An Evaluation of the Effectiveness of Annual Health Checks and Quality of Health Care for Adults with Learning Disability

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Abstract

Background: People with intellectual disability (ID) have poorer health, however there is a lack of comprehensive national data describing their healthcare needs and utilisation. Annual health checks for adults with ID have been incentivised through primary care since 2009, but only half of those eligible receive one. However, it is unclear what impact they have had on important health outcomes, such as emergency hospitalisation.

Objective(s): To evaluate whether annual health checks for adults with ID have reduced emergency hospitalisation, and to describe health, healthcare and mortality for adults with ID.

Design: Retrospective matched cohort study using primary care data linked to national hospital admissions and mortality datasets.

Setting: 451 English GP practices contributing data to Clinical Practice Research Datalink (CPRD)

Participants: 21,859 adults with ID compared to 152,846 age-sex-practice matched controls without ID registered during 2009-13.

Interventions: None

Main outcome measures: Emergency hospital admissions. Other outcomes: preventable admissions for ambulatory care sensitive conditions, mortality.

Data sources: CPRD, Hospital Episodes Statistics, Office National Statistics

Results: Compared to the general population, adults with ID had higher levels of recorded co-morbidity and were more likely to consult in primary care. However, they were less likely to have longer doctor consultations, and had lower continuity of care. They had higher mortality rates (HR=3.6, 95%CI 3.3-3.9), with 37.0% of deaths classified as being amenable to health care intervention (HR=5.9, 95%CI 5.1-6.8). They were more likely to have emergency hospital admissions (IRR=2.82, 95%CI 2.66–2.98), with 33.7% deemed preventable compared to 17.3% in controls (IRR=5.62, 95%CI 5.14-6.13).

Health checks for adults with ID had no effect on overall emergency admissions compared with controls (IRR=0.96, 95%CI 0.87-1.07), although there was a relative reduction in emergency admissions for ACSCs (IRR=0.82, 95%CI 0.69-0.99). Practices with high health check participation also showed a relative fall in preventable emergency admissionsfor their ID patients compared to practices with minimal participation (IRR=0.73, 95%CI 0.57-0.95). There were large variations in health check related content recorded on electronic records.

Limitations: Patients with milder ID not known to health services were not identified. We could not comment on the quality of health checks.

Conclusions: Compared to the general population, adults with ID have more chronic diseases, and greater primary and secondary care utilisation. With more than a third of deaths potentially amenable to health care interventions, improvements in access to, and quality of, healthcare are required. In primary care, better continuity of care and longer appointment times are important examples that we identified. While annual health checks can also improve access, not every eligible adult with ID receives one, and health check content varies by practice. Health checks had no impact on overall emergency admissions, but they appeared influential in reducing preventable emergency admissions.

Future work: No formal cost-effectiveness analysis of annual health checks was performed, but could be attempted in relation to our estimates of a reduction in preventable emergency admissions.

Word Count: 497 (limit 500)

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Abbreviations

ACSCs   Ambulatory Care Sensitive Conditions
BMI   Body Mass Index
BNF   British National Formulary
CHD   Coronary Heart Disease
CI   Confidence Interval
CIPOLD Confidential Inquiry into Premature Deaths of People with Learning Disability
COPD   Chronic Obstructive Pulmonary Disease
CPRD   Clinical Practice Research Datalink
DES   Directed Enhanced Service
DM   Diabetes Mellitus
GE   Gastroenteritis
GP   General Practitioner
HES   Hospital Episode Statistics
HR   Hazard Ratio
HRG   Healthcare Resource Groups
ICD-10 International Classification of Diseases 10th revision
ID   Intellectual Disability [as the preferred term for Learning Disability (LD)]
IHD   Ischaemic Heart Disease
IMD   Index of Multiple Deprivation
IQR   Inter Quartile Range
IRR   Incidence Rate Ratio
LRTI   Lower Respiratory Tract Infection
NHS   National Health Service
ONS   Office for National Statistics
OPCS   Classification of Interventions and Procedures
OR   Odds Ratio
PEG   Percutaneous Endoscopic Gastrostomy
PPI   Patient and Public Involvement
PR   Prevalence Ratio
RCT   Randomised Controlled Trial
RR   Rate Ratio
QOF   Quality and Outcomes Framework
SD   Standard Deviation
TIA   Transient Ischaemic Attack
UK   United Kingdom
UTI   Urinary Tract Infection

Plain English summary

People with a learning disability (LD) such as Down's syndrome have more health problems than the general population, leading to more unplanned visits to hospital which can be very distressing. In response to concerns over healthcare for this group, NHS England introduced annual health checks for all adults with a LD, with GPs being paid to provide them; however only half of those eligible have received one. It is unknown whether health checks make any important lasting difference to health, such as preventing hospital admissions. Using large anonymous databases of GP and hospital records, we investigated whether the introduction of health checks led to any reduction in unplanned hospital admissions for adults with a LD. We also described the health characteristics of these patients, addressing gaps in knowledge. Our main finding was that although health checks did not reduce overall unplanned admissions, they were associated with a reduction in potentially preventable hospital admissions. We also showed that adults with a LD had more recorded illnesses such as epilepsy and mental health problems, and consulted with their GP more, compared to the general population. However, they were less likely to have long GP consultations or to see the same doctor. Lastly, we found that health information recorded during health checks varied across practices. The main implications from our study are that health checks for patients with a LD can be effective in preventing some unnecessary hospital visits, and that practices should be encouraged to ensure more eligible patients receive them.

Word count: 249 (limit 250)

Scientific summary

Background

People with intellectual disability (ID) have more significant health risks and major health problems than the general population, and as a result are more likely to die younger. However, there is a lack of comprehensive national data describing their needs, primary and secondary care utilisation and patterns of mortality. To address concerns regarding the quality of primary care access and healthcare, NHS England have incentivised general practices to carry out annual health checks for adults with ID since 2009. However, approximately only half of those eligible are thought to have received one. It is unclear what exactly happens in these health checks, and what impact they have on important health outcomes, such as emergency hospitalisation.

Objectives

The study had 2 overall aims:

- To describe the health, healthcare quality, equity of healthcare, mortality rates and NHS costs for adults with ID in a national sample.
- To evaluate the process and outcome effectiveness of annual health checks for adults with ID in primary care.

Methods

We carried out a retrospective matched cohort study using a large primary care database (CPRD) linked to national hospital admissions (HES) and mortality datasets (ONS). Overall from 451 English GP practices we initially identified 21,859 adults with ID registered during 2009-13 using an extended list of Read codes for ID and associated conditions. Each adult with ID was matched on age, sex and practice to a maximum of 7 controls without ID or associated conditions (n=152,846). Specific analyses were based on smaller sub-groups of adults with ID: cross-sectional analysis of health and healthcare quality on 1/1/12 (n=14,751); longitudinal

analysis of mortality and hospital admissions during 2009-13 (n=16,666); and individual health checks (n=7,510). A practice based analysis of health checks compared a subset of participating practices (n=126) versus non-participating ones (n=68). Analyses of health checks further considered adults with ID without health checks (n=6,922), assigning a random index date based on the distribution of the dates recorded in the 7,510 adults with health checks during the study.

Outcomes considered for the cross-sectional analyses included chronic disease prevalence, selected health process measures, number of consultations, consultation length, continuity of care and prescribing levels during 2011. NHS costs were also estimated in 2011 assigning published costings to primary and secondary care events where clearly identifiable. Outcomes for longitudinal analyses were mortality and emergency hospital admissions using the linked ONS and HES data respectively to further derive cause of death and primary reason for admission. We also considered emergency admissions for ambulatory care sensitive conditions (ACSCs), which are thought to be potentially preventable with better clinical management. The main outcome studied in relation to the impact health checks was emergency hospital admissions, but we also analysed the sub-group of ACSCs. For the analyses of process measures, we identified and categorised key health areas that health checks were intended to address, as well as general screening tests. We also analysed the recording of a health check as an outcome among all adults with ID in participating practices.

Throughout the study we engaged with two established service user groups, one a network of adults with ID and staff members at St George's, University of London, who collaboratively undertake research (ResearchNet), and the other a local group of family carers of adults with an ID (Merton carers). These meetings initially helped identify and modify important outcomes for our study, as well as providing later assistance in interpreting and disseminating findings.

Statistical analyses comparing ID adults with matched controls, included conditional Poisson models to derive prevalence ratios (PR) and rate ratios (RR), conditional models for odds ratios (OR) and Cox models stratified on the matched sets to obtain hazard ratios (HR). Further adjustment was made for selected co-morbidities, smoking and area deprivation where appropriate.

Results

Cross-sectional comparison with the general population

Adults with ID had high levels of recorded co-morbidity compared to the general population, in particular epilepsy (18.5%, PR=25.33, 95% CI 23.29-27.57) and severe mental illness (8.6%, PR=9.10, 95% CI 8.34-9.92). Large relative differences were also seen for dementia (PR=7.52, 95%CI 5.95-9.49), dysphagia (PR=3.30, 95% CI 3.01-3.61) and hypothyroidism (PR=2.69, 95% CI 2.52-2.87). However, they were less likely to have recordings of CHD (PR=0.65, 95% CI 0.57-0.74) and cancer (PR=0.70, 95% CI 0.61-0.80) in their primary care record. Nearly 1-in-4 adults (23.9%) with ID were classified as having severe or profound ID, or had severe health needs. The recording of disability, continence, vision and hearing impairment was higher among adults with ID than the general population, as were the recording of other key health indicators (smoking, body mass index (BMI), alcohol consumption, blood pressure). Eligible women with ID were less likely to have had a cervical smear during the last 5 years (PR=0.64, 95% CI 0.61-0.66) or a mammogram during the last 3 years (PR=0.75, 95% CI 0.72-0.78). Adults with ID were nearly twice as likely to have received repeat medication during 2011 than controls (PR=1.82, 95% CI 1.79-1.84). They were almost three times as likely to be prescribed a psychotropic drug (PR=2.73, 95% CI 2.66-2.81), with almost 1-in-4 (38.2%) receiving at least one psychotropic prescription during the year. They had a higher primary care consultation rate during 2011 (RR=1.70, 95% CI 1.66-1.74), but once this was accounted for, they were less likely to have had a doctor consultation of greater than 10 minutes (OR=0.73, 95% CI 0.69-0.77), and had lower continuity of care with the same doctor (OR=0.77, 95% CI 0.73-0.82). Overall, their estimated NHS costs during 2011 were estimated to be twice that of patients of the same age and sex without ID (RR=2.05, 95% CI 2.01-2.10). Only 46.8% of adults with ID had received a health check by 1/1/2012.

Longitudinal analysis of hospital admissions and mortality

Adults with ID had higher mortality rates (HR=3.62, 95% CI 3.33-3.93) during 2009-13 compared to matched controls, which remained high after adjustment for differences in

comorbidity (HR=3.05, 95% CI 2.73-3.41). The higher risk was seen across all causes of death, except some cancers and transport accidents. Adults with Down's syndrome were at a much higher risk (HR=9.21, 95% CI 7.22-11.76) compared to their controls, with 1-in-4 deaths (25.4%) having Down's syndrome erroneously recorded as the underlying cause of death. In total, 37.0% of deaths were classified as being amenable to health care intervention, compared to 22.5% in the matched controls. However, since current definitions of amenable mortality do not include urinary tract infection and aspiration pneumonia, it is possible that the true figure for amenable deaths among adults with ID is higher. Despite this, the rate of such deaths was estimated as being almost 6 times higher among adults with ID than they were for adults of the same age and sex within the general population without ID (HR=5.86, 95% CI 5.06-6.80). Almost 7-in-10 deaths (69.1%) among adults with ID had no recording of ID on the death certification data.

Adults with ID were more likely to have an emergency hospital admission during 2009-13 (IRR=2.82, 95% CI 2.66–2.98), with 33.7% being for ACSCs compared to 17.3% in controls (IRR=5.62, 95% CI 5.14-6.13). The most common ACSCs resulting in admission for adults with ID were epilepsy (35.6%), lower respiratory tract infection (18.6%) and urinary tract infections (11.4%). We found no evidence of differences in primary care utilisation, investigation and management preceding admission for common infections between adults with ID and the general population.

Health checks and emergency hospital admissions

Adults with ID with a first health check recorded during 2009-13 showed no difference in the change in their overall emergency admissions compared with controls (IRR=0.96, 95%CI 0.87-1.07), however there was evidence for a relative reduction among those with severe health needs (IRR=0.80, 95% CI 0.67-0.95). When emergency admissions for ACSCs were solely considered, there was evidence of reduced change in admission rare post health check compared to controls (IRR=0.82, 95% CI 0.69-0.99). Sensitivity analyses using adults with ID without health checks did not replicate this reduction over the same time period, providing further evidence that our findings for ACSCs were specific to health checks. An analysis of health checks at practice level, found that practices with high health check participation

showed no change in emergency admission rate among patients with ID over time compared with non-participating practices (IRR=0.97, 95% CI 0.78-1.19), but emergency admissions for ACSCs did fall (IRR=0.74, 95% CI 0.58- 0.95), consistent with the individual level analysis.

Health checks and process measures

Among practices carrying out health checks, adults with ID who have more severe health needs or who were living in communal establishments were more likely to receive a first health check during 2009-11. The patients who subsequently received health checks were already being seen more often in primary care, and being prescribed more medication prior to the introduction of health checks compared to patients who did not receive health checks by 2011. While we failed to detect any evidence that health checks had a significant impact on the overall level of consultations or diagnoses between ID adults with and without health checks, prescribing levels and associated costs did increase, and specific process measures relating to health checks were much more commonly recorded in those with health checks. However, there were large variations in what was being recorded on patient records around the time of the health checks, with notable low recording for health issues concerning mental health (13.8%) and bowels or bladder (13.2%). Among those with a first health check during 2009-10, patients living in more deprived areas were less likely to get a repeated check during the following year (p<0.001).

Conclusions:

The study has identified the following implications for healthcare:

- Adults with ID are at high risk of emergency hospitalisation, particularly unplanned admissions, which represent a third of all emergency hospitalisations for these patients. The finding that the introduction of health checks for adults with ID may have reduced preventable emergency admissions to hospital during the study is important for future planning and policy making.

- Not every eligible adult with ID is offered a health check or receives one, and the experience and recorded content of health checks varies considerably by practice. Encouraging practices to increase the uptake of health checks could reduce health inequalities for adults with ID, as well as ensuring better standardisation of the overall process.

- With more than a third of deaths potentially amenable to health care interventions, this suggests that improvements of access to, and quality of, healthcare among adults with ID are possible and desirable. In primary care, better continuity of care and longer appointment times are important examples we have identified.

- The high prescribing levels of psychotropic drugs to adults with ID combined with low levels of recorded medication reviews, suggest improvements in monitoring could be made, assessing the appropriateness of long term prescribing for these patients.

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- The low level of recording of ID on death certification has implications for surveillance of this population and needs consideration for ways this could be improved. Even when recorded, the questionable coding of ID as an underlying cause for many deaths, suggests more consistent guidance would be helpful.

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The study has also identified the following implications for further research:

- While adults with ID have greater levels of chronic disease than the general population, recording of cancer and coronary heart disease was lower and warrants further investigation as to whether this represents missed diagnoses or lower risk due to difference in lifestyle risk factors.

- The variation in recording in the patient record around the time of the health check needs further explanation, particularly the low recordings in key areas such as mental health and medication reviews. If confirmed, further research could also identify barriers to carrying out standardised health checks, and suggest recommendations for improvement.

- As we did not undertake a formal cost analysis in this study, future research could helpfully estimate whether the cost of health checks is offset by savings from fewer emergency hospitalisations.

Word count: 1,970 (limit 2,000)

Chapter 1 Introduction

Background

The World Health Organisation defines intellectual disability (ID) as "… a condition of arrested or incomplete development of the mind, which is especially characterized by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, i.e. cognitive, language, motor, and social abilities".[1] In the UK, intellectual disability is commonly referred to as learning disability.[2] This should be viewed distinct from the term 'learning difficulty', commonly used across UK education, which can encompass conditions such as dyslexia that do not necessarily imply intellectual impairment, and hence learning disability. Throughout this report we will refer to learning disability as intellectual disability or ID, except where we are explicitly referring to UK documents or outputs that have used learning disability as their preferred term.

There are three core criteria that must be met for a person to be considered to have an ID:[3]

- intellectual impairment ("a significantly reduced ability to understand new or complex information")
- with social or adaptive dysfunction ("a reduced ability to cope independently")
- that has started before adulthood ("with a lasting effect on development")

The most common genetic cause of ID is Down's syndrome,[4] where every child born with Down's will be considered to have some level of ID. Neurological conditions such as cerebral palsy will be strongly associated with ID,[5] though do not necessarily imply low intelligence and hence ID. People with other neurodevelopmental disorders such as autism, may or may not satisfy all these criteria dependent on where on the autism spectrum they lie. Estimates of the prevalence of ID at all ages varies widely between 1% and 3% of the general population across the UK, USA and other high income countries.[6]

People with ID have more significant health risks and major health problems than the general population, and as a result are more likely to die younger.[7] In the NHS, there is evidence that people with ID receive sub-optimal care and this inequity contributes to poor health outcomes including avoidable mortality.[5] In 2008, an independent inquiry into access to health care for people with learning disability led by Sir Jonathan Michael concluded that

people with ID receive less effective care leading to avoidable suffering and death.[8] In addition, the report highlighted the paucity of information on NHS health care for people with ID.

A key focus of national policy has been improving the quality of primary care for people with ID. In 2006, the Disability Rights Commission recommended the introduction of annual health checks,[7] which was further supported by Sir Johnathan Michael's independent inquiry.[8] Subsequently in 2009, a national Directed Enhanced Service (DES) was introduced in England which funds general practices to provide annual health checks to adults with ID and requires that staff receive appropriate training.[9] The health check is intended to identify undetected health problems, improve prescribing and coordination with secondary care[10]. Recent systematic reviews have confirmed that health checks are effective in identifying health problems but found a paucity of evidence on their impact on health status and outcomes,[11] and have stated the need for an increase in quantity and quality of research on health interventions for people with ID.[12]

This study therefore aims to fill key knowledge gaps with a large sample evaluation of the effectiveness of annual health checks and a comprehensive study of health and healthcare in a national sample of adults with ID.

Health of people with intellectual disability (ID)

People with ID experience poorer health outcomes than the general population, such as increased emergency admission to hospital[13] and mortality.[14] The reasons for this poorer health are complex but are not solely explained by unavoidable biological manifestations of the cause of ID. Local ID register based studies have identified markedly higher mortality with estimates in the age-adjusted risk of death ranging between 3 and 18 times higher than those of the general population.[5,15,16] This increased risk of death is seen across a range of conditions and not limited to causes related to the underlying ID. Studies on disease prevalence and morbidity among people with ID, although limited, provide a similar picture with increased risk of epilepsy, diabetes, cardiovascular disease, infections, accidents and sensory impairment.[17-21] For example, it is estimated that more than 25% of people with ID suffer from epilepsy compared to less than 1% of the general population.[18] The concerns over

the health of people with ID have been reinforced by findings from the Confidential Inquiry into Premature Deaths of People with Learning Disability (CIPOLD) which confirmed high premature mortality with a high proportion of unexpected deaths.[22]

There is evidence to suggest that the quality of health care received by people with ID contributes to poorer health. This may be due to difficulties in communication leading to unmet health needs, poorer access to health services and discrimination[7]. The Sir Jonathan Michael independent inquiry into access for healthcare for people with ID concluded that high levels of need were not being met and that people with ID receive less effective care than they are entitled to and that this leads to avoidable suffering and death.[8] The high proportion of unexpected deaths reported by CIPOLD may also indicate that serious health problems are not fully identified in people with ID leading to poor outcomes.[22]

In addition, the Sir Jonathan Michael independent inquiry highlighted the paucity of information on NHS health care for people with ID.[8] These data gaps were further summarised and described by the Learning Disability Observatory in 2011.[23] Current national systems do not routinely allow a description of primary care use, quality of chronic disease care, hospital utilisation and major health outcomes for people with ID. Specifically, national systems such as cancer registration, hospital episode statistics (HES), mortality registration or general practice data collections (such as GPES, the General Practice Extraction Service) either do not systematically record ID or cannot provide analyses separately for people with ID. An initial analysis in 2010 of a primary care database was commissioned as part of the independent inquiry and reported on a range of measures in people with ID and found evidence for higher rates of obesity, poor seizure control and poorer treatment of urinary tract infections.[24] However, this limited analysis was not developed further or submitted for peer-reviewed publication as far as we are aware. Thus, knowledge of the health of people with ID in the UK up to 2015 has still been primarily based on either selective recording, for example in hospital data, or on selected populations from local ID registers.[25] Similarly, we know very little about the cost implications of providing NHS care for people with ID.

