en vaatziektes:
☐ Nee ☐ Ja ☐ Weet niet

Epilepsie:
☐ Nee ☐ Ja ☐ Weet niet

Borst kanker:
☐ Nee ☐ Ja ☐ Weet niet

Darm kanker:
☐ Nee ☐ Ja ☐ Weet niet

Verstandelijke beperking:
☐ Nee ☐ Ja ☐ Weet niet

G Medicatie

62. Jouw huisarts wil weten welke medicijnen je allemaal gebruikt.
Als je een actuele overzichtslijst van de apotheek hebt mag je die ook meenemen.
Medicijnen die niet op deze lijst staan graag hieronder invullen.

Naast medicijnen die door een dokter zijn voorgeschreven gebruik je misschien ook wel andere medicijnen die je zelf gekocht hebt, bijvoorbeeld homeopatische middelen of pijnstillers (paracetamol) of voedingssupplementen
Wil je de medicijnen die niet op de apotheeklijst staan hieronder invullen?

Naam medicijn	Hoeveelheid: aantal mg of tabletten	Hoe vaak per dag	Werken ze goed?	Weet je waar is dit medicijn voor is?

Gebruik je ook psychofarmaca?
(bijvoorbeeld: risperidon, dipiperon, anti depressiva (bijv. citalopram) of ritalin)

☐ Nee
☐ Ja
☐ Weet niet

Indien JA. Wat is de naam van dit medicijn?
Schrijf hier je antwoord op:

Dit was de laatste vraag. Dank je wel voor het invullen. Neem deze ingevulde lijst mee naar de huisarts

H. Eigen vragen voor de huisarts

Hieronder kun je zelf nog vragen invullen die je voor jouw huisarts hebt:

1.

2.

3.

I. Lichamelijk en aanvullend onderzoek door de huisarts

(in te vullen door de huisarts)

1. Algemene indruk (overweeg de volgende punten):
    a. uiterlijk – lichamelijke kenmerken;
    b. leeftijdsschatting;
    c. zelfverzorging;
    d. contact– oogcontact;
    e. houding;
    f. eventueel gedrag ten opzichte van anderen;
    g. klachtenpresentatie;
    h. Anders, nl:

2. Bewustzijn (omcirkel):
    helder/georiënteerd verward inadequaat
    onverstaanbaar apatisch/geen contact

3. Communicatie (kruis aan):
    ☐ praten : hele zinnen
    ☐ praten: losse woordjes
    ☐ spraakcomputer
    ☐ gebarentaal
    ☐ gebruik van picto-kaarten/foto's
    ☐ door lichaamstaal
    ☐ anders, nl…

4. Dysmorfologie (beschrijf):

5. Indruk van het gehoor (gebruik bijv. de fluisterkaart)

6. Otoscopie
AS AD

7. Lengte
cm

8. Gewicht
kg

9. BMI

10. Bloeddruk
mmHg

11. Pols
/min regulair/irregulair gelijkmatig: ja/nee

12. Auscultatie hart
S1S2: Souffles: Extra tonen:

13. Lichamelijk Onderzoek mbt de punten die naar voren zijn gekomen uit de anamnestische vragenlijst

14. Indicatie voor aanvullend bloedonderzoek?
Ja nee

15. Indicatie voor aanvullend urine onderzoek?
Ja nee

16. Verwijzingen noodzakelijk? (omcirkel of beschrijf)
    a. Visustest
       Ja nee
    b. Gehoorscreening
       Ja nee
    c. Klinisch genetica
       Ja nee
    d. Anders, nl……

17. Reanimeerbeleid besproken?
    Ja nee

18. Behandelbeperkingen besproken?
    Ja nee n.v.t.

19. Worden er vrijheidsbeperkende maatregelen toegepast? (denk aan: deuren op slot, verplichte medicatie toediening, verplichte voedingstoediening)
    Ja nee

Actieplan t.b.v. patiënt en begeleiding

Naar aanleiding van de vragenlijst en het lichamelijk onderzoek spraken we het volgende af:

1.

Deze actie wordt uitgevoerd door:

2.

Deze actie wordt uitgevoerd door:

3.

Deze actie wordt uitgevoerd door:

4.

Deze actie wordt uitgevoerd door:

5.

Deze actie wordt uitgevoerd door:

Institute for Health Sciences
Radboudumc