

BMJ Open Healthy Ageing and Intellectual Disability study: summary of findings and the protocol for the 10-year follow-up study

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ABSTRACT

Introduction The Healthy Ageing and Intellectual Disability (HA-ID) study is a prospective multicentre cohort study in the Netherlands that started in 2008, including 1050 older adults (aged ≥50) with intellectual disabilities (ID). The study is designed to learn more about the health and health risks of this group as they age. Compared with the amount of research in the general population, epidemiological research into the health of older adults with ID is still in its infancy. Longitudinal data about the health of this vulnerable and relatively unhealthy group are needed so that policy and care can be prioritised and for guiding clinical decision making about screening, prevention and treatment to improve healthy ageing.

Methods and analysis This article presents a summary of the previous findings of the HA-ID study and describes the design of the 10-year follow-up in which a wide range of health data will be collected within five research themes: (1) cardiovascular disease; (2) physical activity, fitness and musculoskeletal disorders; (3) psychological problems and psychiatric disorders; (4) nutrition and nutritional state; and (5) frailty.

Ethics and dissemination Ethical approval for the 10-year follow-up measurements of the HA-ID study has been obtained from the Medical Ethics Review Committee of the Erasmus MC, University Medical Centre Rotterdam (MEC-2019-0562).

Trial registration number This cohort study is registered in the Dutch Trial Register (NTR number NL8564) and has been conducted according to the principles of the Declaration of Helsinki.

INTRODUCTION

The Healthy Ageing and Intellectual Disability (HA-ID) study is a prospective multicentre cohort study including older adults with intellectual disabilities (ID) in the Netherlands. The study was designed in response to the increasing longevity of people with ID and the lack of epidemiological data about their health and health risks at older ages. The absence of this knowledge raised questions

Strengths and limitations of this study

- This protocol outlines the design of the 10-year follow-up of the Healthy Ageing and Intellectual Disability (HA-ID) study, a prospective multicentre cohort study in which a heterogeneous group of 1050 older adults with intellectual disabilities (ID) is followed over time.
- The longitudinal design of the study makes it possible to make statements about causality and to study health progress and health indicators, which is important for prioritising policy and care and guiding clinical decision making about screening, prevention and treatment to improve healthy ageing.
- The comprehensive set of measurements makes it possible to evaluate the health of older adults with ID from a broad perspective and to investigate the interrelationships between medical domains.
- The data collection consists of measurements that have been shown to be feasible, valid and reliable in older adults with ID, based on previously acquired knowledge and experience within the HA-ID study.
- For financial and feasibility reasons, it has not been possible to perform follow-up measurements on a more regular basis.

about how to organise care and support for this vulnerable and relatively unhealthy group.¹ Based on this need for knowledge, a consortium was established in 2006 consisting of three ID care organisations (Ipe de Bruggen, Amarant and Abrona) and the research group of Intellectual Disability Medicine of the Erasmus MC, University Medical Centre Rotterdam. The HA-ID consortium aims to (1) increase knowledge on healthy ageing in people with ID through scientific research; (2) strengthen the scientific attitude of care professionals through participation in research and continuous education; and (3) innovate care by implementing research

outcomes. In 2008, the HA-ID study started with a focus on physical activity and fitness, nutrition and nutritional state and mood and anxiety. A detailed description of the rationale and design of the baseline measurements can be found elsewhere.¹ After 3 and 5 years, follow-up measurements consisting of medical file research and questionnaires about the health of the participants were completed. New topics were included during this follow-up period: cardiovascular disease (CVD), frailty, mortality and causes of death.²

The baseline results of the HA-ID study showed that older adults with ID had more health problems than their peers in the general population and that these problems occurred at younger ages.^{3,4} Older adults with ID became frail earlier and became more severely frail than their peers in the general population.⁵ High prevalences of polypharmacy,⁶ multimorbidity,⁶ sleep problems,⁷ major depressive disorders,⁸ dysphagia,⁹ obesity,¹⁰ suboptimal nutritional intake¹¹ and low physical activity and fitness levels were found.^{12–15}

Based on data from the 3-year and 5-year follow-ups, frailty at baseline was predictive for the development of comorbidity,¹⁶ a decline in daily functioning and mobility,¹⁷ increased medication use,¹⁶ increased care intensity¹⁸ and a higher mortality risk.¹⁹ Also poor physical fitness was predictive for a decline in mobility,²⁰ daily functioning^{20,21} and for a higher mortality risk.²² Use of atypical antipsychotics, chronic kidney disease, abdominal obesity and histories of stroke and heart failure were predictive for developing CVD over a 3-year period.²³ These first results from the longitudinal data of the HA-ID study provided important insights for policy and care about how to contribute to a better health of older adults with ID. The results of the HA-ID study have been used in developing diagnostic instruments and guidelines^{3,24,25} and to illustrate the vulnerability and poor health situation of people with ID, resulting in changes to the Dutch legislation on long-term financing of support, care and treatment for people with ID.

Following the start of the HA-ID study, other research groups initiated longitudinal studies focusing on various aspects of health in adults with ID, such as the IDS-TILDA study in Ireland,²⁶ the SAge-ID study in Australia²⁷ and a longitudinal cohort study about dementia and mortality in people with Down syndrome in the Netherlands.²⁸ Despite these initiatives, epidemiological research into the health of adults with ID is still extremely limited. Too little is known about the health of this group as they age, or about changes in health status over time and early indicators for health problems. However, this knowledge is important for providing the evidence base for improving care and support of older adults with ID and guiding care providers in preparing for this growing group of elderly with ID. Longitudinal research makes it possible to make statements about causality, which contributes to for example, identifying group-specific risk factors, groups at risk of specific diseases and other negative outcomes such as declining in independence. This knowledge can be

used to reduce the occurrence of specific risk factors and identify, monitor and treating high-risk groups in good time. More longitudinal studies focusing on the health of this specific group are therefore urgently needed.