Annual health checks

A key recommendation of Sir Jonathan Michael's independent inquiry was the creation of a scheme in primary care to provide annual health checks for people with ID, which was outlined in the 2009 national strategy for learning disability.[26] The primary purpose of annual health checks is to address access barriers experienced by people with ID and allow identification of unmet health needs.[9] They also aim to improve prescribing and coordination with secondary care and are identified as a reasonable adjustment in accordance with the Disability Discrimination Act (1995).[27]

Annual health checks for adults with ID were implemented as a Directed Enhanced Service (DES) for primary care in 2009.[28] This DES funds practices to provide annual health checks to adults with ID with an emphasis on those who have higher levels of need and who are known to the local authority services. It also requires that senior practice staff attend an approved multi-professional educational session and that all practice staff receive training to reduce attitudinal barriers and improve communication with this group of patients.

Annual health checks are currently the main NHS intervention to improve the quality of primary care for people with ID.[29] However, estimates from 2011-2012 suggested that only 53% of eligible adults with ID had received an annual health check.[30] It may be that more have been invited for a health check, and for a variety of reasons have either refused or missed their arranged appointment, but this is not known. As of 2016, practices participating in the DES are required to invite registered patients on their learning disabilities register aged 14 years and over for an annual health check.

Evidence base for annual health checks

The presumed long term benefit of health checks assumes that identification of unmet health needs will lead to appropriate intervention and improvements in wellbeing and health outcomes. The Learning Disability Observatory undertook a systematic review of the evidence base for Annual Health Checks in 2011,[11] subsequently updated in 2014[12] which summarised health gains and impacts from similar interventions both in the UK and internationally. The initial review identified 38 studies (45 in the later review) which included a total of over 5,000 individuals receiving a health check. Most studies were small and the majority were

uncontrolled, with only four randomised controlled trials (RCTs) and two controlled studies. The higher quality studies clearly demonstrated that health checks led to improved detection of new health problems, with one RCT reporting 60% increase in diagnosis of new problems and a matched controlled study reporting 2.54 additional health problems identified on average in people receiving health checks.[31,32] These studies also reported increase uptake of preventative interventions such as vaccination, cancer screening and sensory testing. These conclusions are also supported by the larger number of uncontrolled studies.[11,12]

Evidence on health outcomes relating to health checks is far more limited and of poorer quality. Uncontrolled studies in the UK have reported a variety of benefits including improved seizure control and weight management.[33-36] These UK studies were small with less than one hundred participants. One larger before and after study of a domiciliary preventative intervention in the US found a reduction in self-reported pain, falls and emergency room visits,[37] while another larger US study suggested that health screening may help resolve psychiatric problems by identifying physical problems.[38]

The systematic reviews by Robertson et al[11,12] concluded that there was limited evidence on the effect of health checks on health status and that further work was required to establish the effectiveness of health checks. It is highly plausible that health checks, through identifying unmet health needs and preventive interventions, will lead to improvement in health outcomes, but evidence to confirm this is important. However, it is also possible that health needs identified in health checks may not be adequately addressed, and that implementation of health checks by non-enthusiasts, outside of study settings, will not yield the same benefit in terms of newly identified health needs. For example, health checks may lead to recording of poor seizure control in epilepsy, but appropriate management may require expertise or specialist input to review anticonvulsant medication, which may not be available.

Aims of the study

The study had 2 overall aims.

- **Aim 1:** To describe the health, healthcare quality, equity of healthcare, mortality rates and NHS costs for adults with ID in a national sample.

- **Aim 2:** To evaluate the process and outcome effectiveness of annual health checks for adults with ID in primary care.

The original objectives associated with these aims are shown in Table 1.

TABLE 1: ORIGINAL AIMS AND OBJECTIVES OF STUDY

Aim	Objectives	Location in Report
(1) To describe the health, healthcare quality, equity of healthcare and NHS costs for adults with ID in a National sample	Quantify primary and secondary care utilisation by adults with ID including prescribing	Chapter 3 Cross-sectional Findings and Chapter 5 Hospital Admissions
	Describe and quantify specific health risks for adults with ID	Chapter 3 Cross-sectional Findings and Chapter 4 Mortality
	Describe the quality of primary care received by adults with ID	Chapter 3 Cross-sectional Findings
	Determine whether adults with ID experience greater socio-economic inequities than the general population	Chapter 3 Cross-sectional Findings
	Determine annual health service costs for people with ID compared to the general population	Chapter 3 Cross-sectional Findings
(2) To evaluate the process and outcome effectiveness of annual health checks for adults with ID in primary care	Determine whether individuals receiving annual health checks experience improvement in healthcare process measures and health problem identification	Chapter 7 Who Gets Health Checks and What Is Recorded?
	Determine whether individuals receiving annual health checks experience improvement in health outcomes	Chapter 6 Health Checks and Hospital Admissions
	Determine whether practice participation in the Annual Health Check Directed Enhanced Service improves outcomes for people with ID	Chapter 6 Health Checks and Hospital Admissions
	Identify determinants and equity of uptake of annual health checks in practices which participate in the directed enhanced service	Chapter 7 Who Gets Health Checks and What Is Recorded?
	Determine the change in health service costs in the year before and after an Annual Health Check	Chapter 7 Who Gets Health Checks and What Is Recorded?

The first aim of our study, to provide a descriptive analysis of health and healthcare quality for adults with ID, is explored via two distinct analyses. Firstly, we take a snapshot of the health of the adult ID population on 1/1/12 registered in a large primary care database, and describe their chronic disease prevalence compared to an age-sex matched control group without ID (from the same general practices). Similarly, we will describe and compare their primary care utilisation in terms of consultations, as well as process measures and prescribing. We will provide a best estimate of annual healthcare costs by applying NHS reference costs and drug tariffs for healthcare events recorded including primary care consultations, prescribing, hospital admissions and outpatient consultations.

The second distinct series of analyses encompassing the first aim will follow a group of ID adults from 2009 to 2013 to describe their secondary care utilisation. Here, we will compare and summarise emergency hospitalisations with an age-sex practice matched control group without ID. For two indicator conditions (urinary tract infections and lower respiratory tract infections), which are likely to be a common reason for hospitalisation for adults with ID, we will compare their primary care utilisation in the period before the hospital admission with similarly recorded admissions within the general population. Finally, we also describe mortality patterns between 2009 and 2013 and summarise the key differences between adults with and without ID.

For the second aim (evaluation of annual health checks), the primary outcome was identified as emergency hospital admissions. Since the evidence base suggests that health checks improve detection of unmet health needs, chronic disease management and uptake of preventive care,[12] the possible longer term health benefits of health checks may occur across a range of conditions such as better seizure control in epilepsy, reduced cardiovascular risk and early treatment or prevention of infection. For all these conditions, delayed, incomplete or poor management will lead to an emergency hospital admission. Thus, emergency hospital admissions may be an important measure of quality of care for a range of conditions and a common pathway for the benefits of annual health checks. An associated reduction in emergency hospital admissions is likely to be a key measurable and valued benefit from annual health checks, as people with ID experience high levels of emergency admissions.[39] Additionally, unplanned admissions to hospital for patients with ID can be a particularly

stressful event, and unnecessary delays and omissions in treatment can compromise patient safety.[40]

Many unplanned admissions to hospital would be expected to occur even if health checks really were having an underlying beneficial effect. Thus, we also investigate a sub-group of emergency admissions for ambulatory care sensitive conditions (ACSCs).[41] These admissions are thought to be potentially preventable with better clinical management, though there is some variation in how they are explicitly defined,[42] particularly as they were originally developed in the United States.[43] However, most definitions will include a combination of conditions where acute management should prevent an admission (e.g. pyelonephritis), to other chronic conditions such as COPD where effective preventative care may prevent admissions. However, the preventable concept of an ACSC may ultimately depend on the availability and referral to alternative services such as respite care.[44] Some suggested interventions to prevent ACSCs such as improvements in self-management education and telemedicine,[44] may be less effective for patients with ID. Annual health checks may have a role to play here, and while we will have reduced power to investigate this outcome compared to all emergency admissions, it may provide a more relevant estimate of effectiveness.

We also explored a limited economic costing analyses where our data allowed. A more formal cost-effectiveness analysis was not possible within the resources in this study. In addition, a cost-effectiveness analysis would have presumed evidence of effectiveness, and it would have been premature to commit resources to such an analysis before we have determined effectiveness.

Secondary outcomes in relation to health checks included disease specific and generic process and outcome measures. We describe what gets recorded on a patient's electronic record at the time of a health check, and then summarise the overall impact a health check has on a selection of process measures being carried out over time. This will include for example, recording of cardiovascular risk factors such as BMI, blood pressure and smoking, as well as uptake of cervical and breast cancer screening and influenza vaccination. We will also summarise recording of key health areas for patients with ID, such as incontinence, constipation, mobility, vision and hearing.

Why the research is needed now?

Concerns over the quality and equity of NHS healthcare received by people with ID are long-standing[7] and the last few years have seen an increase in targeted NHS action to address these concerns. Specifically, funding for annual health checks in primary care was introduced in 2009 in England[30] and the NHS is still committed to the current Directed Enhanced Service scheme as of 2016.[29] Uptake of the scheme in 2011-12 was 53% of eligible adults with only a small increase shown since 2010-11 (48%).[30] For both clinicians and NHS policy makers, the current economic climate may be a barrier to annual health checks being more widely adopted in primary care, or even to whether or not the scheme is renewed in the future.

In particular, the development of clinical commissioning groups may act as a catalyst for wider implementation of annual health checks as commissioning groups standardise services offered by primary care in their area. Given this, an evaluation of the outcome effectiveness of annual health checks has the potential to influence policy decisions. If our study can demonstrate a clear benefit from health checks, this will strengthen the case for implementation and ensuring access for all people with ID. Lack of evidence of any measureable benefit will not invalidate health checks, but will raise questions over the quality of current implementation and the effectiveness of the service response to identified health needs. Our study should be able to differentiate between these two explanations and guide development of services to maximise health gain from annual health checks.

In summary, our study will evaluate the effectiveness of health checks in improving outcomes as well as processes of care and will also address the paucity of information on quality of healthcare for adults with ID.

Chapter 2 Methods

The Clinical Practice Research Datalink (CPRD)

The Clinical Practice Research Datalink (CPRD) is a large, validated primary care database that has been collecting anonymous patient data from participating UK general practices since 1987.[45] It includes a full longitudinal medical record for each registered patient containing coded information on medical diagnoses, prescribing and tests carried out within the practice. Additionally, referrals to specialists and secondary care settings, and lifestyle information such as smoking and alcohol status, are also recorded in CPRD. By 2015, it has been estimated to include over 4 million active patients, about 7% of the UK population.[45]

Subject to the practice's approval, the CPRD patient data are routinely linked to other national administrative databases by a 'trusted third party' via their NHS number, sex, date of birth and Post Code. These include

- The Index of Multiple Deprivation (IMD), a small area measure of deprivation used in England for allocation of resources[46]
- The Hospital Episode Statistics (HES) database, which routinely records clinical, patient, administrative and geographical information on all National Health Service (NHS) funded inpatient episodes in the UK
- Office for National Statistics (ONS) death certification data

Quality and Outcomes Framework (QOF) and learning disability

Medical diagnoses on CPRD are recorded using Read codes. Before we extracted data from the CPRD we carried out an extensive review of how what Read codes we would use to identify patients with ID. The starting point for this was the Quality and Outcomes Framework (QOF).[47] The QOF was introduced in April 2004 as part of a new general medical services contract in the UK, which would remunerate practices based on performance. One key element was the creation of disease registers for many important co-morbidities such as Coronary Heart Disease (CHD) and Chronic Obstructive Pulmonary Disease (COPD) using sets of nationally agreed Read codes. This has had a notable impact on the recording of these

diseases, such as for CHD,[48] with the assumption being that it has led to diagnostic accuracy overall (e.g. COPD).[49]

ID, classified as learning disability, has been part of the QOF since 2006. Originally there was only one indicator related to this, LD1 ("The practice can produce a register of people with learning disability"). While the rubric for the register suggests all patients with ID were included, the exact specification of business rules from around this time suggested only patients aged 18 years and above were included.[47] In 2014, the disease register indicator was modified to LD001 ("The contractor establishes and maintains a register of patients aged 18 or over with learning disabilities") to make the age criteria more explicit. However, this was changed in 2014/5 to LD003 ("The contractor establishes and maintains a register of patients with learning disabilities"), and the associated business rules now (from version 30 onwards) allow for any ages to be included.

Although published national figures for the QOF learning disability register of patients are available (Appendix 1), the change in the definition make it difficult to consistently estimate the prevalence of ID over time. Firstly, published denominators for the first two years (2006/7 and 2007/8) appear to be based on all adults, so we have had to estimate these. The addition of non-adults to the QOF learning disability register in 2014-5 meant that no separate adult only figures were estimated. The fall in the published prevalence from 0.48% in adults in 2013/4 to 0.44% in 2014/5 for all patients suggests that there may be still be a period of catching up for some practices to include all their ID patients on the register.

It has been argued that the QOF learning disability register provides a poor estimate of the actual number of adults with ID in England.[39,50] This may be because the majority of these patients do not use specialised services for adults with ID, and as a result, are not well known to primary care. The prevalence estimate of 2.17% calculated by Public Health England in 2013[50] would mean that 3 out of 4 patients with ID are not currently on QOF learning disability registers.[51] It seems unlikely that those with a severe or profound ID would not have this recorded on their medical record, so this "hidden majority" would presumably consist of patients with milder disabilities.

Identification of adults with ID in CPRD

Rather than rely on the QOF learning disability register to find all patients with ID in CPRD, we electronically searched the full medical record of all adults using an extended range of Read codes. While there are over 50 Read codes used for QOF definition of learning disability (see Appendix 2**Error! Reference source not found.**), they have been chosen from the main "Mental Retardation" hierarchical structure, and as a result are not an exhaustive list in terms of conditions usually associated with ID. For example, a Read code for Down's syndrome would not automatically put a patient on the QOF learning disability register. There are also some anomalies (e.g. the code ZS34.11 'Learning disability' is not on the QOF list) that we would wish to account for.

To create a more extensive list of candidate Read codes for our definition of ID, we manually reviewed Read codes within relevant hierarchies, in addition to performing word searches using key terms on the full set of codes. We included a wide range of chromosomal and metabolic disorders usually associated with ID. Our intention was to first extract a group of patients with these codes, but then to refine the definition, based on all available information in the individual medical record. The key to our approach was ensuring that we were not missing a significant group of people with ID by relying on QOF codes alone.

A Read code list of 232 codes was sent to CPRD in October 2013 to identify all patients who had any of these codes recorded anywhere in their medical record. We also required patients that were:

- Fully registered at an English practice for at least one day between 1/4/2007 and 31/3/2013 (we subsequently defined study time from 1/1/2009)
- "Acceptable" according to CPRD data criteria that identifies patients who have been fully registered with their GP and who have passed their data quality control checks
- Had a birth year of 1995 or earlier

CPRD then extracted an initial group of 32,876 patients from a total of 520 English practices (Figure 1). 69 practices were subsequently excluded from further consideration as they had stopped providing data to CPRD by 2009, or did not pass CPRD quality controls for data recording during our study period.
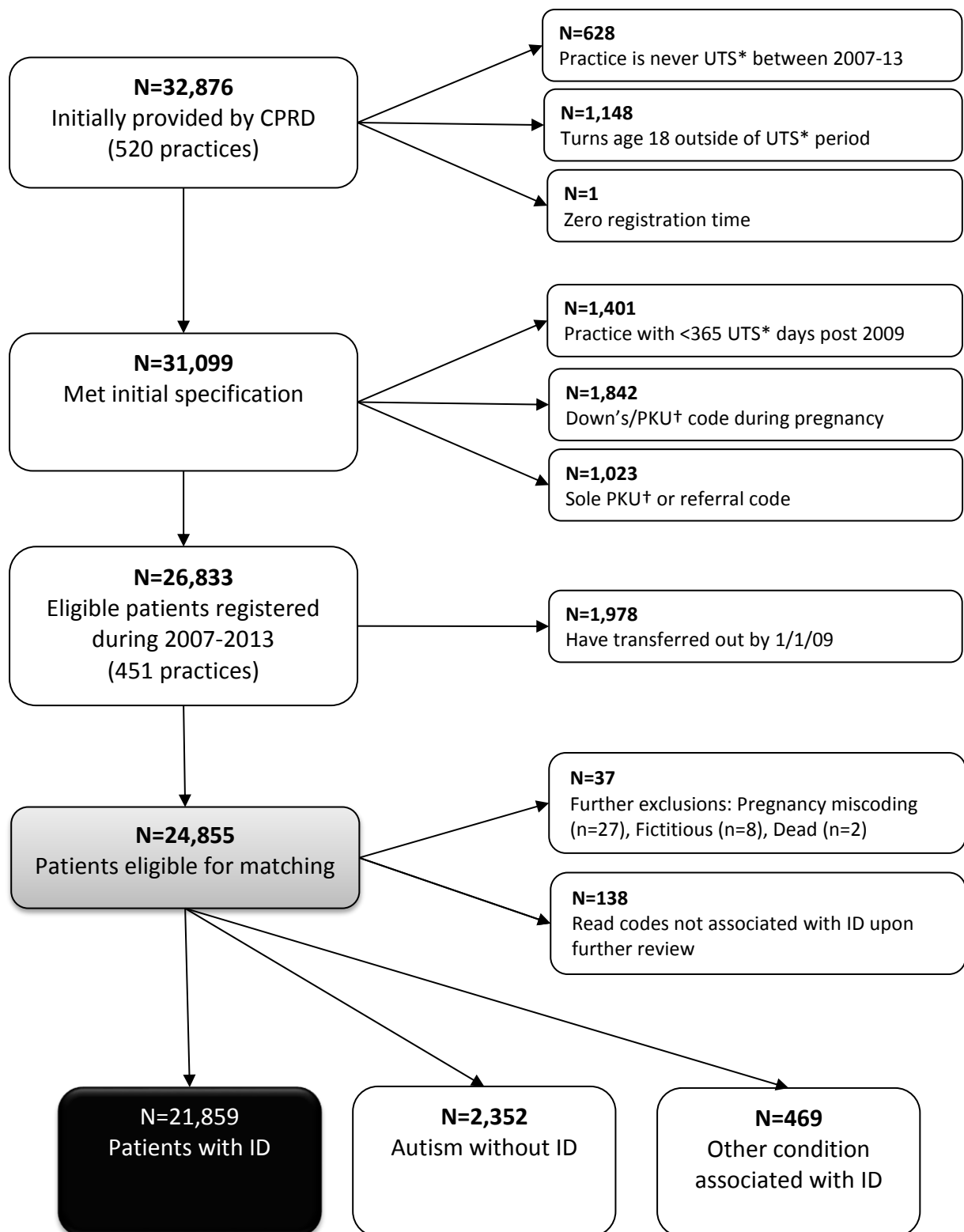
*UTS = Up-to-speed, a CPRD data criterion for when practice starts recording data of acceptable quality
†PKU = Phenylketonuria

FIGURE 1: SUMMARY OF IDENTIFICATION OF PATIENTS WITH INTELLECTUAL DISABILITY (ID)

The initial group of 32,876 candidate patients with ID were used to help refine our Read code list. The final list included 186 Read codes (see Appendix 2), 125 of them are not part of the QOF learning disability code set. However, many of these additional codes were infrequently used as they represent very rare conditions. For these additions, we chose to include diagnoses (e.g. Down's syndrome, Fragile X syndrome) and observations (e.g. "Mental handicap problem", "Low I.Q.") which are strongly related to ID (see Appendix 2for more examples). We also included administration codes that directly implied they have ID (e.g. "Learning disability health exam", "Learning disabilities annual health assessment"). In theory, practices should only be using administration codes for health checks if the patients are on their learning disability register, but this was not absolute. Adopting the refined Read code list, plus a series of exclusions (Figure 1) allowed us to now identify 24,855 patients with ID, or conditions associated with ID, that we wanted to extract age-sex-practice matched controls for.

Exclusions identified after first data extraction

One data issue we identified was with the erroneous historical use of some Read codes for phenylketonuria and Down's syndrome in some practices. It appeared that these codes had been used in the past (mainly during 1994-96) to record screening tests for these conditions in pregnancy and infancy and applied inappropriately to over 2000 (~5%) patients who would been wrongly identified with these conditions based on a simple search for the disease codes. This was one of the main reasons for our two stage extraction as clustering of these patients in some practices would compromise matching in these practices.

Phenylketonuria is a cause of ID but can also be successfully treated. In addition, all new born babies are screened for phenylketonuria so this may explain the extra codes in the same way as the Down's codes. Since the prevalence of phenylketonuria is about 1 in 10,000, it was implausible for a single practice to have 100+ cases (sometimes all born within 2 or 3 years). The clustering of this phenomenon by practice allowed us to quickly identify the problem, and create an automated strategy for correcting it. Briefly, using electronic searches of the medical record, we identified calendar years in which the patient was pregnant (or had given

birth). If during this year (or an adjacent year) they were recorded as having phenylketonuria or Down's syndrome without any other evidence of ID in their record, they were excluded from our definition of ID. A total of 1,842 patients were excluded in this way (Figure 1). We also excluded a further 1,023 patients who had a sole phenylketonuria Read code during infancy without any further confirmation. Ultimately, we decided not to include phenylketonuria in our definition of ID, so any remaining patients who were solely classified by this Read code were classed among the 469 patients designated as "Other condition associated with ID" (Figure 1).