This article describes the design for the 10-year follow-up measurements of the HA-ID cohort. To learn more about changes in health status and indicators for health problems over time, a wide range of health data will be collected. Based on previous measurements and results, the focus will be on five research themes: (1) cardiovascular disease; (2) physical activity, fitness and musculoskeletal disorders; (3) psychological problems and psychiatric disorders (including sleep problems); (4) nutrition and nutritional state (including dysphagia); and (5) frailty. This article presents the design of the HA-ID cohort study and a summary of the main findings up to now, and provides an update of the planned measurements of the 10-year follow-up research themes.

METHODS AND ANALYSIS

Study cohort

The HA-ID cohort consists of older adults with borderline to profound ID. All participants receive care or support from one of the care organisations of the HA-ID consortium. These organisations provide care to a wide spectrum of individuals with ID (in terms of the level of ID, residential status and mobility) in various settings (central residential settings, community-based homes, day activity centres and supported living) in both urban and rural areas in various regions in the Netherlands. At baseline, the care organisations provided care to approximately 10% of the total Dutch ID population receiving care or support from an ID care organisation.²⁹ At the start of the study, 10% of the individuals receiving care from the HA-ID care organisations was 50 or older, comparable to the total Dutch ID population receiving care or support from ID care organisations.²⁹ Based on these numbers, we concluded that the base population was representative for the total population of older adults with ID receiving care or support from ID care organisations in the Netherlands.¹ All individuals with ID within the consortium aged 50 or older by September 2008 were eligible to participate and received an invitation. Ultimately, 1050 of the 2322 (45.2%) invited individuals with ID participated in the baseline measurements. [Table 1](#) presents the baseline characteristics of the participants, which were largely comparable to the overall group of invited individuals with ID and formed a near-representative study population for the total Dutch population of older adults with ID receiving formal support or care, with an under-representation of 80 to 84 year olds, a slight over-representation of women and an under-representation of the more independent group. A more detailed description of the representativeness of the sample has been published elsewhere.¹

[Figure 1](#) summarises the number of participants in the cohort over time. At baseline, measurements consisted

Table 1 Baseline characteristics of the HA-ID cohort (n=1050)¹

| Characteristic | n (%) |
|-------------------------------------------------------------------------------------------|-----------------|
| Sex | |
| Male | 539 (51.3) |
| Female | 511 (48.7) |
| Age | 60 (11, 50–93)* |
| Level of ID | |
| Borderline | 31 (3.0) |
| Mild | 223 (21.2) |
| Moderate | 506 (48.2) |
| Severe | 172 (16.4) |
| Profound | 91 (8.7) |
| Unknown | 27 (2.6) |
| Residential status | |
| Central setting | 557 (53.0) |
| Community based | 432 (41.1) |
| Independent with ambulatory support | 43 (4.1) |
| With relatives | 7 (0.7) |
| Unknown | 11 (1.1) |
| Level of care (ZPP-scores) | |
| Only day care indication | 6 (0.6) |
| Only indication ambulant care | 37 (3.5) |
| Residence with minimal support (1 VG) | 12 (1.1) |
| Residence with support (2 VG) | 39 (3.7) |
| Residence with support and care (3 VG) | 138 (13.1) |
| Residence with support and intensive care (4 VG) | 207 (19.7) |
| Residence with intensive support and intensive care (5 VG) | 325 (31.0) |
| Residence with intensive support, care and regulation of behaviour (6 VG) | 93 (8.9) |
| (Enclosed) residence with very intensive support, care and regulation of behaviour (7 VG) | 142 (13.5) |
| Mental Healthcare ZPP scores | 2 (0.2) |
| Unknown | 49 (4.7) |

*Median (IQR, range).

HA-ID, Healthy Ageing and Intellectual Disability; ID, intellectual disability; VG, Dutch abbreviation for intellectual disability; ZPP, Zorgzwaartepakket, the Dutch classification of levels of support, care and/or treatment as a basis for long-term financing.

of reviewing medical files, administering questionnaires, physical examinations (with portable measuring equipment), fitness tests, observations, interviews, laboratory assessments and diaries.¹ At the 3-year follow-up, medical files were reviewed and professional caregivers completed questionnaires about the participant's health. Five years after the baseline measurements, causes of death were examined in the files of the deceased participants. The

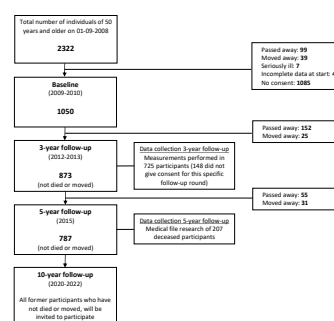


Figure 1 Number of participants in the Healthy Ageing and Intellectual Disability (HA-ID) cohort over time. Flow chart presents (1) the number of participants eligible for participation in the HA-ID cohort, (2) the number of participants who participated in measurements, (3) and the numbers of participants who dropped out of the cohort.

participants themselves were not actively involved in the data collection for these follow-up measurements. At the 3-year and 5-year follow-ups, the cohort consisted of 873 and 787 participants, respectively.

All individuals with ID who participated in the baseline measurements and still receive care or support from one of the participating care organisations will be invited to participate in the 10-year follow-up measurements. There is one exclusion criterion: individuals are excluded from physical measurements if they are so seriously ill that participating in the study is not desirable. This decision is made based on shared decision making with caregivers and professionals. Based on previous mortality rates and historical lost to follow-up, it is estimated that 424 participants from the HA-ID cohort could be invited to participate in the 10-year follow-up measurements. With a conservative inclusion rate estimate of 50%, approximately 212 participants are expected to actually participate in these measurements.

Informed consent procedure

Because not all individuals with ID are mentally capable of giving informed consent, two separate consent procedures are followed. A behavioural scientist evaluates whether the individual is able to understand the specifically designed study information to let them make an informed decision about participation. If an individual is capable of making an informed decision, an easy-to-read information letter with supporting pictures and a consent form will be sent to this individual. If the behavioural scientist assesses the individual as being unable to make an informed decision about participation, an information letter and consent form will be sent to the legal representative of this individual. The professional caregiver of the individual with ID is informed about the study and the informed consent procedure to support the individual or legal representative in making their decision for participation.

Inclusion of the participants started in July 2020 and the data collection in October 2020. Both the inclusion and the data collection are still ongoing.

Research themes

An outline is presented of the published results for each research theme, followed by a description of the data collection for the 10-year follow-up, with a specific focus on newly added measurements. In the 10-year follow-up, we also omitted measurements that turned out to be unfeasible, invalid or unreliable, based on the baseline measurements. For clarity, these measurements are not listed separately below. An overview of all measurements at baseline and the 3, 5 and 10-year follow-ups can be found in [table 2](#).

Cardiovascular disease

The HA-ID study provided many insights into the prevalence of CVD risk factors and the incidence of CVD in older adults with ID. The prevalences of hypertension (53.0%), diabetes (13.7%), metabolic syndrome (44.7%) and chronic kidney disease (15.3%) were similarly to those in the general population.^{30 31} However, the prevalence of peripheral arterial disease (20.7%) and obesity in women (25.6%) as measured by the body mass index (BMI) was significantly higher than in the general population.^{10 32} The incidence of newly diagnosed CVD during a 3-year follow-up period was also examined. Incidence rates for myocardial infarction (2.8 per 1000 person-years), stroke (3.2 per 1000 person-years) and heart failure (12.8 per 1000 person-years) were similar to the general population.²³ The use of atypical antipsychotics, chronic kidney disease, abdominal obesity and histories of stroke and heart failure turned out to be predictive for developing CVD during the 3-year follow-up period.²³

The baseline measurements revealed underdiagnosis of CVD risk factors in the HA-ID cohort. For example, 54% of the participants with diabetes had not been previously diagnosed with this condition. This was the case in 46% of the participants for hypercholesterolaemia, in 50% for hypertension and in 94% for metabolic syndrome.³⁰ Atypical presentation of symptoms, limitations in communication, limited cooperation and resilience make diagnostics in people with ID more challenging.³³ This makes underdiagnosis a common problem in people with ID.^{4 34} The incidence of CVD described above is therefore also probably underestimated.²³

With increasing longevity and increased prevalence of some CVD risk factors, people with ID may be at higher risk of developing CVD. The 10-year follow-up of the HA-ID cohort provides opportunities to learn more about CVD risk factors and the development of CVD over time in older adults with ID. The planned measurements for the 10-year follow-up are summarised in [table 2](#). The presence of CVD risk factors, CVD and CVD treatments/interventions over the past ten years will be assessed by reviewing the medical files of all participants who participated in

the baseline measurements, including the medical files of deceased participants.

Blood will be collected through venepuncture. Blood will be stored for 15 years at -80°C , allowing analyses of relevant biochemical markers now and in the future ([table 2](#)).

The following measurements were added to the physical examination to gain more insight into the presence of CVD and its risk factors. Body composition will be studied with bioelectrical impedance analysis using the Tanita Body Composition Analyser (Tanita DC-430 MA, Tanita, Netherlands). An ECG will be performed to examine heart conditions. In addition, heart rate variability will be measured as a marker for the autonomic nervous system by wearing a heart rate monitor (Polar Vantage V HR H10, Polar Electro Oy, Finland) at rest for 5 min. Finally, various haemodynamic measurements (mean arterial pressure, pulse pressure, resting heart rate, stroke volume, cardiac output, cardiac index, augmentation index, peripheral vascular resistance and pulse wave velocity) will be obtained with a non-invasive electronic blood pressure oscillometric monitoring system (Mobil-O-Graph 24h PWA Monitor, I.E.M. GmbH, Germany).³⁵ Adding the Mobil-O-Graph provides a clearer picture of the presence of arterial stiffness and central systolic blood pressure, two important risk factors for CVD and morbidity.³⁶

Physical activity, fitness and musculoskeletal disorders

The HA-ID study yielded important results about physical activity and fitness. Older adults with ID had very low physical activity and fitness levels.^{12 14} In short, most participants were categorised as 'low active' (5000–7449 steps/day; 25.3%) or 'sedentary' (<5000 steps/day; 38.5%). Only 36.2% of the participants walked ≥ 7500 steps/day.¹² These results are likely to underestimate the problem because physical activity levels were only measured in participants who were physically able to walk at a sufficiently high speed for the pedometers to provide reliable measurements. In addition to these low physical activity levels, people with ID aged 50 and over had physical fitness levels comparable to or worse than people in the general population aged 70 and over.^{13 14} Data from the 3-year and 5-year follow-ups showed that these low physical fitness levels at baseline were indicative of a decline in daily functioning and mobility over the 3-year follow-up period and a higher mortality risk over the 5-year follow-up period.^{20–22 37} Additionally, it was found that being fit is more important for survival than obesity. People who were unfit had a mortality risk four times higher than people who were fit, regardless of obesity.³⁷ Because of the importance of physical fitness, suitable fitness tests for this population are essential. Based on our previous research examining the reliability and feasibility of eight physical fitness tests in older adults with ID^{38 39} we developed the ID-fitscan to assess the physical fitness levels of adults with ID.²⁴

Table 2 Measurements within the HA-ID study: baseline, 3, 5 and 10-year follow-up per research theme