Matched population controls

A list of 24,855 potential patients with ID ("cases") was sent to CPRD in December 2013 (Figure 1), and corresponding age-sex-practice matched controls were extracted and sent to us in March 2014. The matching was done in house by CPRD following our specification. We required any matched control to be alive and registered on a pre-specified index date. For cases who were actively registered on 1/1/2009, and aged 18 by 2009, we chose 1/1/2009 as the index date. For cases who register after this date, we chose their registration date if they were aged 18 in that year. For cases, who turn 18 after 2009, we chose January 1st of that year as the index date. Our choice of index date ensured that virtually all patients with ID would have a full complement of matched controls at the start of our planned longitudinal analyses. For ID patients who remained registered from 2009 to 2013, we anticipated losing an average of about 1 control per ID patient, due to de-registration or death.

In total, 173,797 age-sex-practice matched controls were extracted for the initial set of 24,855 patients who had ID or associated conditions, with 99.7% were successfully matched to 7 controls. Failure to match to 7 controls was generally due to a few large clusters of young patients with ID in some practices.

Defining sub-cohorts for analyses

Further validation work after the extraction of controls identified some further exclusions (Figure 1): 27 adults with ID who were pregnant and received their only code for ID in the year

before pregnancy, 8 adults with ID whose medical record appeared fictitious, and 2 adults with ID whose record clearly indicated they were deceased before 2009. While we initially included 2,352 patients with "Autism without ID" as well as a further group with other related conditions (but no evidence of ID), we chose not to use these groups any further in the study. Therefore, the remainder of the report only considers the 21,859 patients with ID (Figure 1).

Depending on the specific analysis (e.g. cross-sectional or longitudinal), the number of adults with ID included varied (see Figure 2). All analyses of individuals required a minimum registration period of 30 days with their GP practice before the patient was eligible to be in our study. As anticipated, very few elderly patients aged over 85 years with ID were identified during the study. Due to doubts over the validity of the recording of their health status, we made the pragmatic decision to only include patients aged 18 to 84 years at the beginning of follow up.

- The cross-sectional descriptions of disease prevalence, health promotion and consultations in primary care (Chapter 3) were based on 14,751 adults with ID who were alive and still registered on 1/1/2012 (and 86,211 matched controls). 31 practices were no longer providing data to CPRD by this date, so only 408 practices were included in this analysis.

- The longitudinal analyses of mortality (Chapter 4) and hospital admissions (Chapter 5) were based on 16,666 adults with ID from the 343 practices with linkage to HES or ONS data (and 113,562 matched controls). Study follow up time for these patients started from 1/1/2009 for those already registered and 18 years old, or a later date for those registering later or turning 18 in a later year.

- The analyses of health checks and hospital admissions had two distinct components (Chapter 6). For the analysis carried out at practice level, we restricted to 289 practices with complete recording in CPRD during 2009-2012, which identified a total of 14,409 adults with ID. For the analysis specific to individuals, we identified 7,487 adults with ID with a first health check during 2009-2012 (and 46,408 matched controls). A further 6,922 adults with ID without health checks (and 47,662 matched controls) are also included in these analyses.

- Finally, a further analysis of health checks (Chapter 7) was based on a subset of 274 practices which had some participation in the DES (20% of eligible adults with ID must

have had a health check during 2009-2011). This identified a total of 8,311 adults with ID who were registered on 1/1/2009 for at least a year.
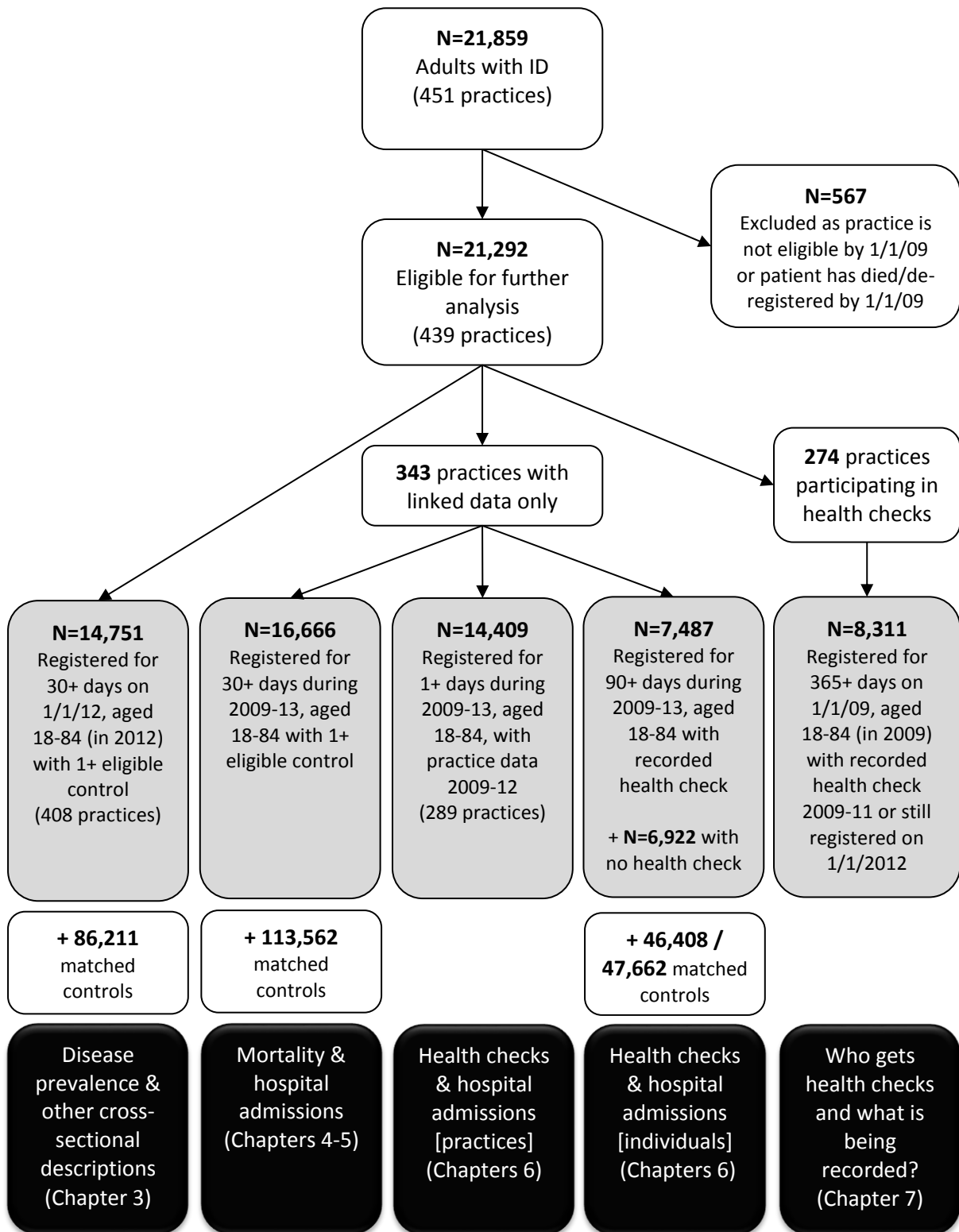
Note: Sub-cohorts are overlapping and individuals may appear in multiple cohorts

FIGURE 2: SUMMARY OF SUB-COHORTS FOR ANALYSES

Identification of health checks

Health checks were identified by specific Read codes used by practices to facilitate future payment (69DB., 9HB3., 9HB5. – see Appendix 1). We specifically focused on first health checks carried out from 2009 onwards, as this was the period from when practices in England received remuneration for carrying them out. A small number of patients had checks recorded prior to 2009, and were not included here. Health checks up to the end of the CPRD data collection period (31/3/2013) were included. The numbers of health checks included in the relevant analyses are shown in Figure 3.


```
┌─────────────────────────────┐        ┌─────────────────────────────┐
│   HOSPITAL ADMISSIONS       │        │   DESCRIPTIVE ANALYSIS      │
│        Chapter 6            │        │        Chapter 7            │
└─────────────────────────────┘        └─────────────────────────────┘

┌─────────────────────────────┐        ┌─────────────────────────────┐
│          N=343              │        │          N=361              │
│ Practices with linked HES   │        │ Practices with 20%          │
│ data and active on 1/1/2009 │        │ participation in            │
│                             │        │ DES 2009-11[1]              │
└─────────────────────────────┘        └─────────────────────────────┘

┌─────────────────────────────┐        ┌─────────────────────────────┐
│         N=7,487             │        │         N=5,583             │
│        Health Checks        │        │        Health Checks        │
│                             │        │                             │
│ ID adults with first health │        │ ID adults with first health │
│ check 1/4/2009 to 31/3/2013 │        │ check during 1/1/2009 to    │
│ registered for 90 days      │        │ 31/12/2011 who were         │
│ prior to health check and   │        │ registered on 1/1/2009 for  │
│ alive at least 90 days      │        │ at least 365 days           │
│ after it                    │        │                             │
└─────────────────────────────┘        └─────────────────────────────┘
```

Matched by date of health check

```
┌─────────────────────────────┐    ┌──────────────────┐  ┌──────────────────┐
│         N=6,922             │    │ Description of   │  │ Analysis among   │
│ Non Health Check Patients   │    │ what gets        │  │ all ID adults    │
│                             │    │ recorded during  │  │ still registered │
│ ID adults with no health    │    │ check, and       │  │ on 31/12/2011 as │
│ check during 2009-13 and    │    │ whether the      │  │ to what predicts │
│ still registered on index   │    │ check influences │  │ who gets a       │
│ date of health check        │    │ process measures │  │ health check     │
│                             │    │ before and after │  │ during 2009-11   │
│                             │    │ the check        │  │ (5,026 checks)   │
└─────────────────────────────┘    └──────────────────┘  └──────────────────┘
```

FIGURE 3: SUMMARY OF HEALTH CHECKS ANALYSES

The analyses were divided into two distinct sections: hospital admissions in relation to health checks (Chapter 6) and a descriptive summary of health checks (Chapter 7). A total of 8,933 first health checks were included across both analyses (with 4,137 of the health checks appearing in both).

For the analysis of hospital admissions, we firstly only included the subset of CPRD practices (n=343) that were actively recording data on 1/1/2009 and were linked to HES data. All patients were required to be registered with the practice for at least 90 days prior to the health check, and be alive for 90 days after it. Patients had to be aged 18 to 84 at time of their first health check to be included. In this analysis, all patients were followed to 31/12/2013, or their death if it was earlier. We were able to retain patients who had de-registered from their practice in the follow up, as linkage to hospital admissions continues as long they remained resident in England. A total of 7,487 ID adults aged 18-84 with a first health check between April 2009 and March 2013 were identified.

The distribution of month of first health check for the 7,487 adults with ID is shown in Figure 4. As the payments for the DES are made at financial year end, there are notable spikes in activity each February and March during the study. The early years (2009-10) were the most common years for first health check, reflecting that the majority of participating practices joined the scheme during its initial years. The distribution of first health check date was used to assign a random index date to a group of 6,922 ID adults without health checks (Figure 3). These patients formed a complementary group in our analysis of hospital admissions to check whether any observed changes in admissions for ID adults were specific to those receiving health checks only.
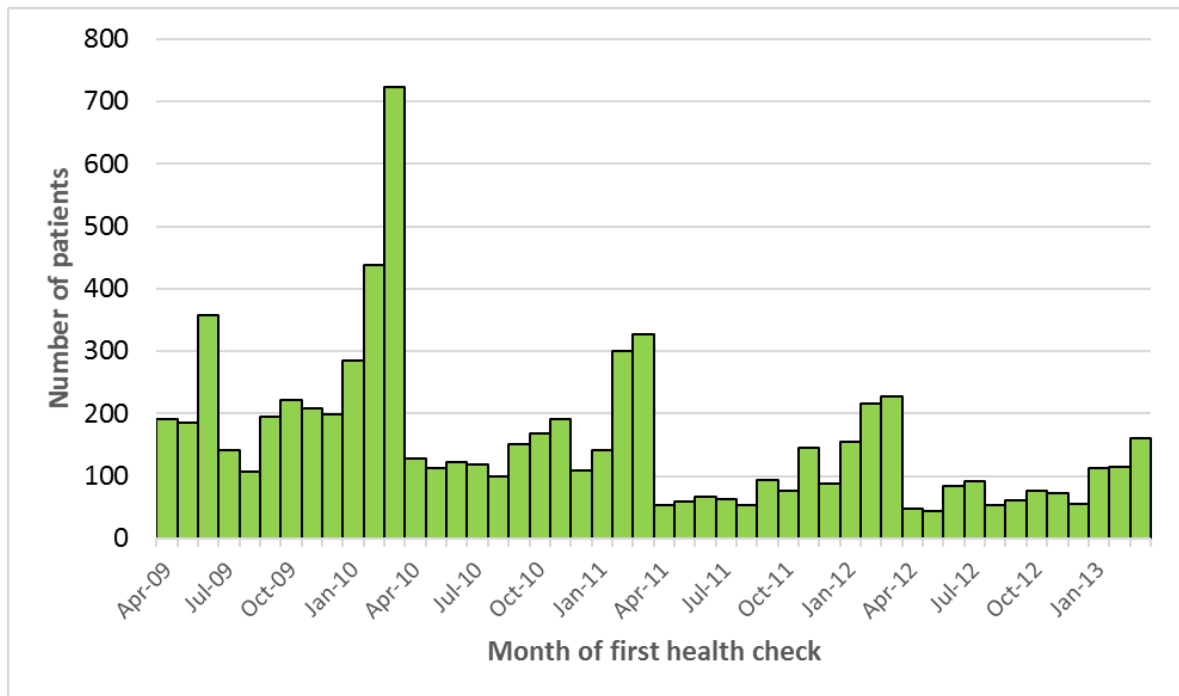
FIGURE 4: DISTRIBUTION OF MONTH OF FIRST HEALTH CHECK APRIL 2009 TO MARCH 2013

For the descriptive analysis of health checks, a total of 5,583 first health checks made during 2009-11 were included (Figure 3). We no longer restricted to practices with linked HES data, so could include from a wider set. However, we did then restrict to 361 practices with some participation in the DES (20% of ID adults with health checks) to try and capture regular procedures around the health checks. As some of these analyses would focus on health process in the year after the health check, we only included checks up to the end of 2011. Finally, we also carried out analysis that investigated predictors of receiving the health check that required patients to be registered throughout 2009-11, which is based on 7,754 adults with ID, where 5,026 receive a first health check during that period.

Definition of severe health needs

Whilst there are specific Read codes that allow for the severity of a patient's ID to be classified (e.g. "Eu81500 - Severe learning disability"), we found less than half of our patients had such a code recorded. For example, among the 14,751 adults with ID alive and registered on 1/1/2012, only 45% had a code indicating the severity of their ID (Table 2). Amongst those

with severity recorded, and using the highest level in their record, 38% were classed as mild, 35% moderate, 24% severe and 3% profound.

	n	% of all ID Adults	% who are men	Mean age (sd)
Severity Recorded	6,565	44.5%	57.2%	43.5 (15)
Severity Not Recorded	8,186	55.5%	58.4%	40.9 (16)
Mild	2,515	38.3%	56.6%	43.7 (15)
Moderate	2,298	35.0%	58.7%	43.4 (16)
Severe	1,567	23.9%	56.6%	43.6 (15)
Profound	185	2.8%	53.5%	40.7 (14)

With missing severity in over half the sample we had to consider two options. The first would be to only look at severity in the sub-group with it recorded. However, this approach is problematic, as the existence of such Read codes likely do not occur at random in our study group, and this group with severity recorded will not be representative of our total group. For example, the mean age of patients in 2012 with recorded severity was 2.6 years older than those with no severity recorded (Table 2).

Therefore, we considered an alternative approach that used Read codes that identify severity where available, and where these were not present, used a selection of other codes in their record that would indicate that the patient had severe or complex health needs. We identified 6 health areas that encapsulated a wide range of support or severe health needs:

- **Epilepsy:** Read codes as per QOF definition, but excluding absence seizures
- **Mobility:** Wheelchair use or greater problem, cerebral palsy
- **Visual:** Blind or low vision
- **Hearing:** Deafness, significant impairment, hearing aid use
- **Continence:** Bowel or bladder (recorded after age 12)
- **PEG Feeding:** Percutaneous endoscopic gastrostomy

We refined this list by cross-checking the prevalence of these codes and conditions in the patients with severe or profound ID versus mild or moderate ID (the full list of codes used is provided in Appendix 2). All categories were significantly associated with severe or profound ID with the exception of hearing impairment. However, we retained it to enable our definition to be as complete as possible in terms of various health needs. Finally, we improved precision, by imposing a restriction that for a patient to have a high level of support or severe health needs, they needed to fulfil two or more of these categories (Figure 5). This ensured we were not just creating a marker for age related frailty for example. The only exception to this rule was that if they already had Read codes indicating severe or profound ID.
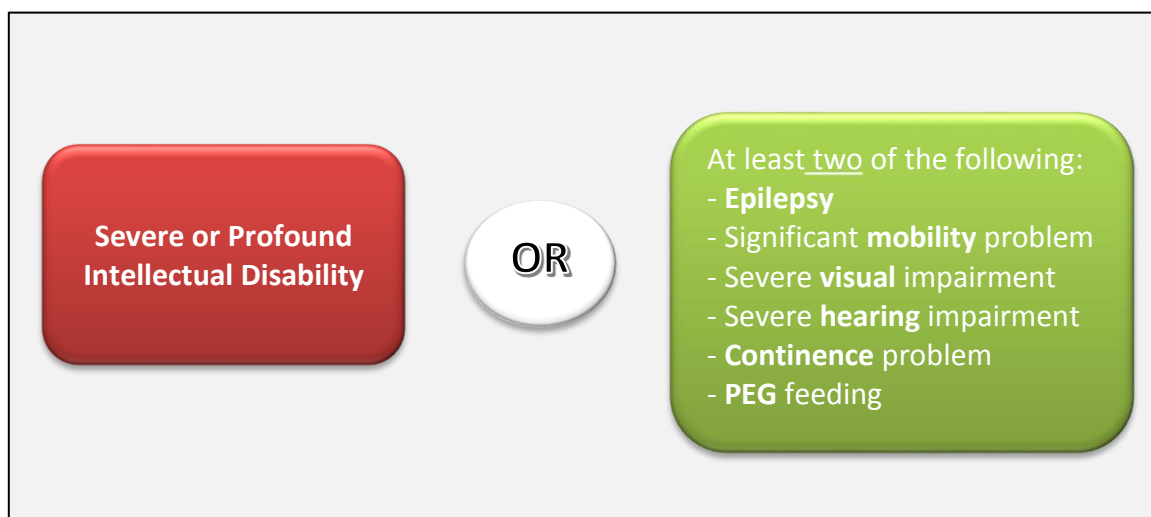
FIGURE 5: DEFINITION OF SEVERE HEALTH NEEDS USED AS A PROXY FOR SEVERITY OF ID

In the cross-sectional analyses (Chapter 3), this approach identified a total of 3,527 ID patients with severe health needs (23.9% of all ID patients). This group was made up of 1,752 patients with severe or profound ID who are automatically included, plus the additional inclusion of 686 patients with mild or moderate ID and 1,089 patients with no severity recorded on their record. The proportion with severe health needs (13.5%) among those without severity recorded on their GP record, was very similar to what was estimated from those with mild or moderate ID recorded (14.3%). This suggests that those without severity recorded, as well as being younger, have primarily mild or moderate ID.

Other sub-groups of interest

In addition to adults with ID with severe health needs, we also identified other ID sub-groups of interest: living arrangements, autism spectrum disorder and Down's syndrome.

We wanted to describe the living arrangements of our patients with ID, but were limited by the inconsistent recording of information in relation to this e.g. carer details, or whether they lived with their family. The clearest distinction we could make was to identify patients who were living in dependent settings, such as residential or nursing homes, and to compare these patients with the remainder who were not classified in this way. We could primarily do this by use of an address flag on the CPRD database, which can identify clusters of patients living at the same address. We have used this flag previously to identify elderly patients in care homes.[52] Here we assumed that the presence of 3 or more people with ID at the same address indicated communal or shared accommodation. Use of this address flag can vary by practice, so in addition we also used some specific Read codes for living arrangements (see Appendix 3) to bolster our definition.

We also stratified analyses where possible by whether the adult with ID also had a record of autism spectrum disorder, and separately by whether or not they had Down's syndrome. The Read codes for these are provided in Appendix 3.

Definition of a consultation

We defined a consultation as a unique event where the patient was seen or telephoned by a doctor or nurse. However, identifying patient consultations is not always straightforward in CPRD, as many of the administration entries on the computer system can confusingly resemble a consultation if not accounted for. Although there is a specific variable for "consultation type" it is not consistently used across practices, and cannot solely be relied on to identify consultations.