| Type | Outcome | Details | Moment of data collection | | | |
|--------------------------------------------------------------------|------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------|------------------------------|-------------------------|-------------------------------|
| | | | Baseline measurements (2009-2010) | 3-year follow up (2012-2013) | 5-year follow up (2015) | 10-year follow up (2020-2022) |
| Demographics | | | | | | |
| Medical file | Age | – | X | X | X | X |
| | Sex | – | X | | | |
| | Residential status | Central setting (with or without 24-hour support), community based (with or without 24-hour support), independent with ambulatory support (by appointment), with relatives, with partner, independent. | X | | | X |
| | Level of care | Care Intensity Packages (Dutch ZZP-scores) ⁷⁷ | X | X | | X |
| 1. Cardiovascular disease | | | | | | |
| Physical assessment | Brachial blood pressure* | Omron M7 (OMRON Healthcare, the Netherlands). | X | | | |
| | Central blood pressure and arterial stiffness | Mobil-O-Graph 24h PWA Monitor (IEM GmbH, Germany) including pulse wave velocity. | | | | X |
| | Ankle-Arm-Index* | Omron M7 (OMRON Healthcare, the Netherlands) (arm). Boso classico and 8-MHz Doppler probe (Huntleigh MD II, UK) (ankle). Ankle-arm-index calculated: systolic blood pressure ankle divided by systolic blood pressure arm. | X | | | X |
| | Heart rate variability | Polar Vantage V HR H10 (Polar Electro Oy, Finland). | | | | X |
| | Electrical activity of the heart | ECG. | | | | X |
| | Fat percentage | Formulas Durnin and Womersley ⁷⁸ for calculating fat percentage from the sum of four skinfolds: triceps, biceps, subscapular and suprailliacal. Thickness of skinfolds measured with skinfold calliper (Harpenden, Baly International, UK). | X | | | X |
| | Body composition | Tanita Body Composition Analyser DC-430 MA (Tanita, the Netherlands). | | | | X |
| Venipuncture | Biochemical markers* | Fasting plasma levels: glucose, cholesterol (total/HDL*/LDL), haemoglobin*, haemoglobin A1c, triglyceride, C reactive protein, interleukin 6, Tumour Necrosis Factor alpha, albumin, vitamin D, calcium, creatinine, cystatin C, troponin, N-terminal pro-B-type natriuretic peptide etc. The participants' blood is stored for 15 years at –80°C, in order to perform additional analyses afterwards. | X | | | X |
| Medical file | CVD* | Presence of CVD (heart failure, myocardial infarction, stroke, transient ischaemic attack, cardiac arrhythmias, angina pectoris, aortic aneurysm, peripheral arterial disease, hypertension, etc), CVD risk factors (diabetes mellitus, central obesity, metabolic syndrome, rheumatoid arthritis, incriminating family history, etc) and treatments/interventions (revascularisation of the coronary artery, pacemaker and implantable cardioverter-defibrillator). | X | X | | X |
| | Endocrine disorders* | Presence of endocrine disorders (such as diabetes mellitus*, hypercholesterolaemia and metabolic syndrome). | X | | | X |
| 2. Physical activity, fitness and musculoskeletal disorders | | | | | | |
| Fitness assessment | Manual dexterity* | Box and block test. ⁷⁹ | X | | | X |
| | Reaction time | Auditive and visual reaction time test. ^{80 81} | X | | | |
| | Balance* | Berg Balance Scale. ⁸² | X | | | |
| | | Comfortable and maximum walking speed (5 m). ^{24*} | X | | | X |
| | Grip strength* | Static balance test (for stances). ²⁴ | | | | X |
| | | Jamar Hand Dynamometer (#5030J1, Sammons Preston Rolyan, USA). ²⁴ | X | | | X |
| | Muscle endurance | 30s chair stand. ²⁴ | X | | | X |
| | | 5 times chair stand. ²⁴ | | | | X |
| | Cardiorespiratory endurance | 10m Incremental shuttle walking test. ⁸³ Results of this test recalculated to VO2max. ⁸⁴ | X | | | |
| | | 2 min step test, ⁴¹ with heart rate monitor (Polar RS400, Polar Electro Oy, Finland). | | | | X |
| Flexibility | Extended version of Modified back saver sit and reach test. ^{85 86} | X | | | | |

Continued



Table 2 Continued

| Type | Outcome | Details | Moment of data collection | | | |
|------------------------------------------------------------|------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------|------------------------------|-------------------------|-------------------------------|
| | | | Baseline measurements (2009-2010) | 3-year follow up (2012-2013) | 5-year follow up (2015) | 10-year follow up (2020-2022) |
| Measurement at home | Physical activity | Pedometer NL-1000 (New Lifestyles, USA). ActiGraph wGT3X-BT Accelerometer (ActiGraph, USA). | X | | | X |
| Questionnaires professional caregiver | | Self-assembled questionnaire about the participants' habitual physical activity. | X | | | |
| | | International Physical Activity Questionnaire – short version. ⁴⁰ | | | | X |
| | Activities of daily life/mobility | Animated Activity Questionnaire. ⁵¹ | | | | X |
| | Mobility* | Self-assembled questionnaire based on the Hauser Ambulation Index ⁸⁷ and the characteristics of the Gross Motor Function Classification Scale. ⁸⁸ | X | X | | X |
| | Falling | Self-assembled questionnaire about the number of falls in the last 3 months. | | X | | X |
| | Symptoms/limitations related to (hip/knee) OA | Hip disability and OA Outcome Score. ^{52 53} Knee injury and OA Outcome Score. ⁵⁴ | | | | X |
| | Use of lower extremity aids | Self-assembled questions about the presence/use of aids for extra support of the lower extremity (such as orthopaedic footwear, splints and braces). | X | | | X |
| Physical assessment | Clinical/symptomatic OA | Physical examination to examine the ACR criteria for clinical OA of the hip and the knee. ^{49 89} The following tests will be performed ⁹⁰ : palpable warmth of the knee joint, joint crepitus of the knee, bony enlargement of the knee joint, quadriceps wasting, bone margin tenderness, patellofemoral joint tenderness, anserine tenderness, tibiofemoral joint tenderness, bulge sign of the knee, range of motion flexion and extension of the knee, range of motion flexion and extension of the hip, range of motion endorotation and exorotation of the hip. In addition, the laxity of the joints will be tested ⁹¹ and the gait and the postural alignment will be observed. ⁹² | | | | X |
| Interview | Self-report pain | The participants undergo a comprehension test to test whether their self-reported pain on a face-scale is a valid measurement. ⁵⁰ When they succeed they will be asked to grade their pain during examination of the joint tenderness, flexion of the joints and hip internal rotation on a face-scale. | | | | X |
| Observation | Observed pain | The healthcare professional will perform the Rotterdam Elderly Pain Observation Scale (REPOS) to observe pain behaviour during the physical examination for OA. A NRS-obs will be asked from the professional caregiver as part of the REPOS observation. ⁹³ | | | | X |
| Medical imaging | Radiographic hip/knee OA | X-rays of the hip and knee: anterior posterior (AP) view of both knees (if possible weight-bearing), lateral view of right and left knee, skyline view of the patellofemoral joint of right and left knee, AP view of pelvis, faux profile view of right and left hip (only made by participants who are able to stand up (with support)). | | | | X |
| Medical file | Musculoskeletal disorders* | Presence of musculoskeletal disorders in the medical file (such as OA, scoliosis*, spasticity and bone fractures). | X | | | X |
| 3. Psychological problems and psychiatric disorders | | | | | | |
| Measurement at home | Sleep-wake and circadian rhythm | Actiwatch AW7 (Cambridge Technology Ltd, UK). GENEActiv Original (Activinsights Ltd, UK). | X | | | X |
| Interview | Self-report depression | Inventory of Depressive Symptomatology Self Report. ⁹⁴ Phrasing of the questions adapted to people with ID. | X | | | X |
| | Self-report anxiety | Glasgow Anxiety Scale for people with an Intellectual Disability. ⁹⁵ | X | | | X |
| | | Hospital Anxiety and Depression Scale–anxiety subscale. ⁹⁶ Phrasing of the questions adapted to people with ID. | X | | | |
| | Quality of life | Intellectual Disability Quality of Life. ⁹⁷ | X | | | |
| | Diagnostic interview depression and/or anxiety | Participants with scores above the preset cut-off scores on one of the depression or anxiety questionnaires are further examined using the Psychiatric Assessment Schedule for Adults with Developmental Disability ICD-10 version. Interviews are conducted with the participant or his/her caregiver. ⁹⁸ | X | | | X |
| Questionnaires professional caregiver | Informant-report depression and anxiety* | Anxiety, Depression and Mood Scale. ^{99*} | X | | | X |
| | | Signaalijst Depressie Zwakzinnigen. ^{100*} | X | | | X |
| | Somatic complaints | Somatic complaints subscale of the Symptom Checklist-90. ¹⁰¹ | X | | | |
| | Life-events | Self-assembled checklist about life events based on other checklists, earlier life event-studies and experience from professionals working with people with ID. | X | | | X |

Continued

Table 2 Continued

| Type | Outcome | Details | Moment of data collection | | | |
|-----------------------------------------------------------------------------------------------------------------|--------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------|------------------------------|-------------------------|-------------------------------|
| | | | Baseline measurements (2009-2010) | 3-year follow up (2012-2013) | 5-year follow up (2015) | 10-year follow up (2020-2022) |
| | Social outcome | Self-assembled checklist about number of contacts with family, friends and peers and visiting leisure clubs. | X | | | |
| | Cognitive functioning* | Dementia questionnaire for people with intellectual disabilities. ¹⁰² | X | | | X |
| | Aberrant behaviour | Aberrant Behaviour Checklist. ⁶⁰ | | | | X |
| | Sleep problems | Self-assembled questions about sleep problems, including problems with falling asleep and waking up early. | X | | | X |
| | Sleep hygiene | Self-assembled questions about sleep hygiene (such as sleeping conditions, bedtimes, sleeping rituals, eating habits and use of television, smartphone or tablet before going to bed and provided professional support). | | | | X |
| Psychological file | Psychological problems and psychiatric disorders | Baseline: level of intellectual disability, autism, depression, anxiety, dementia, psychoses, other psychiatric disorders and serious behavioural problems. 10-year follow-up: baseline variables+mood disorders, autism spectrum disorder, attention deficit hyperactivity disorder, obsessive-compulsive disorder, attachment disorders, personality disorders, psychotic disorders, post-traumatic stress disorder, cognitive disorders (including dementia), traumatising and support or treatment received by the participant. | X | | | X |
| Medical file | Sleep disorders/sleep problems | Presence of sleep disorders/problems in the medical file (such as problems with falling asleep and waking up early). | X | | | X |
| Physical assessment | Cortisol concentration last month | A small hair sample of at least 1 cm (length) will be taken from the posterior vertex close to the scalp. ¹⁰³ | | | | X |
| 4. Nutritional intake and nutritional state | | | | | | |
| Physical assessment | Height* | – | X | | | X |
| | Weight* | – | X | | | X |
| | Body circumferences | Measuring tape for hip, calf* and upper arm circumference. | X | | | X |
| | Bone quality* | Ultrasonometer (Lunar Achilles Insight, General Electric Healthcare, USA) for measuring bone stiffness calcaneus. | X | | | X |
| Diary | Food intake | Self-assembled 3 day food intake diary. | X | | | X |
| Meal time observation | Dysphagia* | Dysphagia Disorder Survey. ⁶⁷ | X | | | X |
| Questionnaires professional caregiver | Malnutrition* | Mini Nutritional Assessment. ¹⁰⁴ | X | | | X |
| | | Short Nutritional Assessment Questionnaire for Residential Care. ⁷⁰ | | | | X |
| | Eating disorders* | Screening Tool of fEeding Problems. ¹⁰⁵ | X | | | X |
| | Gastro-oesophageal reflux disease | Self-assembled questionnaire consisting of 50 items involving risk factors and symptoms of gastro-oesophageal reflux disease. | X | | | |
| Dental file | Dental condition | Baseline: dental condition, premedication/sedation during check-up or treatment, dental prosthesis and enamel wear. 10-year follow-up: baseline variables + number of dentist/dental hygienist visits, number of elements in the upper/lower jaw, dental wear, dental caries, plastic restorations, crowns and bridges, implants, gingivitis/periodontitis, mobile elements and loss of dental elements due to trauma. | X | | | X |
| Medical file | Gastrointestinal diseases* | Presence of gastrointestinal disease in the medical file (such as gastro-oesophageal reflux disease*, gastric ulcer, constipation* and dysphagia*). | X | | | X |
| 5. Frailty | | | | | | |
| All outcomes/measurements with an asterisk* in this table are part of the overarching research theme 'Frailty'. | | | | | | |
| General health data | | | | | | |
| Medical file | Aetiology of intellectual disability | Presence of the aetiology of the intellectual disability in the medical file (such as a specific genetic syndrome). | X | | | X |
| | Malignancies* | Presence of malignancies in the medical file. | X | | | X |
| | Pulmonary diseases* | Presence of pulmonary disease in the medical file (such as asthma*, chronic obstructive pulmonary disease* and sleep apnoea syndrome). | X | | | X |
| | Neurological disorders | Presence of neurological disorders in the medical file (such as dementia, epilepsy and Parkinson's disease). | X | | | X |
| | Diseases of the genitourinary system | Presence of diseases of the genitourinary system in the medical file (such as urinary tract infections, incontinence and renal failure). | X | | | X |
| | Visual and hearing impairments* | Presence of visual and hearing impairments in the medical file. | X | | | X |
| | Medication use* | Medication use (medicament and dosage) as stated in the medical file. | X | | | X |
| | Hospitalisation* | Number of hospitalisations in the past period. | | X | | X |