To automate a definition of consultations in CPRD, we restricted it to events on the system where the consultation type (e.g. surgery consultation) and staff member (e.g. senior partner) met our definition, excluding administrative events and repeat prescribing. For ID patients,

we also excluded consultations on days where a health check was recorded. Within the consultations we identified, we could further sub-divide into whether the consultation had been doctor or nurse led, and whether it had been face-to-face (GP surgery or home visit) or by telephone. Further details of the definition used for consultations are given in Appendix 4.

It is possible to ascertain the length of the patient consultation from within CPRD, using the recorded duration on the system. For face-to-face consultations with a doctor, we classified consultation length into standard (1-10 minutes) and long (more than 10 minutes), excluding a small number of zero length consultations. As each clinician has a unique identifier on the system, we could estimate continuity of care by calculating the highest proportion of doctor consultations with the same doctor. We used a cut-off of more than 50% to summarise continuity, so if a patient had 5 total consultations, they would need at least 3 with the same doctor to achieve this. While other indices of continuity have been proposed,[53] our summary has the advantage of being largely independent of number of consultations.

Difficulties with Hospital Episodes Statistics (HES) linkage

Of the 451 practices initially extracted by CPRD, 353 (78%) had linkage to HES data. When the linked dataset (ID adults and controls) was provided by CPRD in March 2014, the HES data was only available to 31/3/2012 due to a national postponement in linkage of all HES data during 2014-15. As our analyses had been powered for follow-up into 2013, the uncertainty over extended linkage presented a dilemma. While waiting for this issue to resolve, we were able to proceed with analyses not involving HES data. When the HES linkage to 31/3/2013 was finally performed and delivered to us in January 2015, we then had a further issue that patients from practices which dropped out from CPRD during the linkage postponement, could not have their follow-up extended. We made the decision to keep these patients in the analyses, but terminated their follow-up for hospital admissions outcome at 31/3/2012. This affected about 2.6% of total linked patients in the original extracted dataset.

Missing entity data in CPRD

During the initial data acquisition, we discovered a data extraction error that existed in the complete database held by CPRD. This had occurred between extraction of data from the general practices and the build of the CPRD database. Briefly, the Vision system used by the practices allows for more complex data entries that cannot be conveyed simply by Read codes to be held in additional data areas called "Entities". For example, the diastolic and systolic measurements for blood pressure would be held this way. For three outcome measures we were interested in (medication review, diabetic retinal screening, glomerular filtration rate), we discovered significantly lower than expected recording in CPRD, due to an unspecified historical issue with the entity data within some practices. After raising this with CPRD in the summer of 2014, it took another year to provide a potential data fix. However, the fix could only be applied to current practices, which meant they were unable to correct practices no longer contributing to CPRD. Thus our reporting of these outcomes, particularly medication review, are subject to under recording. Sensitivity analyses including only those where a fix was possible suggested this may be around 5-10%. However, even where the fix could be applied, the overall low recording of recent medication reviews left us to query the data integrity for this outcome.

Economic costs

We included a descriptive analysis of NHS costs to our study. The intention was to use the CPRD and HES data to best estimate where possible a before and after cost comparison to assess the impact of annual health checks on NHS costs, and an estimate of NHS costs for care for adults with ID compared to the general population. We did not however commit to a formal cost-effectiveness analysis as our data does not include some elements of NHS costs or social care costs which would be required for a robust cost-effectiveness analysis.

We identified several sources of external data to guide us in estimating NHS costs. Firstly, the Unit Costs of Health and Social Care produced by the Personal Social Services Research Unit (PSSRU)[54] provided us with many key primary costs, including consultations. We used the costings produced for 2012, which for example produce a guidance cost of £3.70 per minute of patient contact with a general practitioner (including qualification costs and direct care

staff costs). Duration of consultation is generally available on CPRD, and so it is possible to estimate costs using this scaling.

Secondly, prescribing costs were identified by the Prescription Cost Analysis documents produced by the Health and Social Care Information Centre.[55] This allows a net ingredient cost to be identified by drug name, form and strength, which can be linked to prescribing information on CPRD. We again used 2012 costings to estimate prescribing costs.

Finally, for hospital admissions we relied on two sources of data. Firstly, the National Schedule of Reference Costs Data for NHS trusts and NHS foundation trusts costings provided costings for all elective and non-elective hospital stays.[56] We generally relied on costings for 2011-12. These costing are coded by Healthcare Resource Groups (HRGs), which are "standard groupings of clinically similar treatments which use common levels of healthcare resource"[57] (we used HRG4). We then used the ICD-10 and OPCS codes on the HES data to translate these into HRGs using the HRG4 2011-12 reference costs Grouper software.[58]

A brief summary of the datasets and assumptions used in the economic cost estimation is given in Appendix 5**Error! Reference source not found.**.

Statistical analysis

For the cross-sectional analyses (Chapter 3) depending on the outcome being studied, we calculated prevalence, odds or relative risk ratios between ID patients and their matched controls using conditional Poisson and logistic models (StataCorp. 2013. Stata Statistical Software: Release 13. College Station, TX: StataCorp LP). The models were conditioned on the ID adult-control(s) match-sets; thus all comparisons are implicitly adjusted for matched factors: age, sex, and practice (which will factor in regional and urban–rural variations). For prevalence ratios, Poisson models were fitted with robust error variances corrections to provide reliable estimates.[59] Where the outcome was based on a sub-group defined not solely by age and sex (e.g. influenza vaccination among those with eligible co-morbidity, see Table 12), then only match-sets which included an ID adult and at least one control could be used. An exception to this was when we analysed attainment of QOF indicators (see Table 16), this approach was not feasible. As patients could not be matched in this analyses, we fitted a (non-

conditional) log binomial model adjusting for sex and age. Practice was included in the model assuming an exchangeable correlation structure. Where the outcome was number of consultations over the previous year (see Table 17), an offset for number of registered days was added to the Poisson model, to allow for patients who had been registered for less than a year. In the consultation analyses, we further adjusted for comorbidity using a weighted score of QOF conditions.[60] For analyses on consultation length and continuity, we also adjusted for total number of consultations. For cross-sectional analyses with economic cost as the outcome (see Table 20), we fitted (conditional) fixed effects negative binomial regressions to account for over-dispersion, with bias corrected confidence intervals produced from non-parametric bootstrap estimation (1,000 simulations).

For the analyses with mortality as the outcome (Chapter 4) we estimated crude death rates and hazard ratios (HRs) for comparisons between adults with ID and their matched controls. Hazard ratios were calculated via Cox regression (SAS version 9.4; SAS Institute Inc, Cary, NC), with further adjustment for: a weighted score of QOF conditions which has been shown to predict mortality in the general population,[60] smoking and socioeconomic status using the Index of Multiple Deprivation.[46] For comparisons within sub-groups (defined by the ID adult), we compared the hazard ratios and confidence intervals derived from each ID adult versus control comparison (e.g. ID adults with Down's syndrome vs controls) and calculated p-values for these between-group differences. We additionally carried out un-matched analyses focusing only on adults with ID (page 102), fitting models that directly compared each subgroup category (e.g., those with vs. without Down's syndrome), adjusting for age and gender differences and stratified according to practice.

For the analyses on hospital admissions (Chapter 5) we estimated crude admission rates for adults with ID and their matched controls. Incident rate ratios (IRR) for emergency hospitalisation were calculated using conditional Poisson models described previously, stratifying again on match-sets and similarly adjusting for co-morbidities, smoking and deprivation. For examination of primary care utilisation preceding admission, it was not possible to preserve the matching. Instead we used logistic regression to estimate an odds ratio for adults with ID vs. controls adjusting for differences in age and sex.

The analyses which investigated the impact of health checks on hospital admissions (Chapter 6) primarily used the conditional Poisson model to compare the rate of change over time at a practice or individual level. At practice level, these were conditioned on practice, and all admissions from registered ID adults in each period were counted, using an offset term to account for total time registered. The effect of practice participation on hospital admissions was estimated by the interaction between practice participation (fully vs. none) and period (2011-12 vs. 2009-10). At individual level, we conditioned on individual as opposed to match-set, as accounting for the matching variables is not paramount in matched cohort analyses.[61] This model was fitted to ID adults and controls separately, estimating the individual change in hospital admission rate after as compared to before health check, with an offset accounting for time registered. A combined model of ID adults and controls with a case-period interaction provides an estimate of the effect of health checks on admission rates among adults with ID, adjusted for temporal trends in admissions. All models used a sandwich estimator to obtain robust standard errors.

The analyses of hospital admissions in individuals with health checks also considered ID adults without health checks in two sets of sensitivity analyses to check the robustness of our findings. Firstly, using the assigned random index date (see page 29) instead of health check date, we simply repeated the analysis on this set of patients and their matched controls, to see whether any observed changes in the health check patients were also observed here. Secondly, we also considered a direct comparison of ID adults with and without health checks using Poisson and negative binomial models, with adjustment for adjusting for age, sex, and selected co-morbidities (severe health needs, epilepsy, dementia, Down's syndrome).

The analyses of health process measures were largely descriptive (Chapter 7), summarising the recorded information on patient records before and after health checks. We calculated the change in consultation and prescription rates in a period before (2006-08) and during the introduction of health checks (2009-11) using conditional Poisson regression described previously. We contrasted the change between patients with ID with and without health checks but not attempt a formal statistical comparison. Finally, we also carried out an analysis that investigated which factors predicted a health check among a subset of ID patients registered during 2009-11 in practices that were carrying out health checks. Here a logistic

model was fitted, with health check (yes/no) as the outcome and practice included in the model as a random effect.

Patient and public involvement (PPI)

Throughout the course of the study, a collaborative approach to PPI was taken[62] and we engaged two groups through regular meetings every 8-12 weeks.

- **ResearchNet** - network of service user and staff members at St George's, University of London who collaboratively undertake research to develop services and improve patient experience
- **Merton carers group** - local group of family carers of adults with an ID

The focus of these meetings initially was to identify important outcomes for our study and concerns for patients and carers. This involvement subsequently contributed to changes to the design of the study in terms of choice of outcomes, examination of potential modifying factors and help in interpreting and disseminating findings.

We have summarised some of the key issues that came out of these initial meetings with ResearchNet (Table 3) and the Merton carers group (Table 4). We tried where possible to explore many of these issues, such as the addition of dysphagia, aspiration pneumonia, constipation and anxiety as potential outcomes in our analysis. The focus on consultation length and continuity of care by health professionals as key measures of health care effectiveness were important additions to the study that ultimately strengthened some of our published research findings.[63] The groups stressed the importance of living arrangements for adults with ID (e.g. living with their family), and although the data could not adequately assess this, we were able to identify a sub-group of patients with ID who were recorded as living in shared or communal living arrangements (see page 33). However, not every issue raised by the groups could be adequately explored, due to limitations with our data.

Discussion of health checks with both groups, identified varied views on the effectiveness and acceptability of health checks and differing experiences of delivery of the health check programme. This highlighted the importance of describing process measures for the health checks, as well our main focus on changes in hospital admissions.

A paper is currently being written for publication which qualitatively explores the views and experiences of the members of the parent carer and ResearchNet groups (through group interviews) of their involvement in this research. Preliminary findings suggest almost unanimous agreement from both groups that their involvement was meaningful to them and that their participation felt genuine (see Appendix 6).

TABLE 3: FACTORS IDENTIFIED BY RESEARCHNET WHICH INFLUENCED ANALYSIS

Area	Specific Details
Prominent health issues	Constipation Depression ("problems with feelings"), Anxiety Diabetes Epilepsy Podiatry ("Feet") Hearing & Vision Hydrocephalus Lungs and breathing problems, Aspiration pneumonia Swallowing difficulties, Dysphagia Teeth
Other issues affecting health	Living arrangements (such as whether they lived with their family, whether they lived independently, whether they lived in a residential care home, supported living) were mentioned as an explanation for the variation in how many people had health checks and in accessing primary care generally.
Healthcare for patient with ID	Seeing the same doctor, your regular doctor Having long enough appointments to discuss several things Hard to make GP appointments as relying on others to make the appointment or take you to the GP
Health checks	The group identified some checks that they thought could keep you healthy in future, that should be part of health checks: BP checks, feet checks, heart checks, kidney / urine checks, blood tests, memory tests, scans and x-rays, weight measurement, smears, advice on self-examination. Some mentioned that the following had been particularly helpful to them from their health checks: Weight loss advice, help with pain, help with depression including tablets, regular medications for epilepsy or diabetes, calming tablets, help with addiction. Dislike of health check if it led to blood tests or injections but others recognised these things could be valuable and it was possible to overcome those fears. There was particular interest in the group about being able to talk about mental health issues with your doctor, particularly being anxious or depressed. Some mentioned that you needed more time to talk about these issues.

TABLE 4: FACTORS IDENTIFIED BY MERTON CARERS GROUP FOR INVESTIGATION AND ANALYSIS

Area	Specific Details
Diagnosis and management	Epilepsy diagnosis and management and quality of seizure control Identification of depression Hearing and vision problems Vitamin D deficiency and osteoporosis diagnoses in older people Later cancer diagnoses Gout and osteoarthritis Monitoring of therapy e.g. having thyroid function tests if on thyroxine
Medication	Concern over number of medications prescribed Risks of inappropriate prescribing Overuse of antipsychotic medications for behavioural problems Monitoring of epilepsy medication
Preventive care	Importance of overweight and obesity Smoking in those with less severe levels of disability Screening for hypothyroidism in some conditions e.g. Down's syndrome.
Organisation of care	Impact of place of residence (e.g. with family carer, supported independent, group home) Being able to see the same GP, length of appointments Organisation of health checks, variation in duration & place of delivery of health checks (e.g. reports as short as 10 minutes, some as long as 2 hours, some done over phone, some as home visits). What is actually covered in health checks? Content should be according to the Cardiff health check, but not always so, there was marked variation in what was covered

Chapter 3 Cross-sectional Findings

Introduction

In presenting a summary of the health and healthcare of adults with ID in primary care in England, we chose to carry out a series of cross-sectional analyses on a fixed date (1st January 2012) that would be towards the end of our study period. It also had the benefit of maximising the number of CPRD practices contributing data at that time, as some practices in our study stopped contributing data later in 2012. This date allowed a total of 408 practices to be used in the cross-sectional analyses. From these practices, a total of 14,751 patients with ID who were aged 18-84 years in 2012 are included, and these were age-sex-practice matched to 86,211 controls without ID (see Figure 2). All patients had been registered with the practice for a minimum of 30 days.

Please note that some of these results have already appeared in publication in Carey et al,[63] and are re-produced here under the terms of the Creative Commons Attribution License (CC BY-NC 3.0).

Prevalence of ID among adults in 2012

We were able to estimate the adult prevalence of recorded ID in primary care in 2012, by obtaining age-sex totals of all registered patients in CPRD on 1st January 2012. These totalled approximately 2.7 million patients aged 18-84 years from the eligible 408 practices. This allowed us to estimate that the 14,751 adults with ID aged 18 to 84 years in 2012 represent 0.54% of the total registered population for this age group. For comparative purposes, the published prevalence from QOF in for 2011-12 (effectively estimated at 31st March 2012) for all adults aged 18+ years was 0.45% (see Appendix 1) derived from all 8,123 practices in England. Thus our decision to include a wider set of Read codes for ID, and not just those used for the QOF learning disability register (see Appendix 2), increased our cohort of adults with ID by about 20%.

The estimated prevalence in the registered population of adults on 1st January 2012 differed by gender, with a higher rate seen in men (0.63%) than in women (0.45%). When the prevalence was estimated by age (in 2012), there were incremental reductions seen with

increasing years of life. Among 18-34 year olds it was 0.72%, for 35-54 year olds it was 0.59%, and for 55-84 year olds it fell to 0.34%.

There was considerable variation in the prevalence rate of ID when it was calculated in each of the 408 practices (Figure 6).
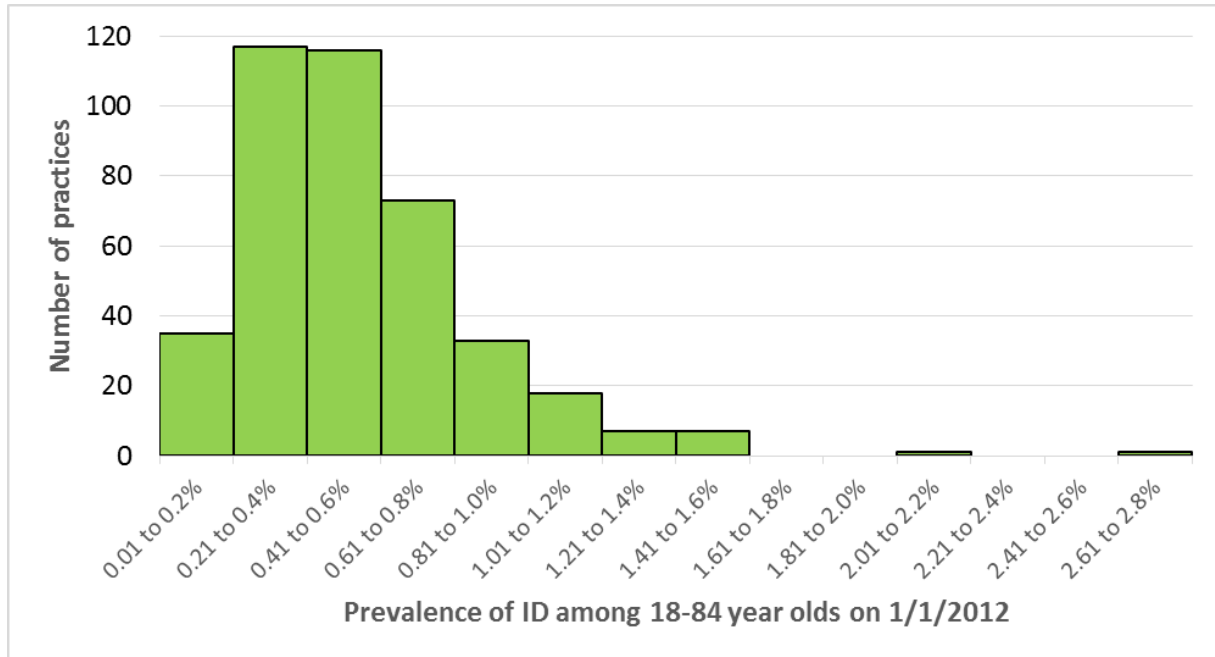
FIGURE 6: PREVALENCE OF ID BY PRACTICE IN ADULTS REGISTERED ON 1/1/2012

- Only 34 practices (8%) reported a prevalence of greater than 1 in 100 registered patients having ID recorded.
- There were two notable outliers in terms of prevalence (2.22% with 61 total ID patients, 2.68% with 114 total ID patients). More than 2 in 3 ID patients in these practices were estimated to be living in communal or shared accommodation, suggesting these practices are located near large such residences.
- While not outliers in terms of prevalence, 5 practices had more than 120 ID patients registered (n=173 with prevalence=1.07%, n=164 with prevalence=1.51%, n=139 with prevalence=0.93%, n=124 with prevalence=1.08%, n=122 with prevalence=1.56%)
- 47 practices (12%) had less than 10 registered ID patients, of which 9 practices had less than 5 ID patients.

Overall characteristics of adults with ID

The distribution of age (calculated in 2012) for the 14,751 adults with ID registered on 1/1/2012 is shown in Figure 7. The resulting distribution is different to the pattern seen in the general UK population[64] which is indicated by the red dotted line. There are two peaks (around 18-25 years and 45-50 years) which offset the dearth in the older ID population which is seen from about age 60 onwards.
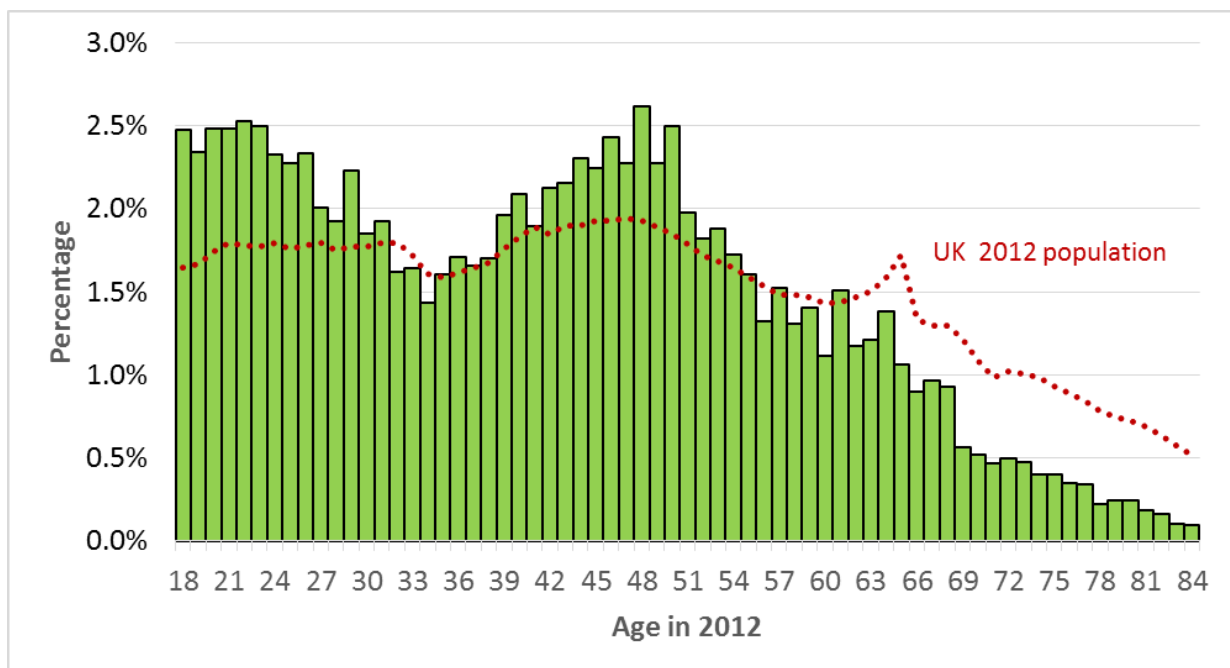
FIGURE 7: AGE DISTRIBUTION OF ID ADULTS REGISTERED ON 1/1/2012

Further characteristics of our sample of adults with ID are shown in Table 5. The average age was 42.1 years, and 58% were male. The percentage of males among adults with ID gradually fell with age, from 61% among the youngest (18-34 years) to 53% among the oldest group (55-84 years). About 3 in 4 patients had their ethnicity recorded on their primary care record, with over 90% being recorded as White. Adults with ID with a non-white ethnicity recorded were much younger (mean 34.8 years) but were small in patient numbers, and as a result we did not pursue ethnicity further as a sub-group of interest in this report. Overall, 87% of our sample were on their practices' QOF registers for learning disability.

TABLE 5: MAIN CHARACTERISTICS OF ADULTS WITH ID

Characteristic		n	% of all ID Adults	% who are men	Mean age (sd)
All		14,751	100%	57.9%	42.1 (16)
Gender	Women	6,216	42.1%	0%	43.3 (16)
	Men	8,535	57.9%	100%	41.2 (16)
Age in 2012	18-34 years	5,365	36.3%	61.2%	25.3 (5)
	35-54 years	6,041	41.0%	57.5%	44.8 (5)
	55-84 years	3,345	22.6%	53.1%	64.1 (7)
Ethnicity	White	10,192	69.1%	56.7%	43.1 (16)
	Other	921	6.2%	56.0%	34.8 (13)
	Not recorded	3,638	24.7%	61.4%	41.0 (15)
ID Sub-groups	On QOF Learning Disability register	12,862	87.2%	58.1%	42.1 (16)
	Down's syndrome	1,571	10.7%	53.9%	40.4 (13)
	Autistic spectrum disorder	1,512	10.3%	76.4%	32.5 (13)
	Has Severe Health Needs	3,527	23.9%	52.6%	44.2 (16)
	Communal/shared accommodation	3,138	21.3%	55.8%	49.3 (15)
Deprivation*	1 - Least Deprived Fifth	1,563	10.6%	58.8%	41.2 (16)
	2	2,000	13.6%	57.7%	42.9 (16)
	3	2,232	15.1%	59.5%	41.9 (16)
	4	2,764	18.7%	56.0%	42.2 (16)
	5 - Most Deprived Fifth	3,056	20.7%	57.8%	42.4 (16)
	Not available	3,136	21.3%	57.9%	41.7 (15)
Time with practice	Registered for <1 year	1,037	7.0%	55.8%	38.2 (16)
	Registered for 1-5 years	2,945	20.0%	56.8%	40.2 (16)
	Registered for 5+ years	10,769	73.0%	58.3%	43.0 (16)
Annual health check	None by 1/1/2012	7,845	53.2%	58.2%	40.3 (16)
	At least one by 1/1/2012	6,906	46.8%	57.4%	44.1 (15)

* - Deprivation was defined as IMD quintile[46]

About 1 in 10 of our adults with ID were recorded as having Down's syndrome. Similarly, 1 in 10 had an additional diagnosis of autistic spectrum disorder to their ID. These patients were markedly younger (mean= 32.5 years), and were dominated by males (76%). About a fifth of ID patients (21%) were identified as living in a communal setting, and this group was notably older (mean= 49.3 years).

Socio-economic status was approximated by Index of Multiple Deprivation (IMD) quintiles,[46] linked at postcode level to the patient's residence (linked practices only). Although there was a trend towards more adults with ID being found in increasing quintiles of IMD, representing higher deprivation, this mirrors the pattern seen in complete population extracts of CPRD,[65] and reflects a small geographical bias within CPRD where there are comparatively less practices in the north of England.[45] Almost 3 in 4 adults with ID (73%) had been registered at their practice for at least 5 years. Just under half (43%) had received an annual health check by 1st January 2012.

Disease prevalence among adults with ID

We chose to describe chronic disease prevalence by focusing on the range of conditions collated by the Quality and Outcomes Framework.[66] For most of these we used version 26 of the business rules, which were in operation circa 2012-3. These identify the set of read codes used in definitions, and for the most part stay consistent from year to year. For each condition, we searched for the presence of any read code in the medical record up to 1st January 2012 to allow the description of prevalence. For cancer and depression, we firstly describe lifetime prevalence, but also include date specific period prevalence in line with the QOF definition. For asthma, epilepsy, and hypothyroidism, in line with the QOF definitions, a recent prescription was also required to give a measure of period prevalence. Severe mental illness was subdivided into schizophrenia and affective disorder. We also included additional conditions of anxiety and dysphagia.

Table 6 summarises disease prevalence for adults with ID compared to their controls using prevalence ratios (PR). These were calculated using conditional Poisson models (see Statistical analysis, page 36) which take account for the matched design.

TABLE 6: PREVALENCE OF CHRONIC DISEASE IN ID ADULTS VERSUS CONTROLS ON 1/1/2012

Disease	ID (n=14,751)		Controls (n=86,221)		ID vs. Controls Prevalence Ratio
	n	%	n	%	PR (95% CI)
Anxiety	2,398	**16.3%**	12,580	**14.6%**	**1.13** (1.09-1.18)
Asthma†	1,208	**8.2%**	5,717	**6.6%**	**1.25** (1.18-1.33)
Atrial fibrillation	122	**0.8%**	821	**1.0%**	**0.91** (0.75-1.09)
Cancer‡	238	**1.6%**	2,090	**2.4%**	**0.70** (0.61-0.80)
- Diagnosis since 1/4/03	156	**1.1%**	1,490	**1.7%**	**0.65** (0.55-0.76)
Chronic kidney disease	468	**3.2%**	1,746	**2.1%**	**1.64** (1.49-1.82)
COPD	160	**1.1%**	1,184	**1.4%**	**0.84** (0.71-0.99)
Dementia	160	**1.1%**	134	**0.2%**	**7.52** (5.95-9.49)
Depression‡	2,609	**17.7%**	15,179	**17.6%**	**1.03** (0.99-1.06)
- Diagnosis since 1/4/06	1,626	**11.0%**	9,520	**11.0%**	**1.01** (0.96-1.06)
- Diagnosis in last year	237	**1.6%**	1,723	**2.0%**	**0.80** (0.70-0.92)
Diabetes	1,017	**6.9%**	3,786	**4.4%**	**1.64** (1.53-1.75)
Dysphagia	692	**4.7%**	1,263	**1.5%**	**3.30** (3.01-3.61)
Epilepsy†	2,731	**18.5%**	633	**0.7%**	**25.33** (23.29-27.57)
Heart failure	121	**0.8%**	324	**0.4%**	**2.26** (1.84-2.78)
Hypertension	1,583	**10.7%**	10,416	**12.1%**	**0.93** (0.89-0.98)
Hypothyroidism†	1,169	**7.9%**	2,649	**3.1%**	**2.69** (2.52-2.87)
Ischaemic heart disease	244	**1.7%**	2,316	**2.7%**	**0.65** (0.57-0.74)
Osteoporosis	246	**1.7%**	822	**1.0%**	**1.84** (1.60-2.12)
Peripheral vascular disease	61	**0.4%**	423	**0.5%**	**0.90** (0.69-1.17)
Rheumatoid arthritis	73	**0.5%**	550	**0.6%**	**0.82** (0.65-1.05)
Severe mental Illness	1,266	**8.6%**	823	**1.0%**	**9.10** (8.34-9.92)
- Schizophrenia	995	**6.8%**	591	**0.7%**	**9.94** (8.99-10.99)
- Affective Disorder	371	**2.5%**	333	**0.4%**	**6.66** (5.73-7.73)
Stroke & TIA	267	**1.8%**	944	**1.1%**	**1.74** (1.52-1.98)

† - Also require recent medication as per QOF definition[66]

‡ - Cancer and depression were summarised as diagnoses ever. QOF definitions only count diagnoses from 2003 for cancer) and 2006 for depression[66]

Almost 1 in 5 adults with ID were recorded with epilepsy that is currently managed (18.5%), compared to less than 1 in 100 adults without LD (0.7%). This represents a prevalence rate 25 times higher than controls (PR=25.3, 95%CI 23.3-27.6). Other large relative differences in prevalence were seen for severe mental illness (8.6% of adults with ID, PR=9.1, 95% CI 8.3-9.9) and dementia (1.1% of adults with ID, PR=7.5, 95%CI 6.0-9.5). Adults with ID had a moderately increased risk of dysphagia, hypothyroidism and heart failure (PR between 2 and 3.5) compared to the general population. Also significantly higher in adults with ID (PR between 1.5 and 2), were osteoporosis, stroke, diabetes and chronic kidney disease.

Not all recorded disease prevalence was higher in adults with ID. Recorded lifetime prevalence of IHD (PR=0.65, 95% CI 0.57-0.74) and cancer (PR=0.70, 95% CI 0.61-0.80) were both significantly lower than that seen in the general population. While a record of depression was equally likely in adults with ID, when only diagnoses in the last year were considered, adults with ID were 20% less likely to have one recorded in their record (PR=0.80, 95% CI 0.70-0.92).

Figure 8 displays a mean count of all QOF conditions from Table 6 (excluding Anxiety and Dysphagia which are not counted by QOF) in adults with ID and controls. The disparity between the groups is already evident at age 18, where the mean count is approximately 3 times higher among adults with ID (0.31 vs 0.11). The higher burden of co-morbidity persists through middle age, but after about age 65, the two lines in Figure 8 start to quickly converge. Co-morbidity levels were then more similar between adults with ID and matched controls in their 70's. Among the few adults with ID in their 80's in our study (n=116), levels of co-morbidity were lower than their matched controls.
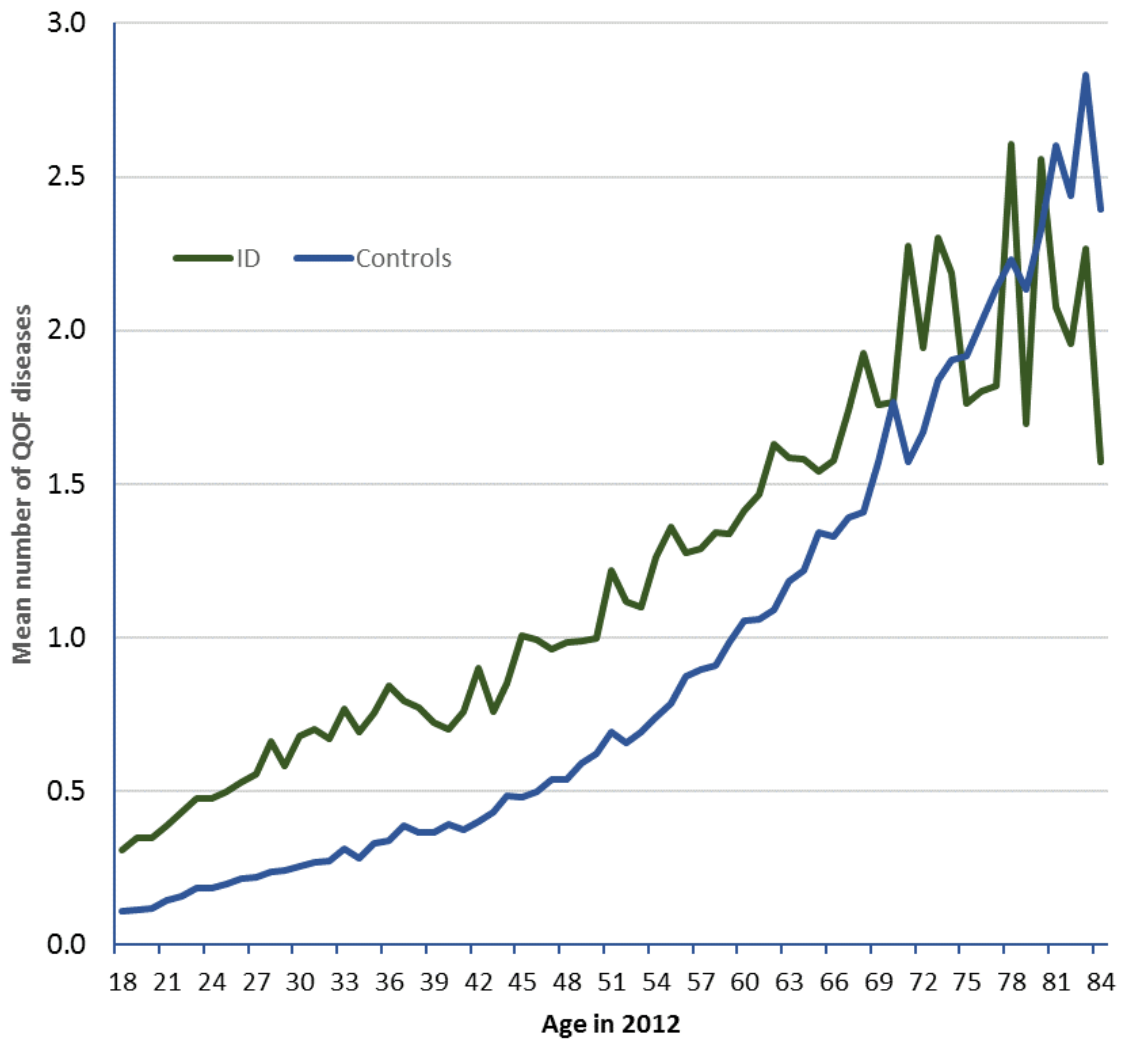
FIGURE 8: MEAN NUMBER OF QOF CONDITIONS BY AGE IN ID ADULTS AND CONTROLS

Disease prevalence in sub-groups

When the prevalence comparisons with the general population were made by age group (Table 7) there were some interesting observations. Both cancer and IHD which were lower overall in adults with ID, were both significantly higher (PR=2.0 for cancer, PR=2.7 for IHD) when only the youngest ages (18-34 years) were considered. In general, most of the observed differences overall were much greater for the youngest group, with epilepsy 40 times greater. Heart failure (PR=12.1), osteoporosis (PR=10.1), hypothyroidism (PR=7.6) and chronic kidney disease (PR=5.9) all also showed much greater disparities within this age group. The exception to this trend with age was severe mental illness, where the disparity between adults with ID and the general population increased with age. Among the oldest age group (55-84 years), only epilepsy (PR=18) and severe mental illness (PR=12) were more than twice as prevalent within adults with ID compared to controls.

Within adults with ID, there were some differences in disease prevalence by gender (Figure 9). Generally, females had higher recorded disease than males. For example, there were higher rates in women for hypothyroidism (12.4% vs. 4.7%), chronic kidney disease (4.5% vs. 2.2%), cancer (2.2% vs. 1.2%) and a recording of depression ever (22.0% vs. 14.6%). In men, the only condition notably higher was IHD (1.9% vs. 1.3%).

Disease prevalence by severity of ID where recorded is summarised in Figure 10. More than a third of adults with severe or profound ID (36.2%) had epilepsy, compared to about 1 in 6 for mild or moderate ID (16.%). Compared to their general population controls, adults with severe or profound ID were 50 times more likely to have epilepsy (PR=50.4, 95% CI 39.9-63.8). Dysphagia was recorded in about 1 in 9 adults with severe or profound ID (11.0%). However most other conditions were lower in severe or profound ID, such as anxiety (9.4%), depression (9.6%), diabetes (4.5%), hypertension (6.9%) and severe mental illness (5.9%). Compared to their general population controls, adults with severe or profound ID were 4 times less likely to have a diagnosis of depression recorded in the last year (PR=0.26, 95% CI 0.14-0.49).

TABLE 7: PREVALENCE OF CHRONIC DISEASE IN ID ADULTS VERSUS CONTROLS BY AGE

Disease	Age 18-34y		Age 35-54y		Age 55-84y	
	% ID adults	PR (95% CI)	% ID adults	PR (95% CI)	% ID adults	PR (95% CI)
Anxiety	12.8%	**1.32** (1.23-1.44)	19.1%	**1.15** (1.09-1.21)	16.8%	**0.95** (0.87-1.03)
Asthma†	8.2%	**1.50** (1.36-1.66)	8.4%	**1.24** (1.13-1.36)	7.8%	**1.00** (0.88-1.13)
Atrial fibrillation	0.1%	**3.40** (1.00-11.48)	0.5%	**1.33** (0.89-1.99)	2.7%	**0.80** (0.64-0.99)
Cancer	0.5%	**1.98** (1.29-3.03)	1.1%	**0.69** (0.54-0.89)	4.3%	**0.62** (0.53-0.74)
Chronic kidney disease	0.3%	**5.85** (2.74-12.49)	2.1%	**3.55** (2.85-4.44)	9.8%	**1.32** (1.18-1.49)
COPD	0.02%	**2.61** (0.21-33.01)	0.8%	**1.48** (1.08-2.03)	3.3%	**0.70** (0.58-0.85)
Depression	11.6%	**1.05** (0.97-1.14)	20.9%	**1.01** (0.96-1.06)	21.7%	**1.04** (0.97-1.12)
Depression (last year)	1.9%	**0.91** (0.73-1.12)	1.6%	**0.73** (0.59-0.90)	1.2%	**0.78** (0.56-1.08)
Diabetes	2.1%	**3.26** (2.58-4.10)	6.6%	**1.88** (1.68-2.10)	15.2%	**1.36** (1.24-1.48)
Dysphagia	2.8%	**5.85** (4.64-7.37)	4.4%	**3.28** (2.84-3.80)	8.3%	**2.70** (2.36-3.10)
Epilepsy†	17.2%	**39.99** (33.26-48.06)	19.9%	**24.31** (21.48-27.52)	18.1%	**17.97** (15.44-20.92)
Heart failure	0.5%	**12.05** (5.86-24.81)	0.4%	**3.98** (2.38-6.65)	2.2%	**1.60** (1.24-2.07)
Hypertension	1.5%	**3.25** (2.46-4.29)	9.1%	**1.11** (1.02-1.21)	28.6%	**0.81** (0.77-0.86)
Hypo-thyroidism†	4.3%	**7.56** (6.18-9.25)	9.2%	**3.15** (2.86-3.47)	11.5%	**1.72** (1.55-1.91)
IHD	0.1%	**2.68** (0.91-7.89)	0.8%	**0.74** (0.55-0.99)	5.6%	**0.62** (0.54-0.72)
Osteoporosis	0.6%	**10.07** (5.57-18.22)	1.1%	**3.72** (2.77-5.01)	4.3%	**1.29** (1.08-1.54)
Rheumatoid arthritis	0.2%	**2.23** (1.02-4.89)	0.5%	**1.02** (0.70-1.50)	1.0%	**0.62** (0.43-0.88)
Severe mental Illness	4.3%	**7.10** (5.84-8.64)	9.4%	**8.12** (7.18-9.19)	13.9%	**12.37** (10.61-14.41)
Stroke & TIA	3.2%	**4.47** (2.33-8.53)	7.6%	**2.42** (1.81-3.22)	10.9%	**1.50** (1.29-1.76)