Continued



Table 2 Continued

| Type | Outcome | Details | Moment of data collection | | | |
|---------------------------------------|----------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------|------------------------------|-------------------------|-------------------------------|
| | | | Baseline measurements (2009-2010) | 3-year follow up (2012-2013) | 5-year follow up (2015) | 10-year follow up (2020-2022) |
| Questionnaires professional caregiver | Mortality | Date of death, as stated in the medical file. | | X | X | X |
| | Cause of death | Cause of death, as stated in the medical file. | | X | X | X |
| | Activities of daily life* | Barthel Index. ^{106,+} | X | X | | X |
| | Instrumental activities of daily life* | Questionnaire based on the Instrumental Activities of Daily Living of Lawton and Brody ¹⁰⁷ and the Groningen Activities Restriction Scale. ¹⁰⁸ | X | X | | X |
| | Daytime activities* | Self-assembled questions about daytime activities and/or work of the participant. | X | | | X |
| | Smoking | Self-assembled questions about the smoking habits of the participant (how many cigars, cigarettes and/or pipe per day and past smoking habits). | X | | | X |
| | Alcohol use | Self-assembled questions about the participant's alcohol consumption (alcohol use per day and alcohol use in the past). | X | | | X |
| | Drug use | Self-assembled questions about the drug use of the participant (use of cannabis and hard drugs per day and drug use in the past). | | | | X |
| | Use of caffeinated drinks | Self-assembled questions about the use of caffeinated drinks (coffee, tea, coke, energy drink and chocolate milk) by the participant. | | | | X |

* All outcomes/measurements with an asterisk* in this table are part of the overarching research theme 'Frailty'.

ACR, American College of Rheumatology; CVD, cardiovascular disease; ECG, electrocardiogram; HDL, high-density lipoprotein; ICD-10, International Classification of Diseases 10th revision; LDL, low-density lipoprotein; NRS-obs, Numeric Rating Scale observation; OA, osteoarthritis; ZZZ, Zorgzwaartepakket, the Dutch classification of levels of support, care and/or treatment as a basis for long-term financing.

In the 10-year follow-up measurements, physical activity and fitness levels will be assessed again (see table 2). Based on previous results and experiences, some changes were made to the measurements. Physical activity will be measured using the ActiGraph (wGT3X-BT Accelerometer, ActiGraph, USA), an instrument that can make measurements at very low walking speeds and provides more detailed information about the physical activity levels of the participant. Complementary to this, we will use the International Physical Activity Questionnaire-Short Form (IPAQ-SF) to collect physical activity data.⁴⁰ The ID-fitscan,²⁴ supplemented with the 2 min step test,⁴¹ will be used to assess physical fitness. Physical fitness tests that turned out to be less suitable at the baseline measurements are excluded.²⁴

The 10-year follow-up will also focus on musculoskeletal disorders, in particular osteoarthritis. Osteoarthritis is common in older people in the general population, leading to pain, joint instability, limitations in daily activities and decreased quality of life.^{42 43} Little is known about the prevalence of knee and hip osteoarthritis in people with ID. High prevalence is expected because many factors that have been associated with osteoarthritis (such as obesity, poor physical fitness levels, poor motor skills, gait abnormalities, musculoskeletal complications and developmental problems) are more common in adults with ID than in the general population.^{14 44-48}

Osteoarthritis of the hip and the knee will be assessed by applying the American College of Rheumatology (ACR) criteria for the diagnosis of osteoarthritis. These criteria cover clinical symptoms, consisting of pain and functional limitations of the joint and include radiological characteristics from X-rays as well.⁴⁹ The 10-year follow-up includes several tests to identify the presence of the ACR criteria,

including physical examinations with pain observations (Rotterdam Elderly Pain Observation Scale (REPOS) filled out by the health professional performing the physical examination, supplemented by a Numeric Rating Scale observation filled out by the professional caregiver during the physical examination and a face-scale for self-report of pain⁵⁰). The REPOS will also be used to assess pain during rest and daily activities that may provoke osteoarthritis complaints. Also, the Animated Activity Questionnaire will be used to identify whether the participants have complaints due to osteoarthritis during daily living activities, filled out by the professional caregivers of the participants.⁵¹ Additional, data about gait characteristics that may be related to osteoarthritis will be collected through a structured observation. To signal pain, stiffness and range of motion the standardised questionnaires (the Hip disability and Osteoarthritis Outcome Score^{52 53} and the Knee disability and Osteoarthritis Outcome Score⁵⁴) will be used.

Psychological problems and psychiatric disorders

At baseline, data were collected on the prevalence of depression and anxiety disorders. The prevalence of major depressive disorder was 7.6%,⁸ which is higher than in the general population (1.8%–4.0%).⁵⁵ Only 4.4% of the participants met the criteria for one of the anxiety disorders.⁸ This was lower than expected and lower than the prevalence in the general population (10.2%–11.6%).⁵⁶ This may be explained by the fact that proxy reports had to be used in 78% of the participants. It is difficult for respondents such as professional caregivers to recognise symptoms of anxiety (eg, pounding heart, worrying). This may have led to underestimation of the prevalence of anxiety disorders.

In the general population, there is a strong association between sleep problems and anxiety and mood disorders.⁵⁷ Data on sleep and sleep-wake rhythm were, therefore, also collected at baseline based on wrist-worn accelerometry (Actiwatch AW7, Cambridge Technology Ltd, Cambridge, UK^{49 50}). It was found that 23.9% of the participants lay awake for more than 1 hour before falling asleep. In addition, 63.1% lay awake for more than 90 min after sleep onset and before final morning awakening, 20.9% slept less than 6 hours and 9.3% were already awake for more than 60 min before getting out of bed.⁵⁸ In total 72.1% of the participants were classified as having at least one of these sleep problems.⁵⁸

During the 10-year follow-up, data about anxiety disorders, depression and sleep will be collected again, with some changes and additions to the baseline data collection (see [table 2](#)). The 10-year follow-up has been extended with data retrieval from the psychological files about the presence of mood disorders, autism spectrum disorder, attention deficit hyperactivity disorder, obsessive-compulsive disorder, attachment disorders, personality disorders, psychotic disorders, post-traumatic stress disorder and cognitive disorders (including dementia). In older people with ID, there is an association between the presence of a mental health diagnosis and problem behaviour.⁵⁹ Data about problem behaviour will, therefore, also be collected within the 10-year follow-up using the Aberrant Behaviour Checklist (ABC).⁶⁰ The ABC is a widely used behaviour rating scale and measures problem behaviour using five subscales: irritability, lethargy, stereotypy, hyperactivity and excessive speech. In addition, a potential objective biomarker for long-term stress in people with ID will be evaluated, which may help to future diagnostic assessment. Long-term stress over the recent months will be retrospectively examined with a hair cortisol measurement. Recently published studies in the general population indicate that there is a strong association between the level of hair cortisol, life events and symptoms of anxiety and depression.^{61–64}

Data on sleep and sleep-wake rhythm will still be collected with accelerometry; however, we will now use the GENEActiv (Original, Activinsights Ltd, UK). Data from the GENEActiv are comparable to data collected by the Actiwatch that was used at baseline.⁶⁵ Extra questions about sleep hygiene and sleep circumstances have been added to learn more about the influence of these factors on sleep in older adults with ID.

Nutritional intake and nutritional state

The baseline measurements of the HA-ID study yielded insights into the dietary intake and nutritional state of older adults with ID. Three-day dietary records completed by professional caregivers revealed inadequate dietary intake, with none of the participants meeting all Dutch recommendations for a healthy dietary intake. The food intake was too low in calories in 68.6% of the participants, too low in protein in 30.2%, too low in dietary fibre in 98.2% and too high in saturated fat in 89.5% of

the participants.¹¹ Forty-two per cent of the participants had vitamin D deficiency, of which 9% had severe vitamin D deficiency.⁶⁶ Vitamin D supplement were routinely provided to 45% of the participants and this group had significantly higher mean vitamin D serum levels than those without supplement. This calls for more attention for prescribing vitamin D in older adults with ID.⁶⁶ These results also indicate that there is plenty of room for improvement in healthy nutrition.

Mealtime observations using the Dysphagia Disorder Survey⁶⁷ showed moderate to severe dysphagia in 51.7% of the participants, which is comparable to the prevalence in nursing homes.⁹ In 89.5% of the participants with dysphagia, this had not been previously diagnosed. The high degree of underdiagnosis illustrates the importance of screening and diagnosing dysphagia to prevent complications in clinical practice. Greater age, Down syndrome, mobility impairment, needing help with feeding and use of benzodiazepines were positively and independently associated with dysphagia.⁹

The prevalence of sarcopenia was also studied. Fourteen per cent of the participants were classified as having sarcopenia, which developed at a relatively young age compared with the general population. At a prevalence of 12.7%, sarcopenia was already significantly present in participants aged 50–64.⁶⁸ Additionally, the bone quality was low in 43.9% of participants. Being female, greater age, more severe ID, mobility impairment and anticonvulsant drug use were positively associated with low bone quality.⁶⁹ Higher BMI was negatively associated with low bone quality.⁶⁹ These results suggest an approach for periodic screening of high-risk groups for low bone quality and target groups for prevention in clinical practice.⁶⁹

In the 10-year follow-up, the baseline measurements will be repeated (see [table 2](#)). To gain a better picture of the degree of malnutrition among older adults with ID, the Short Nutritional Assessment Questionnaire for Residential Care (SNAQRC) will be added to the data collection. The SNAQRC is a screening instrument for early detection of undernutrition in nursing or residential home settings using a traffic light system in which BMI and four questions related to involuntary weight loss, loss of appetite and eating with help are combined.⁷⁰ The SNAQRC will be completed by professional caregivers.

At baseline, a short dental file examination provided some data on the dental condition of the participants. To get a comprehensive picture of the dental condition and dental hygiene of older adults with ID, the dental file review will be extended. Data will be collected about dental condition, premedication and sedation during check-up and treatment, dental prosthesis, enamel wear, the number of dentist and dental hygienist visits, the number of elements in the upper and lower jaw, dental wear, dental caries, plastic restorations, crowns and bridges, implants, gingivitis and periodontitis, mobile elements and loss of dental elements due to trauma.



Frailty

Frailty is a clinically recognisable state of increased vulnerability resulting from age-associated decline in reserves and functions across multiple physiological systems.⁷¹ Frailty leads to deterioration of daily functioning and mobility, increased disability, development of comorbidity and increased care intensity.^{17 72 73} As a result, signalling frailty could play a valuable role in care planning, potentially improving quality of life and increasing the life expectancy of frail people with ID. In the general population, frailty is usually measured by tools such as the frailty phenotype.⁷⁴ However, we theorised that the ID population might require a more specific approach than the available tools allow. Based on the baseline data, an ID-Frailty Index was created consisting of 51 items.³ The ID-Frailty Index focuses on multiple aspects of daily functioning, opposed to a broader focus on physical frailty and mobility impairment.⁷⁵ As a result, the ID-Frailty Index could be applied to a larger proportion of the study population than the frailty phenotype and was deemed more suitable for measuring frailty in older adults with ID.⁷⁵ Furthermore, the ID-Frailty index showed a stronger relationship with mortality than the frailty phenotype.⁷⁵ The 3-year follow-up data showed that higher scores on the ID-Frailty Index resulted in a greater risk of death.¹⁹ Finally, the ID-Frailty Index was predictive for a decline in mobility and increases in disability, polypharmacy and care intensity.^{16–18}

In the 10-year follow-up, all previous measurements that were used to create the ID-Frailty index will be repeated (see [table 2](#)). This lets us investigate the characteristics of frailty over time. In an attempt to further increase the practical and clinical usability of the ID-Frailty Index, a shortened version was developed. During the 10-year follow-up, the utility of this short form of the ID-Frailty Index will be further investigated.