† - Also require recent medication as per QOF definition.
Note that dementia and peripheral vascular disease are dropped from the analysis as there were too few cases in the under 55's.
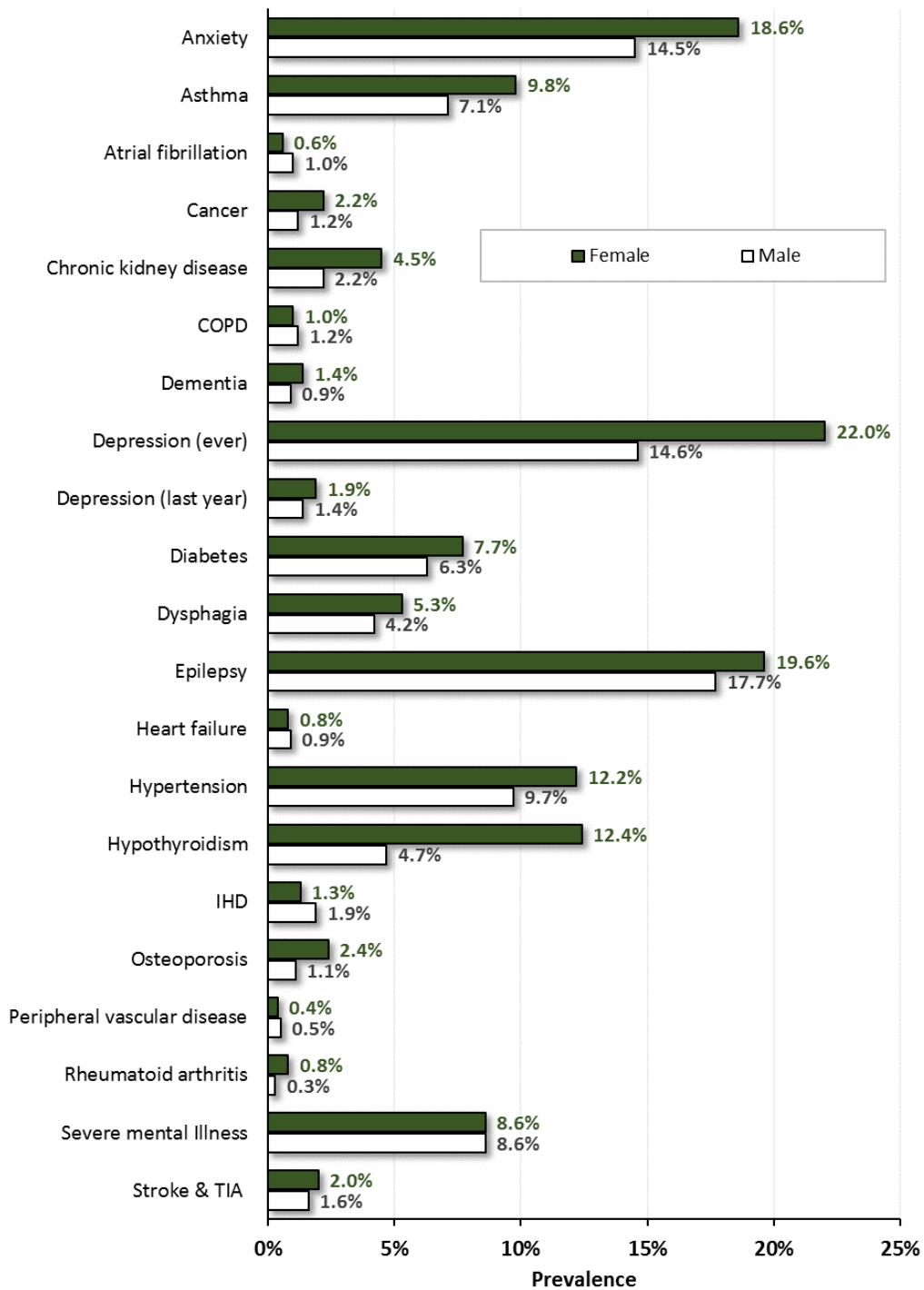
FIGURE 9: PREVALENCE OF CHRONIC DISEASE IN ID ADULTS BY GENDER
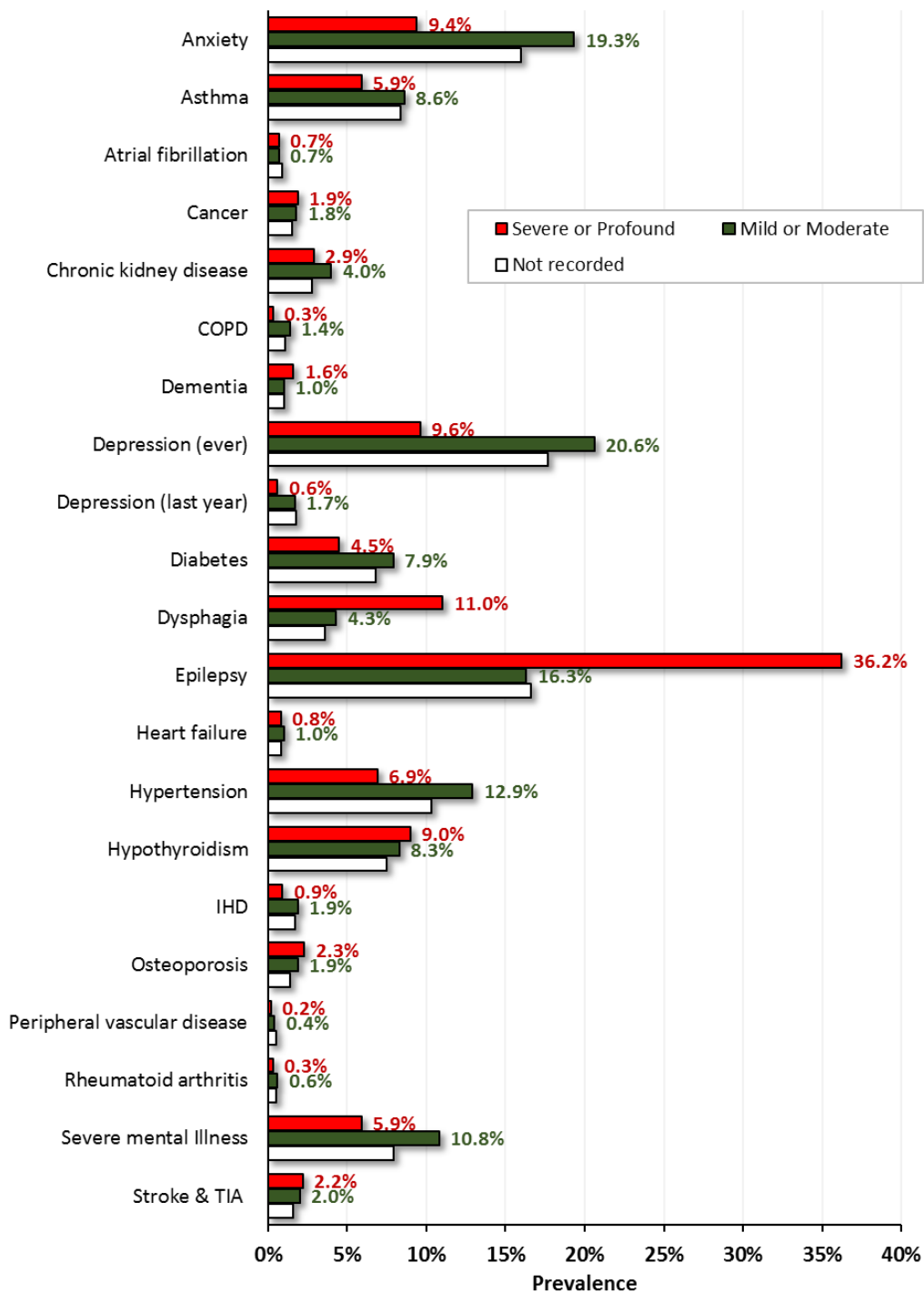
FIGURE 10: PREVALENCE OF CHRONIC DISEASE IN ID ADULTS BY RECORDED SEVERITY

Among adults with ID identified as living in communal settings there were variations in disease prevalence (Figure 11). Epilepsy (27.8%), severe mental illness (12.6%), hypothyroidism (11.5%), dysphagia (8.4%), dementia (2.9%) and stroke (3.4%) were all higher. However,

anxiety (13.2%), currently treated asthma (5.3%) and depression diagnosed in the last year (0.7%) were all lower.
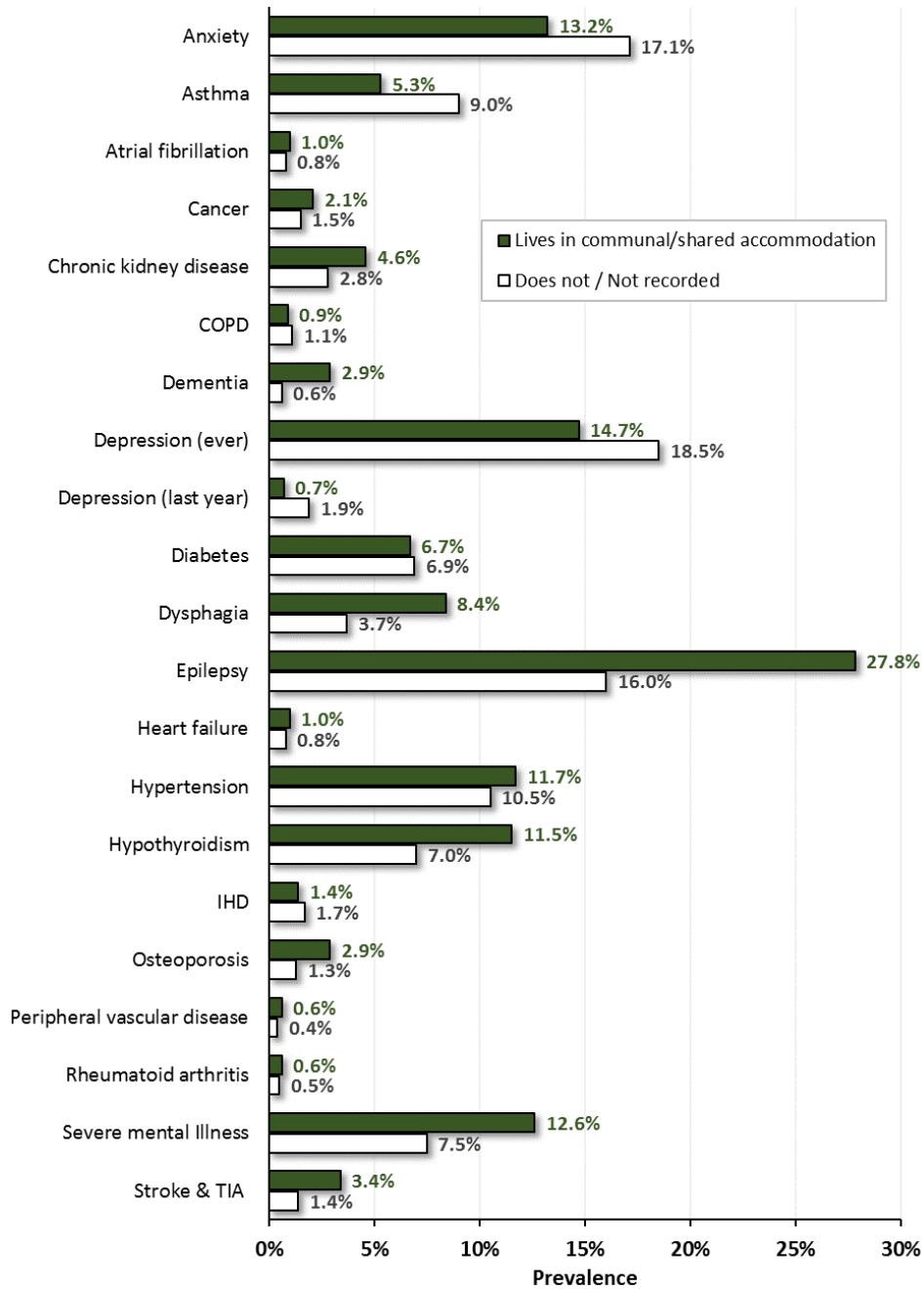
FIGURE 11: PREVALENCE OF CHRONIC DISEASE IN ID ADULTS BY LIVING ARRANGEMENTS

Among ID adults with Down's syndrome (Figure 12) the prevalence of hypothyroidism (31.9%), dysphagia (6.1%), dementia (5.8%) and heart failure (1.6%) were all higher. However most recorded chronic disease was lower, for example COPD (0.1%), diabetes (4.8%), epilepsy (6.8%), depression ever (8.7%), hypertension (1.7%) and severe mental illness (1.9%).
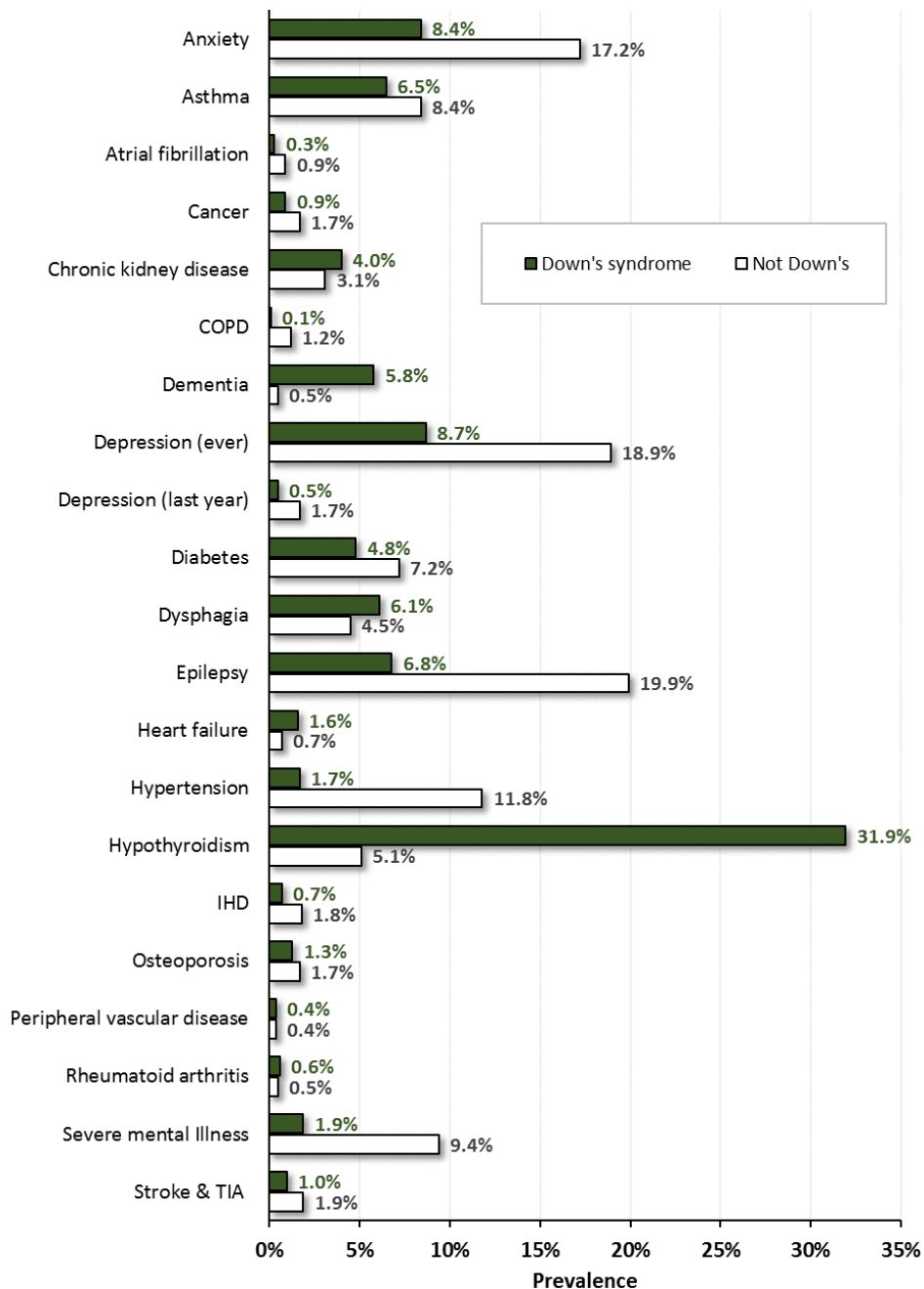
FIGURE 12: PREVALENCE OF CHRONIC DISEASE IN ID ADULTS BY DOWN'S SYNDROME

Finally, for disease prevalence among adults with ID only, we present in Table 8 a series of prevalence ratios for each condition mutually adjusted for all the sub-groups of interest (gender, severity, communal accommodation, Down's syndrome, autism) and age. Many of the patterns observed in the previous figures persist.

Women with ID were more likely to have many of these conditions recorded, with the greatest relative disparities observed for rheumatoid arthritis (PR=2.8), hypothyroidism (PR=2.4), osteoporosis (PR=1.9), chronic kidney disease (PR=1.7) and cancer (PR=1.5). Men on the other hand were only significantly more likely to have IHD and atrial fibrillation recorded (both PR=0.5).

Adults with severe or profound ID had lower recording of many conditions compared to those with mild or moderate patients. For example, both IHD and severe mental illness were half as likely to be recorded in this group (PR=0.5). Notable exceptions to this trend were dysphagia (PR=2.3) and epilepsy (PR=2.1), which were much higher in severe or profound ID patients.

Adults with ID living in communal or shared accommodation had much higher recording of several conditions, even after adjustment for age and severity. These included stroke (PR=2.5), dementia (PR=2.1) and severe mental illness (PR=1.8). However, some conditions were surprisingly lower e.g. IHD (PR=0.4). As expected, the large disparities seen for dementia (PR=19.3), hypothyroidism (PR=6.5) and heart failure (PR=2.9) for patients with Down's syndrome remained after adjustment. Patients with ID and autism spectrum disorder generally had lower recording of all conditions, the lone exception in Table 8 being Anxiety (PR=1.4).

TABLE 8: ADJUSTED CHRONIC DISEASE PREVALENCE RATIOS BY SUB-GROUPS IN ID ADULTS

Disease	Female vs. Male	Severe/ Profound vs. Mild/Moderate	Communal Accommodation vs. Not	Down's Syndrome vs. Not	Autism Spectrum Disorder vs. Not
	PR‡ (95% CI)	PR‡ (95% CI)	PR‡ (95% CI)	PR‡ (95% CI)	PR‡ (95% CI)
Anxiety	1.31 (1.22-1.40)	0.51 (0.43-0.60)	0.74 (0.65-0.86)	0.53 (0.44-0.62)	1.39 (1.23-1.58)
Asthma†	1.36 (1.22-1.52)	0.78 (0.64-0.96)	0.62 (0.52-0.73)	0.76 (0.62-0.93)	0.64 (0.49-0.84)
Atrial fibrillation	0.54 (0.37-0.79)	1.02 (0.51-2.07)	0.71 (0.45-1.12)	0.59 (0.24-1.41)	0.55 (0.19-1.60)
Cancer	1.59 (1.24-2.04)	1.11 (0.75-1.64)	0.86 (0.65-1.16)	0.65 (0.38-1.11)	0.94 (0.51-1.74)
Chronic kidney disease	1.72 (1.45-2.04)	0.73 (0.53-1.00)	0.91 (0.75-1.09)	1.83 (1.40-2.39)	0.51 (0.26-1.00)
COPD	0.73 (0.53-1.00)	0.24 (0.10-0.59)	0.48 (0.33-0.70)	0.18 (0.04-0.70)	0.62 (0.24-1.61)
Dementia	1.21 (0.89-1.63)	1.16 (0.68-1.98)	2.10 (1.50-2.96)	19.25 (13.64-27.15)	0.30 (0.04-2.13)
Depression	1.49 (1.38-1.59)	0.50 (0.43-0.59)	0.73 (0.64-0.83)	0.49 (0.42-0.58)	1.07 (0.93-1.22)
Diabetes	1.09 (0.97-1.23)	0.64 (0.50-0.82)	0.69 (0.59-0.81)	0.81 (0.65-1.02)	0.68 (0.50-0.92)
Dysphagia	1.15 (0.98-1.34)	2.32 (1.68-3.20)	1.54 (1.20-1.98)	1.32 (1.06-1.64)	0.79 (0.58-1.09)
Epilepsy†	1.09 (1.02-1.16)	2.08 (1.89-2.30)	1.60 (1.46-1.75)	0.32 (0.26-0.39)	0.84 (0.74-0.95)
Heart failure	0.78 (0.54-1.12)	0.82 (0.46-1.48)	0.80 (0.53-1.21)	2.87 (1.92-4.30)	0.83 (0.33-2.11)
Hypertension	1.10 (1.00-1.21)	0.60 (0.50-0.72)	0.75 (0.66-0.84)	0.19 (0.13-0.27)	0.55 (0.42-0.73)
Hypo-thyroidism†	2.35 (2.10-2.62)	0.93 (0.78-1.11)	1.18 (1.04-1.34)	6.50 (5.81-7.25)	0.81 (0.59-1.10)
IHD	0.54 (0.43-0.69)	0.56 (0.33-0.97)	0.44 (0.31-0.62)	0.70 (0.39-1.26)	0.41 (0.15-1.11)
Osteoporosis	1.86 (1.44-2.39)	1.22 (0.84-1.76)	1.39 (1.05-1.83)	0.82 (0.53-1.26)	0.46 (0.22-0.95)
Peripheral vascular dis.	0.79 (0.47-1.33)	0.45 (0.14-1.42)	1.85 (1.06-3.24)	0.85 (0.38-1.90)	0.44 (0.14-1.38)
Rheumatoid arthritis	2.79 (1.75-4.45)	0.60 (0.26-1.40)	0.87 (0.55-1.39)	1.31 (0.66-2.59)	0.27 (0.03-2.05)
Severe mental Illness	1.02 (0.92-1.13)	0.49 (0.39-0.61)	1.81 (1.56-2.10)	0.19 (0.13-0.28)	1.06 (0.89-1.26)
Stroke & TIA	1.15 (0.88-1.50)	0.98 (0.66-1.45)	2.53 (1.98-3.24)	0.47 (0.29-0.76)	0.27 (0.14-0.52)

‡ - All characteristics mutually adjusted for each other, and adjusted for age
† - Also require recent medication as per QOF definition.