General health data

In addition to these five research themes, data on other health variables will also be collected such as data on other diseases, medication use, hospitalisation, mortality, activities of daily life, smoking and alcohol/drug use ([table 2](#), under the heading ‘General health data’).

Procedure

To limit the burden and impact on participants and their professional caregivers, all measurements will be done in settings close to where the participants live. All measurements will be carried out by test administrators consisting of professionals working in the care organisations. All test administrators will be trained to ensure accurate administration and correct scoring of the measurements. All measurements for a specific participant will be scheduled within 1 week. This test week consists of a physical examination performed by medical staff, fitness tests supervised by movement therapists or physiotherapists, observations to assess pain during activities of daily life performed by trained healthcare professionals, a mealtime observation

to screen for dysphagia performed by speech and language therapists and a maximum of two interviews by trained and qualified professionals aimed at screening and diagnosing anxiety and depression. The participant will wear portable measuring equipment on the wrist and hip for 7 days to monitor physical activity and sleep-wake rhythm. If separate consent is provided, blood samples and a tuft of scalp hair will be collected. For logistical reasons, the hip and knee X-rays take place outside this test week. All measurements together require a maximum time investment of 4 hours for each participant. However, the time investment per participant will probably vary because not every participant can undergo all measurements. The study will not interfere with routine medical practice. In addition to measurements for which active involvement of the participants is needed, the professional caregiver will be asked to complete questionnaires about the participant’s health and data will be collected from the medical, psychological and dental files. The medical file review is performed using the records of all participants who participated in the baseline measurements, including the medical files of deceased participants. A complete overview of all measurements within the HA-ID study can be found in [table 2](#). After the test week, the participant’s physician and behavioural scientist receive a report with a summary of the results of the measurements.

Patient and public involvement

Patients and the public were not involved in the design of this study.

Statistical analysis

In line with the previous measurements, the 10-year follow-up will provide cross-sectional and longitudinal data. Various statistical analyses will be applied. Descriptive statistics are used to answer questions about the prevalence and incidence of health conditions and possible risk factors. Multivariable regression analyses are used to answer questions about differences between subgroups and associations between variables, considering possible confounders and to adjust for these covariates. Survival analysis with Cox proportional hazard models will be used to investigate relationships between various factors (including age, sex, level of ID and comorbidity) and several health conditions and mortality over time. For repeated measurements, the dependency of measurements for the same participant will be adjusted by using generalised linear mixed-effects models.

Implications for practice

The HA-ID study so far has yielded knowledge of various health problems that are prevalent in older adults with ID, and how these compare to the general population. This knowledge suggested approaches for improving care for adults with ID. The 10-year follow-up will provide a deeper understanding of the course of health over time and risk factors for health problems in older adults with ID. Research into CVD risk factors in this population, for

example, is still very limited. More knowledge about CVD risk factors and possible group-specific risk factors will give a better estimate of the cardiovascular risk profile of older adults with ID. The 10-year follow-up will also give a clearer picture of how frailty develops over time and whether there are certain groups of people with ID who are at higher risk for adverse outcomes.

What characterises the HA-ID study is that it is a prospective multicentre cohort study in which, compared with other ID studies, a relatively large (n=1050) and heterogeneous group of older adults with ID is followed over time. The extensive measurements let us evaluate the health of older adults with ID from a broad perspective and investigate the interrelationships between medical domains such as CVD, physical fitness, psychological problems and psychiatric disorders, nutrition and frailty. Looking across research themes is especially important because multi-morbidity is common in people with ID.⁴

We know from experience that conducting epidemiological research into this field can be difficult and involves challenges in selecting suitable measuring instruments; some require certain levels of cognitive, physical or verbal ability that may not be compatible with those of the participants. To allow for optimal comparison between the general population and our cohort, we have aligned the measurements of the 10-year follow-up as much as possible to existing cohort studies of (specifically older) adults in the general population. However, feasibility, validity and reliability in older adults with ID were the leading criteria when selecting measuring instruments, using previously acquired knowledge and experience from the HA-ID study. How invasive and time-consuming instruments are was also considered, as were the feasibility for a large proportion of our population, the extent to which it is possible to do the measurement at the care organisations and the extent to which the instruments can be used by a large group of professionals without making concessions in terms of inter-rater reliability. In addition, the costs of the measuring instruments were examined, considering use in clinical practice. The HA-ID study is continuously searching for innovative and feasible measuring instruments that can be implemented for data collection.

A limitation of our study is that financial and feasibility reasons mean it has not been possible to perform follow-up measurements more regularly. Fortunately, the presence of routine registrations performed by the care organisations in medical, psychological and dental files lets us retrospectively collect data on the health of the participants over the past 10 years. Given the age of our study population and the length of follow-up, selection bias caused by the survival of healthier participants may distort our results. We are aware of this healthy survivor effect and address this when analysing and interpreting our results. It should be noted, that we do have access to the medical files of participants who have passed away. This lets us retrospectively collect data on the health of this group.

Results from the 10-year follow-up measurements are important for prioritising policy and care and underpinning clinical decision making about screening, prevention and treatment to improve healthy ageing of adults with ID. Longitudinal data collected in the 10-year follow-up of the HA-ID cohort therefore has high added value.

Ethics and dissemination

As for the previous parts of the HA-ID study (MEC-2008-234 and MEC-2011-309), ethical approval for the 10-year follow-up has been obtained from the Medical Ethics Review Committee of the Erasmus MC, University Medical Centre Rotterdam (MEC-2019-0562).⁷⁶ Local ethical committees and boards of individuals with ID and their representatives of the three involved care organisations were informed.

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