Co-morbidity – QOF conditions vs. the Charlson index

To further investigate the burden of chronic disease among adults with ID, and to compare this with the general population, we compared three different approaches (Table 9). Firstly, we took a frequency count of the conditions from Table 6 that are in QOF (this excludes anxiety and dysphagia). We compared this with a co-morbidity score based on QOF conditions, which was developed using UK primary care data, and uses 9 conditions in total.[60] Finally, we used the Charlson index, a well-known and widely used predictor of mortality, which was developed in the US in the 1980s and incorporates 17 common chronic conditions.[67]

TABLE 9: CHARLSON INDEX, QOF CONDITIONS AND SCORE IN ID ADULTS VERSUS CONTROLS

	ID (n=14,751)		Controls (n=86,221)		ID vs. Controls Prevalence Ratio
	n	%	n	%	PR (95%CI)
Number of QOF Diseases*					
- 0	6,320	**42.8%**	53,856	**62.5%**	
- 1	5,056	**34.3%**	20,901	**24.2%**	
- 2	2,138	**14.5%**	7,174	**8.3%**	
- 3 or more	1,237	**8.4%**	4,290	**5.0%**	
- 2 or more vs. 0-1					**1.80** (1.74-1.86)
QOF Score†					
- 0	9,643	**65.3%**	77,050	**89.4%**	
- 1 to 2	4,131	**28.0%**	6,384	**7.4%**	
- 3 or more	977	**6.6%**	2,787	**3.2%**	
- Mean score of ≥1 vs. 0					**3.35** (3.25-3.45)
Charlson Index‡					
- 0	10,323	**70.0%**	63,561	**73.7%**	
- 1 to 2	3,803	**25.8%**	20,090	**23.3%**	
- 3 or more	625	**4.2%**	2,570	**3.0%**	
- Mean score of ≥1 vs. 0					**1.16** (1.12-1.19)

* - Frequency count of all the QOF diseases listed in Table 6 except Anxiety and Dysphagia.
† - Scoring system: Atrial Fibrillation (1), Diabetes (1), Stroke & TIA (1), Epilepsy (2), Heart Failure (2), Psychosis, schizophrenia + bipolar affective disorder (2), COPD (2), Cancer (3), Dementia (3).
‡ - Scoring system: COPD (1), Dementia (1), Diabetes without complications (1), Heart Failure (1), Mild liver disease (1), Myocardial infarction (1), Peptic ulcer disease (1), Peripheral vascular disease (1), Rheumatological disease (1), Stroke & TIA (1), Non-metastatic cancer (2), Diabetes with complications (2), Hemiplegia (2), Renal disease (2), Moderate liver disease (3), AIDS (6), Metastatic cancer (6).

Adults with ID had more multi-morbidity (2 or more recorded QOF conditions from Table 6), with 22.9% compared to 13.3% of the control group (PR=1.80, 95% CI 1.74-1.86). When the Charlson index and the QOF co-morbidity score were compared there was a difference in how the two populations (adults with and without ID) were categorised. Adults with ID were more than 3 times as likely to have a QOF score of 1 or more (34.7% vs. 10.6%, PR=3.35, 95% CI 3.25-3.45), whereas the proportions having an estimated Charlson index of 1 or more was much more similar between groups (30.0% vs 26.3%, PR=1.16, 95% 1.12-1.19). The difference between the performance of the two scores is primarily due to the inclusion of epilepsy and severe mental illness within the QOF score, but not within the Charlson index. This suggests that the Charlson index may not be a comprehensive summary of co-morbidity within the ID population, and as a result, a poorer predictor of mortality for this sub-group.

The mean QOF co-morbidity score among adults with ID was 0.76 (SD=1.18) compared to 0.21 (SD=0.71) for the control group. Figure 13 further summarises the mean QOF co-morbidity scores by selected sub-groups. The greatest disparity between ID adults and controls was seen among the youngest age group (0.48 vs. 0.04), primarily due to epilepsy. ID adults with Down's syndrome had less co-morbidity than ID adults without Down's, but this may be partly explained by their younger overall age in our sample (Table 5). Adults with ID living in communal establishments, or with severe health needs, had mean scores roughly twice as high as adults with ID not designated as such. While there was a small trend of more co-morbidity with deprivation in the control population, no such trend existed within the ID population. This suggests that our socio-economic status (the IMD based on residential postcode) behaves differently within the ID population, and may not predict morbidity and mortality in the same way as in the general population.
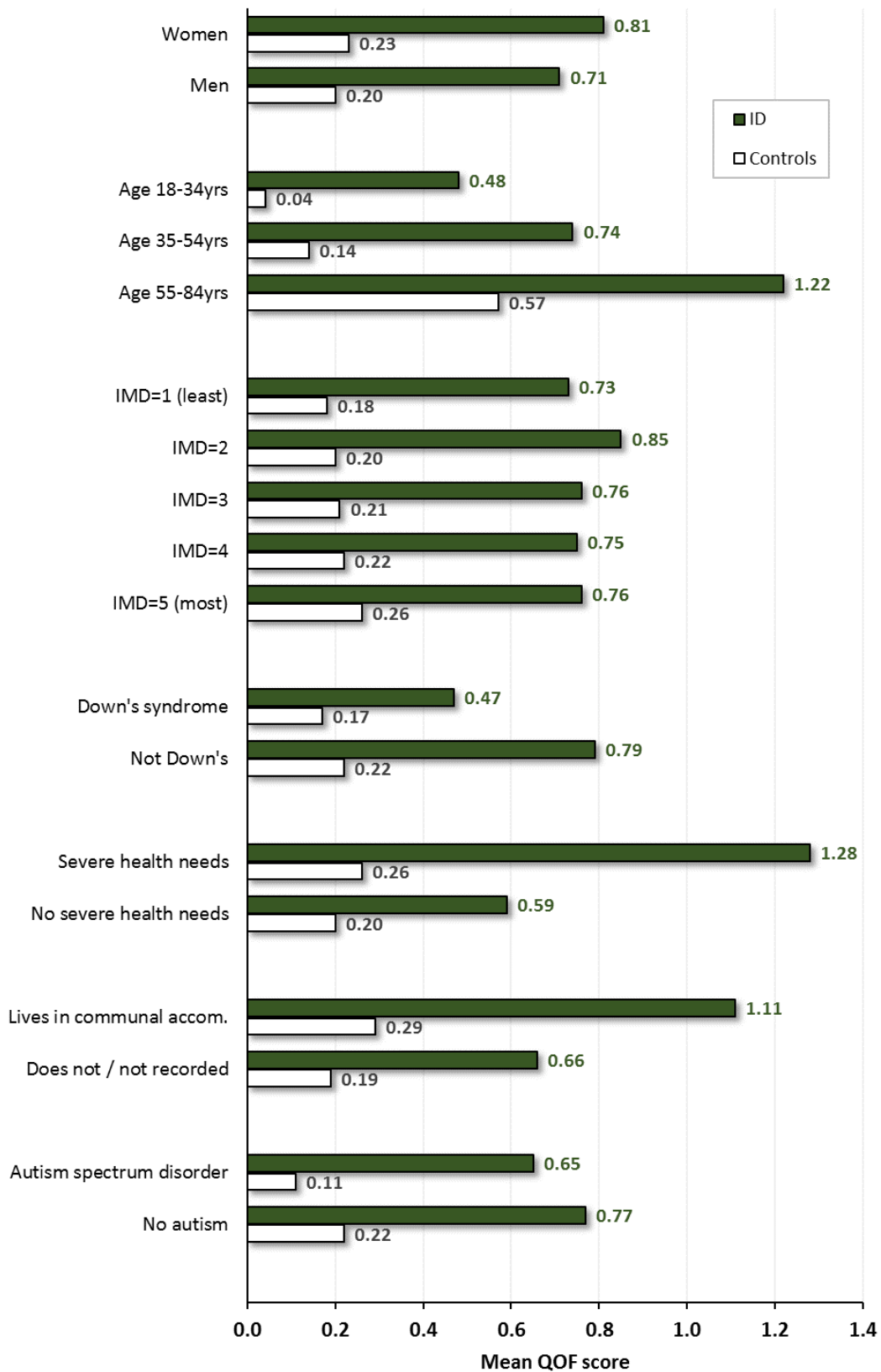
FIGURE 13: MEAN QOF CO-MORBIDITY SCORE IN ID ADULTS AND CONTROLS BY SUBGROUPS

Recording of disability and other problems

We investigated the recording of selected disability (mobility problems, vision loss, hearing impairment) and other problems (continence, constipation, behavioural) in the patient record for adults with ID compared to the control group, summarised by prevalence ratios (Table 10). Further adjustment of these ratios for differences in co-morbidity between the groups made little difference and did not explain the findings (data not shown), so we only present the unadjusted prevalence ratios in Table 10 .

TABLE 10: PREVALENCE OF DISABILITY AND OTHER PROBLEMS IN ID ADULTS VERSUS CONTROLS

Recorded Disability / Problem	ID (n=14,751)		Controls (n=86,221)		ID vs. Controls Prevalence Ratio
	n	%	n	%	PR (95% CI)
Mobility					
- Recorded ever	6,111	**41.4%**	753	**0.9%**	**47.58** (43.63-51.88)
- Some difficulty	1,677	**11.4%**	418	**0.5%**	**24.02** (21.53-26.79)
Vision					
- Bilateral visual loss or low vision	687	**4.7%**	510	**0.6%**	**7.86** (7.01-8.82)
Continence (age ≥12 years)					
- Recorded ever	3,017	**20.5%**	3,199	**3.7%**	**5.68** (5.41-5.96)
- Bowel problem	579	**3.9%**	240	**0.3%**	**14.43** (12.39-16.80)
- Urinary problem	1,755	**11.9%**	2,663	**3.1%**	**4.00** (3.77-4.23)
Hearing					
- Recorded ever	7,361	**49.9%**	9,403	**10.9%**	**4.58** (4.47-4.71)
- Impairment	2,752	**18.7%**	7,111	**8.3%**	**2.28** (2.19-2.37)
- Deaf	1,220	**8.3%**	2,784	**3.2%**	**2.59** (2.42-2.76)
Behavioural Problems					
- Last Year	564	**3.8%**	155	**0.2%**	**21.34** (17.86-25.50)
- Last 5 Years	2,072	**14.1%**	742	**0.9%**	**16.28** (14.97-17.71)
Constipation					
- Ever	3,370	**22.9%**	7,135	**8.3%**	**2.78** (2.68-2.88)

About 4 in 10 adults with ID (41.4%) had some recording of mobility status in their record, with about 1 in 10 overall (11.4%) reporting some form of difficulty recorded including use of

an aid or wheelchair. By comparison, a record of mobility (0.9%), or a mobility problem (0.5%) was rare in the matched control group. Thus, compared to adults of the same age and sex, those with ID were 24 times (PR=24.0, 95% CI 21.5-26.8) to have a recorded mobility disability or problem.

A recording of low or loss of vision was found in 1 in 20 adults with ID (4.7%), almost 8 times as likely (PR=7.9, 95% CI 7.0-8.8) than that recorded in the control group (0.6%). A hearing impairment was recorded in about 1 in 5 adults with ID (18.7%), which was twice as likely (PR=2.3, 95% CI 2.2-2.4) as that seen for controls (8.3%).

An incontinence problem (beyond age 12) was recorded in about 1 in 5 adults with ID (20.5%), over 5 times more likely (PR=5.7, 95% CI 5.4-6.0) than that seen for controls (3.7%). Where the incontinence was specified in the adult with ID, it was more likely to be recorded as a urinary problem (11.9%) rather than a bowel problem (3.9%). However, when compared to the control group, bowel problems (PR=14.4, 95% CI 12.4-16.8) were relatively more likely to be recorded for adults with ID rather than a urinary problem (PR=4.0, 95% CI 3.8-4.2). A record of constipation ever was about 3 times more likely among adults with ID (22.9% vs 8.3%, PR=2.8 95% CI 2.7-2.9).

Behavioural problems were far more commonly recorded for adults with ID, with 14.1% having one recorded in the last 5 years, and 3.8% in the last year. Less than 1% of controls had a behavioural problem recorded in the last 5 years.

There were some differences by gender in the recording of disability and other problems among adults with ID (Figure 14). Mobility problems were more common in women than men (14.1% vs. 9.4%). Among women, a record of a continence problem (24.7%), particularly urinary (16.1%) was also higher, along with constipation (27.5%). Hearing problems, visual loss and behavioural problems were much more similar between men and women with ID.
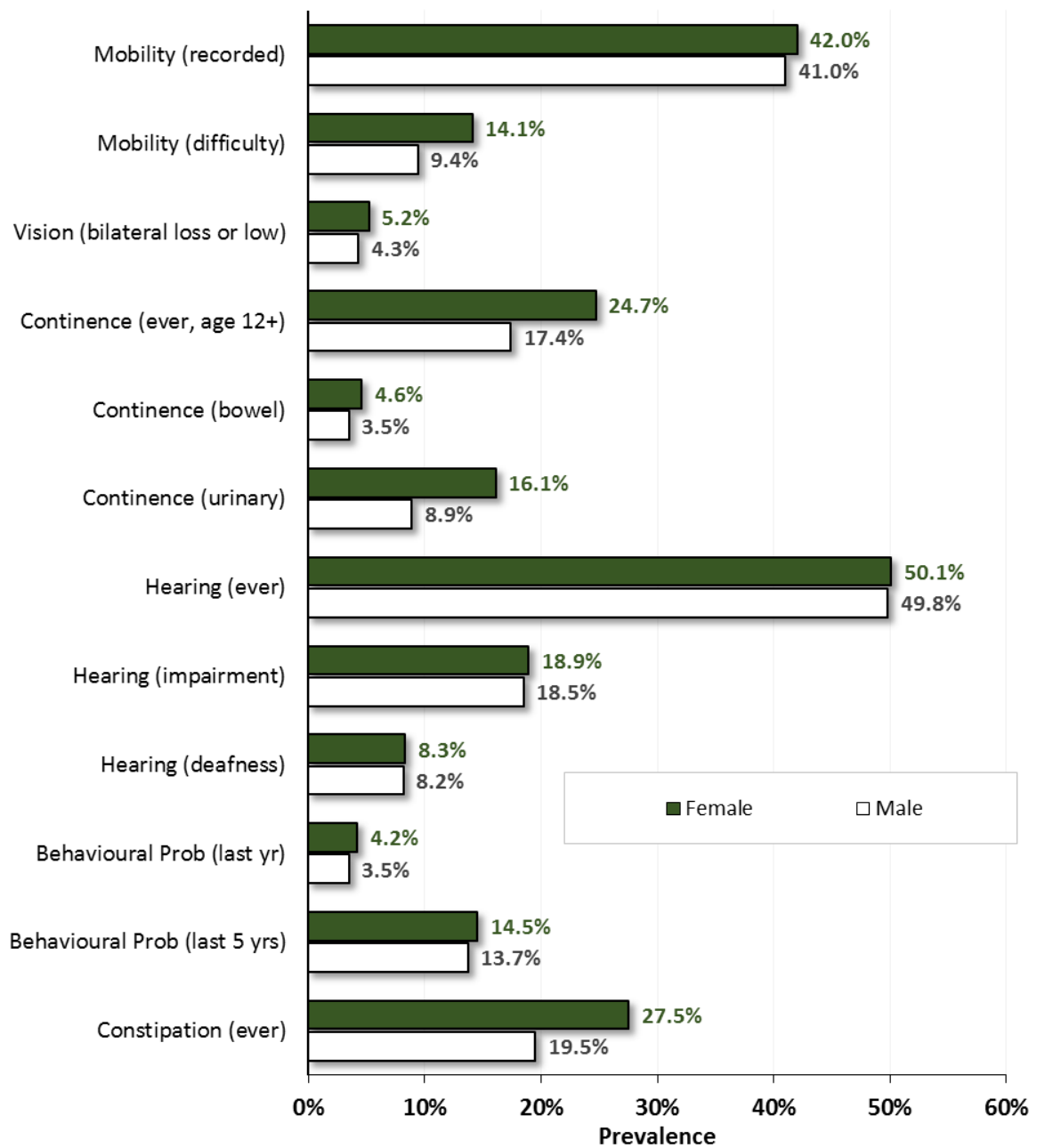
FIGURE 14: PREVALENCE OF DISABILITY AND OTHER PROBLEMS IN ID ADULTS BY GENDER

The recording of disability and other problems was more marked among ID adults living in communal or shared accommodation (Figure 15). More than 1 in 5 adults identified as living communally had a mobility problem recorded (21.4%), while 1 in 3 adults had a continence problem recorded (31.1%), and similarly 1 in 3 had a record of constipation ever (34.6%). Behavioural problems were also much more likely to be recorded among this sub-group, with 1 in 4 (24.4%) adults with ID having one recorded in the last 5 years.
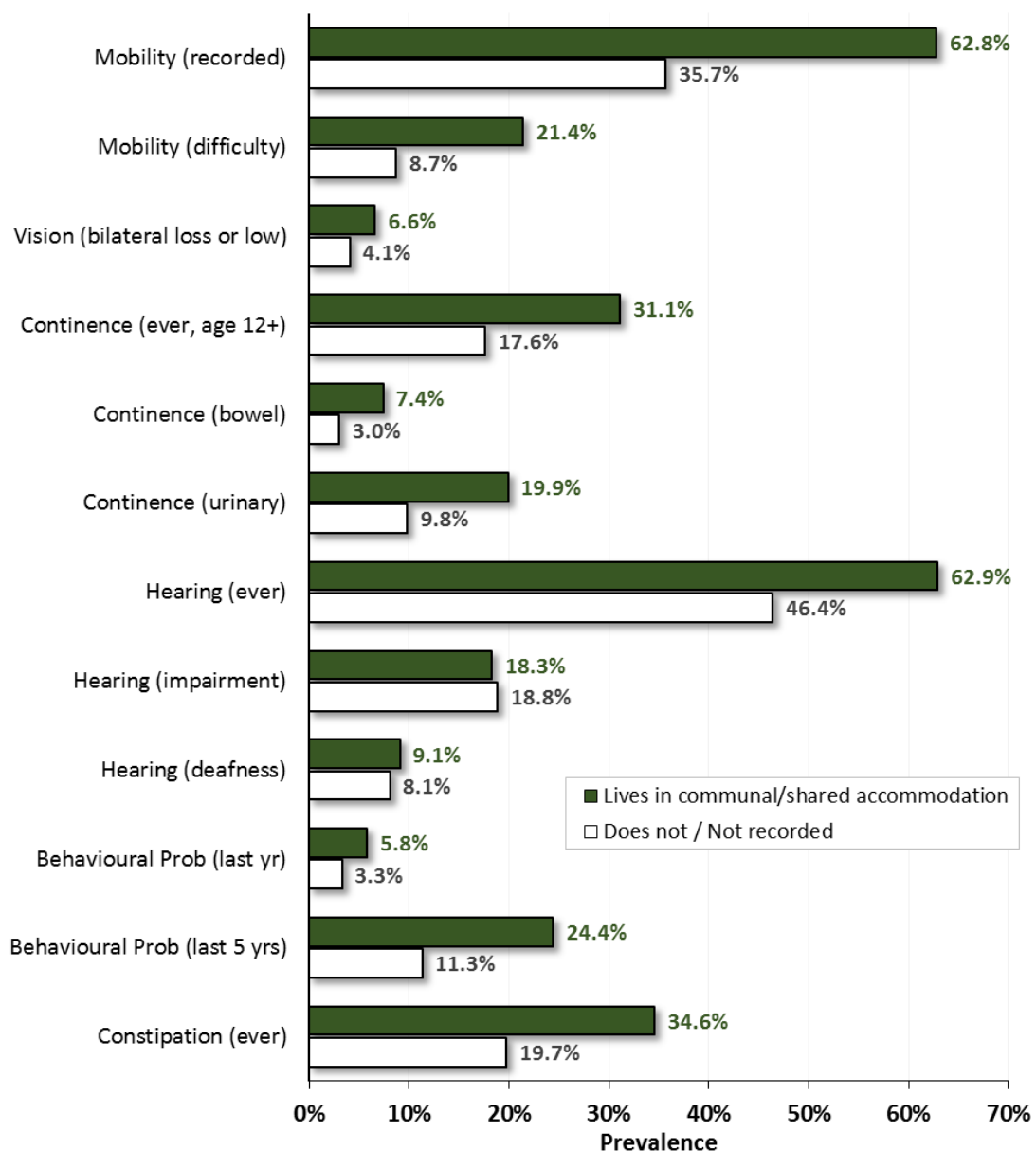
FIGURE 15: PREVALENCE OF DISABILITY AND OTHER PROBLEMS IN ID ADULTS BY LIVING ARRANGEMENTS

Among adults with Down's syndrome there were fewer differences in the recording of disability and other problems (Figure 16). The main difference was much higher recording of hearing, with 1 in 3 adults with Down's syndrome being recorded as having an impairment (37.4%), and about 1 in 6 being recorded as having deafness (16.1%).
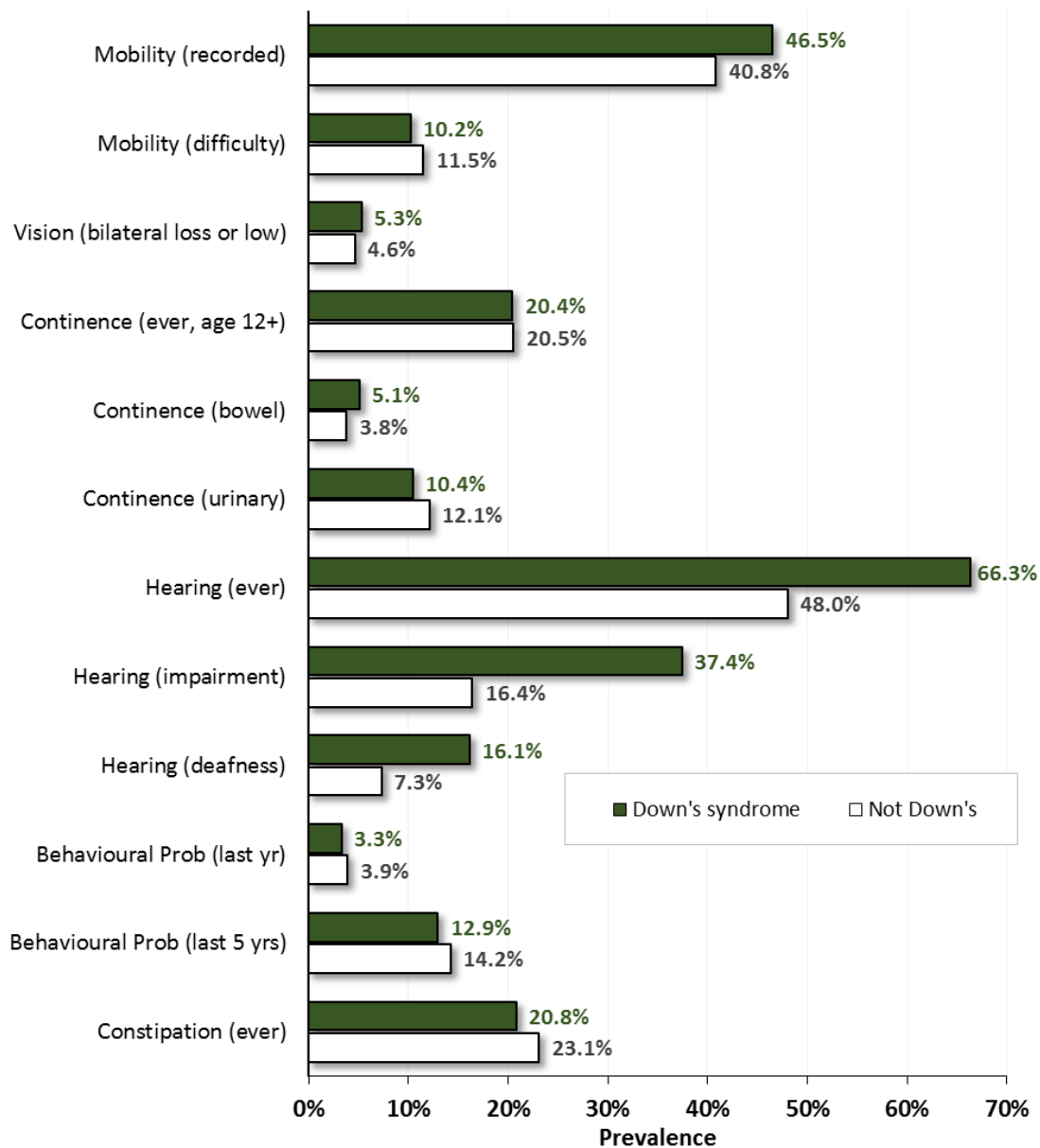
FIGURE 16: PREVALENCE OF DISABILITY AND OTHER PROBLEMS IN ID ADULTS BY DOWN'S SYNDROME

Recording of smoking, body mass index, alcohol consumption and blood pressure

Table 11 summarises the recording of smoking, body mass index (BMI), alcohol consumption and blood pressure in adults with ID and their matched control group as of 1st January 2012.

More than 9 in 10 adults with ID (92.4%) had a smoking status recorded in the last 5 years, which was about 10% higher (PR=1.10) than that seen in the control group. Among those with a status recorded, about 7 in 10 adults with ID were recorded as having never smoked (71.8%), compared to about half the control group (48.2%). Adults with ID were 36% less likely to be recorded as a current smoker (PR=0.64, 95% CI 0.61-0.66)).

For BMI, adults with ID were twice as likely to have a valid recording made in the last year compared to controls (PR=2.19, 95% CI 2.14-2.23). Approximately three-quarters of adults with ID (77.0%) had a BMI recorded in the last 5 years. Among those with a BMI recorded in the last 5 years, more than 1 in 3 adults (36.4%) with ID were classed as obese (BMI>30), and were more likely to be obese (PR=1.33, 95% CI 1.29-1.37) than the general population. About 1-in-10 adults with ID (9.6%) were classed as being underweight (BMI<20) compared to 6.5% of controls (PR=1.48, 95% CI 1.40-1.57).

A record of alcohol consumption sometime in the last 5 years was found in approximately three-quarters of adults with ID (74.1%), which was much higher than the control group (45.7%). Among those with a record in the last 5 years, adults with ID were 42% less likely to be reported as a current drinker (PR=0.58, 95% CI 0.57-0.59).

Blood pressure was also more likely to be recorded among adults with ID, with 6 in 10 (61.5%) having a measurement during the last year. However, there was little difference in levels between the groups, with 89.8% of adults with ID with a measurement of less than 150/90 mmHg compared to 86.9% of all controls.

Among sub-groups, some of the biggest disparities were seen for smoking status among adults with ID and severe health needs or Down's syndrome (Figure 17). Only 6.7% with severe health needs were classed as current smokers, compared to 17.8% among those not reporting severe health needs. Very few adults with Down's syndrome (1.9%) were recorded as current smokers. Among those with a BMI recorded, there were also differences among adults with ID and severe health needs or Down's syndrome (data not shown). ID adults with

Down's syndrome were more likely to be classed as obese (46.8%), than those without Down's (35.1%), while being underweight (BMI <20) was more common among those with severe health needs versus those without (13.6% vs. 9.2%).

TABLE 11: RECORDING OF SMOKING, BMI, ALCOHOL CONSUMPTION AND BLOOD PRESSURE IN ID ADULTS VERSUS CONTROLS

Disease	ID (n=14,751)		Controls (n=86,221)		ID vs. Controls Prevalence Ratio*
	n	%	n	%	PR (95% CI)
Smoking recorded					
- Last 5 years	13,629	**92.4%**	72,284	**83.8%**	**1.10** (1.10-1.11)
Smoking status (most recent)					
- Never	10,591	**71.8%**	41,512	**48.2%**	
- Current	2,236	**15.2%**	20,411	**23.7%**	
- Ex	1,648	**11.2%**	20,314	**23.6%**	
- Missing	276	**1.9%**	3,984	**4.6%**	
Current smoking vs. not					**0.64** (0.61-0.66)
BMI recorded					
- Last year	7,771	**52.7%**	21,061	**24.4%**	**2.19** (2.14-2.23)
- Last 5 years	11,352	**77.0%**	49,987	**57.9%**	**1.34** (1.32-1.35)
BMI value (last 5 years only)					
- 10 to 20	1,083	**9.5%**	3,239	**6.5%**	
- 20 to 25	2,969	**26.2%**	15,518	**31.1%**	
- 25 to 30	3,170	**27.9%**	16,941	**34.0%**	
- 30 to 40	3,363	**29.6%**	12,328	**24.7%**	
- 40 or more	767	**6.8%**	1,871	**3.8%**	
Obesity (>30) vs. non-obese					**1.33** (1.29-1.37)
Alcohol status recorded					
- Last year	6,903	**46.8%**	13,571	**15.7%**	**3.05** (2.97-3.12)
- Last 5 years	10,925	**74.1%**	39,404	**45.7%**	**1.64** (1.62-1.66)
Alcohol status (last 5 years only)					
- Non	3,980	**36.4%**	4,553	**11.6%**	
- Current	4,918	**45.0%**	30,795	**78.2%**	
- Ex	1,861	**17.0%**	3,744	**9.5%**	
- Unknown	166	**1.5%**	312	**0.8%**	
Current drinker vs. not					**0.58** (0.57-0.59)
Blood Pressure recorded					
- Last year	9,073	**61.5%**	33,492	**38.8%**	**1.61** (1.58-1.63)
- Last 5 years	12,473	**84.6%**	62,608	**72.6%**	**1.17** (1.16-1.18)
Blood Pressure (last 5 years only)					
- <150/90 vs. not	11,196	**89.8%**	54,404	**86.9%**	**1.03** (1.02-1.04)

* Prevalence ratios derived from conditional Poisson models. Where the analysis was based on a sub-group that required a measurement in the last 5 years only match-sets which included an ID adult and at least one control could be used. The number of match-sets (m) and matched controls (n) used for these analyses were: body mass index (m=10,756, n=40,387), alcohol status (m=9,861, n=31,740), blood pressure (m=12,197, n=55,052).
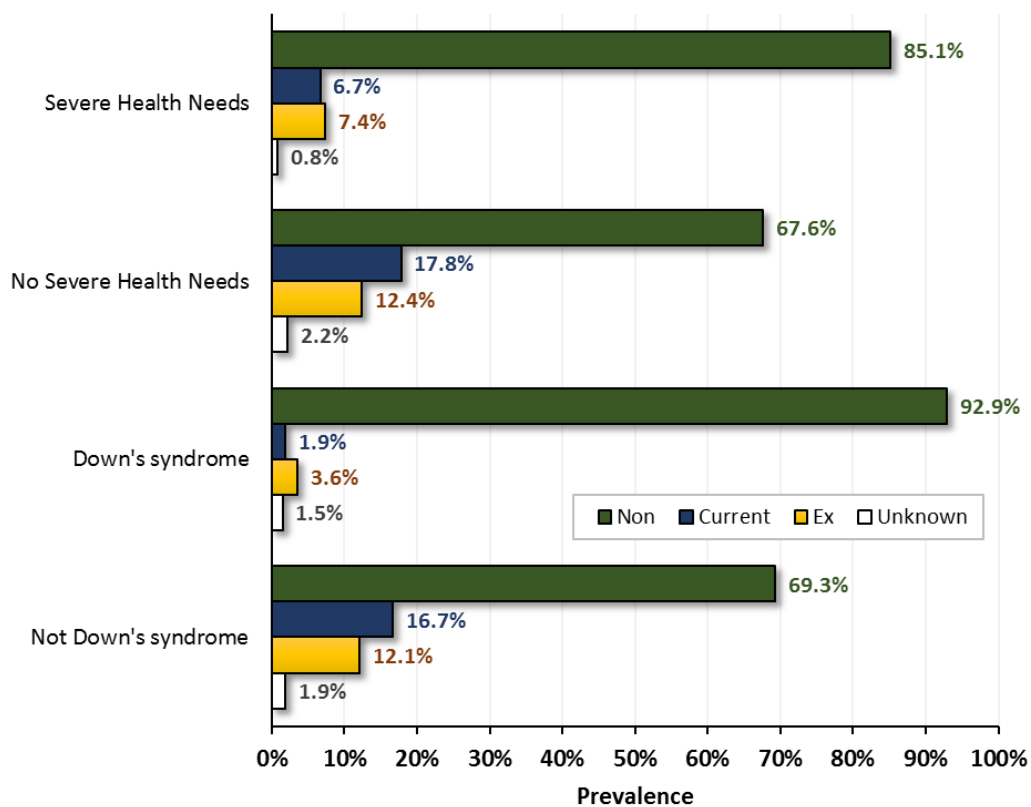
FIGURE 17: SMOKING STATUS BY SEVERE HEALTH NEEDS AND DOWN'S SYNDROME

Recording of health promotion

A summary of some health promotion measures such as vaccination and screening, is shown in Table 12. About 4 in 10 adults had a vaccination for influenza in the last year (41.5%). When restricted to a sub-group with relevant co-morbidity (CHD, Stroke, Diabetes or COPD) this rose to 76.9% for adults with ID. This was marginally higher than the rate (73.1%) found across all (matched and un-matched) controls with similar co-morbidity (CHD, Stroke, Diabetes or COPD). A similar difference was observed when the statistical analysis only included controls with at least one of these co-morbidities who were matched to these cases (PR=1.03, 95% CI 0.98-1.07).

TABLE 12: RECORDING OF HEALTH PROMOTION INTERVENTIONS IN ID ADULTS VERSUS CONTROLS

Health Promotion Measure	ID (n=14,751)		Controls (n=86,221)		ID vs. Controls Prevalence Ratio*
	n	%	n	%	PR (95% CI)
Influenza vaccination					
- Last year	6,128	**41.5%**	14,115	**16.4%**	**2.61** (2.55-2.68)
CHD, Stroke, DM or COPD only	1,493	_	7,039	_	
- Last year	1,148	**76.9%**	5,144	**73.1%**	**1.03** (0.98-1.07)
Cervical screening					
Women 25-64 years only	4,618	_	27,481	_	
- Smear ever	2,062	**44.7%**	25,088	**91.3%**	**0.49** (0.48-0.51)
- Hysterectomy ever	195	**4.2%**	2,218	**8.1%**	**0.56** (0.48-0.64)
- Excepted ever	2,206	**47.8%**	2,593	**9.4%**	**5.06** (4.80-5.34)
No hysterectomy & not excepted	2,242	_	22,771	_	
- Smear last 5 years	1,176	**52.5%**	19,304	**84.8%**	**0.64** (0.61-0.66)
Mammogram					
Women 50-69 years only	1,846	_	11,709	_	
- Last 3 years	861	**46.6%**	7,310	**62.4%**	**0.75** (0.72-0.78)
Urinalysis					
- Last year	433	**27.6%**	1,095	**11.9%**	**2.15** (2.09-2.22)
Thyroid function					
- Last year	4,958	**33.6%**	15,765	**18.3%**	**1.88** (1.83-1.93)
Down's syndrome ID adults only	1,571	_	9,178	_	
- Last year (Down's only)	974	**62.0%**	1,604	**17.5%**	**3.64** (3.41-3.88)
Contraception use/advice					
Women 18-54 years only	4,646	_	26,652	_	
- Last year	1,586	**34.1%**	8,450	**31.7%**	**1.04** (0.99-1.08)
Medication Review					
- Last year	5,467	**37.1%**	17,690	**20.5%**	**1.84** (1.80-1.88)
Prescribed medication in 2011	12,649	_	57,493	_	
- Last year	5,412	**42.8%**	17,351	**30.2%**	**1.46** (1.43-1.50)

* Prevalence ratios derived from conditional Poisson models. Where the analysis was based on a sub-group not solely defined by age and sex, only match-sets which included an ID adult and at least one control could be used. The number of match-sets (m) and matched controls (n) used for these analyses were: influenza (m=803, n=1,589), cervical screening (m=2,237, n=11,398), medication review (m=12,417, n=50,629)

Cervical smear coverage in adults with ID was much lower than controls. Among women with ID aged 25-64 years old, less than half had a smear ever (44.7%). Almost half (47.8%) had a code in their record of being "excepted" from a smear in the past, much higher than that seen in the controls. These exceptions are based on QOF rules[47] which cover Read codes indicating that the screen was "not wanted", "refused", "not indicated" or the GP was in receipt of a disclaimer on their record.

When the comparison of cervical smears was restricted to the last 5 years among those with no record of a hysterectomy or an exception ever, adults with ID were still 36% less likely than adults without ID to have had a smear (PR=0.64, 95% CI 0.61-0.66) during this period. Severity of ID influenced the likelihood of a recent smear, with women with ID and severe health needs having lower coverage (31.5%) than those without severe health needs (57.1%).

Mammograms were less likely among adults with ID compared to the general population, with less than half women aged 50-69 years having a record of one during the last 3 years (46.6%). Other investigative tests however were more common among adults with ID, with higher recorded rates of urinalysis (27.6%) and thyroid function (33.6%) tests in the last year. Contraceptive advice or recorded use was similar between adults with ID (34.1%) and without ID (31.7%).

Medication reviews during the last year were more commonly recorded among adults with ID than controls, both among all patients (37.1% vs. 20.5%) and among those prescribed medication during the year (42.8% vs. 30.8%). However, these figures are likely to be underestimating the true scale as we have some reservations about the completeness of medications reviews during this period on the CPRD database (see page 35).

Overall prescribing trends

We first summarised prescribing by collating whether each patient had been receiving a prescription in 2011 or not (Table 13). We further summarised by dividing the drugs into common groupings using British National Formulary (BNF) chapter headings.[68] We further summarised different drugs, by using BNF sub-chapters. Thus for example BNF 2.6.1 (Nitrates) is counted as a different drug to BNF 2.6.2 (Calcium channel blockers).

TABLE 13: PRESCRIBING SUMMARY DURING 2011 IN ID ADULTS VERSUS CONTROLS

Prescribing group	ID (n=14,751)		Controls (n=86,221)		ID vs. Controls Prevalence Ratio
	n	%	n	%	PR (95% CI)
Overall					
- Any prescription	12,649	**85.8%**	57,493	**66.7%**	**1.29** (1.28-1.30)
BNF Chapter Headings (1-13)					
- (1) Gastro-intestinal system	5,086	**34.5%**	17,347	**20.1%**	**1.75** (1.71-1.80)
- (2) Cardiovascular system	3,519	**23.9%**	17,509	**20.3%**	**1.23** (1.19-1.26)
- (3) Respiratory system	3,314	**22.5%**	11,810	**13.7%**	**1.66** (1.61-1.72)
- (4) Central nervous system	8,847	**60.0%**	24,916	**28.9%**	**2.11** (2.07-2.14)
- (5) Infections	5,583	**37.9%**	24,165	**28.0%**	**1.36** (1.33-1.39)
- (6) Endocrine system	2,610	**17.7%**	9,417	**10.9%**	**1.69** (1.62-1.75)
- (7) Obstetrics, gynaecology, & urinary-tract disorders	1,985	**13.5%**	10,609	**12.3%**	**1.06** (1.02-1.10)
- (8) Malignant disease and immunosuppression	63	**0.4%**	460	**0.5%**	**0.81** (0.63-1.06)
- (9) Nutrition and blood	2,721	**18.5%**	5,606	**6.5%**	**2.88** (2.76-3.01)
- (10) Musculoskeletal and joint diseases	2,388	**16.2%**	10,461	**12.1%**	**1.36** (1.31-1.42)
- (11) Eye	1,630	**11.1%**	4,944	**5.7%**	**1.96** (1.86-2.07)
- (12) Ear, nose, and oropharynx	2,285	**15.5%**	7,040	**8.2%**	**1.92** (1.84-2.01)
- (13) Skin	5,651	**38.3%**	13,950	**16.2%**	**2.39** (2.32-2.45)
Repeat Prescribing Only					
- Any repeat prescription	10,507	**71.2%**	34,421	**39.9%**	**1.82** (1.79-1.84)
- 1-2 drug classes	3,730	**25.3%**	18,404	**21.4%**	_
- 3-5 drug classes	3,758	**25.5%**	9,810	**11.4%**	_
- 6-10 drug classes	2,463	**16.7%**	5,052	**5.9%**	_
- 11+ drug classes	556	**3.8%**	1,155	**1.3%**	_

Adults with ID were 29% more likely than their matched population controls to have received a prescription during the year, with almost all receiving one (85.8%). When only repeat prescriptions were considered, the disparity increased, and adults with ID were nearly twice as likely (PR=1.8) to be on repeat medication during 2011. Approximately 1 in 5 adults with

ID (20.5%) were prescribed at least 6 different drug classes as repeat medication during the year, much higher than seen for controls (7.2%).

When the prescribing was summarised by different BNF chapter headings (1-13 only) some further patterns emerged. Adults with ID were more likely to be prescribed from all drug classes, except the small number of drugs prescribed for malignant disease and immunosuppression. Adults with ID were more than twice as likely to be prescribed drugs from the following groups: nutrition and blood, skin diseases and central nervous system. 6 in 10 adults with ID were prescribed a drug from the central nervous system group, with carbamazepine (10%), sodium valproate (9%), risperidone (7%) being the most frequent drug substances prescribed. Within controls the pattern in the central nervous system chapter was completely different with paracetamol or codeine phosphate (17%) and citalopram (10%) being the most prescribed.

An alternative summary measure of prescribing was to calculate the total volume of drugs prescribed in 2011. We calculated the mean number of prescriptions per patient, and then summarised this as a rate per 1,000 patients (Figure 18). This revealed larger relative differences for adults with ID, suggesting that not only were they more likely to receive a drug from a particular class, but also more likely to be prescribed more drugs from that class over the year. For example, the prescribing volume of drugs for central nervous system, nutrition and blood, and skin diseases all showed rates 5 to 6 higher for adults with ID compared to matched controls. The mean volume of central nervous system drugs (13,387 per 1,000 patients) signifies that on average an adult with ID was receiving a drug from this class every month during 2011.
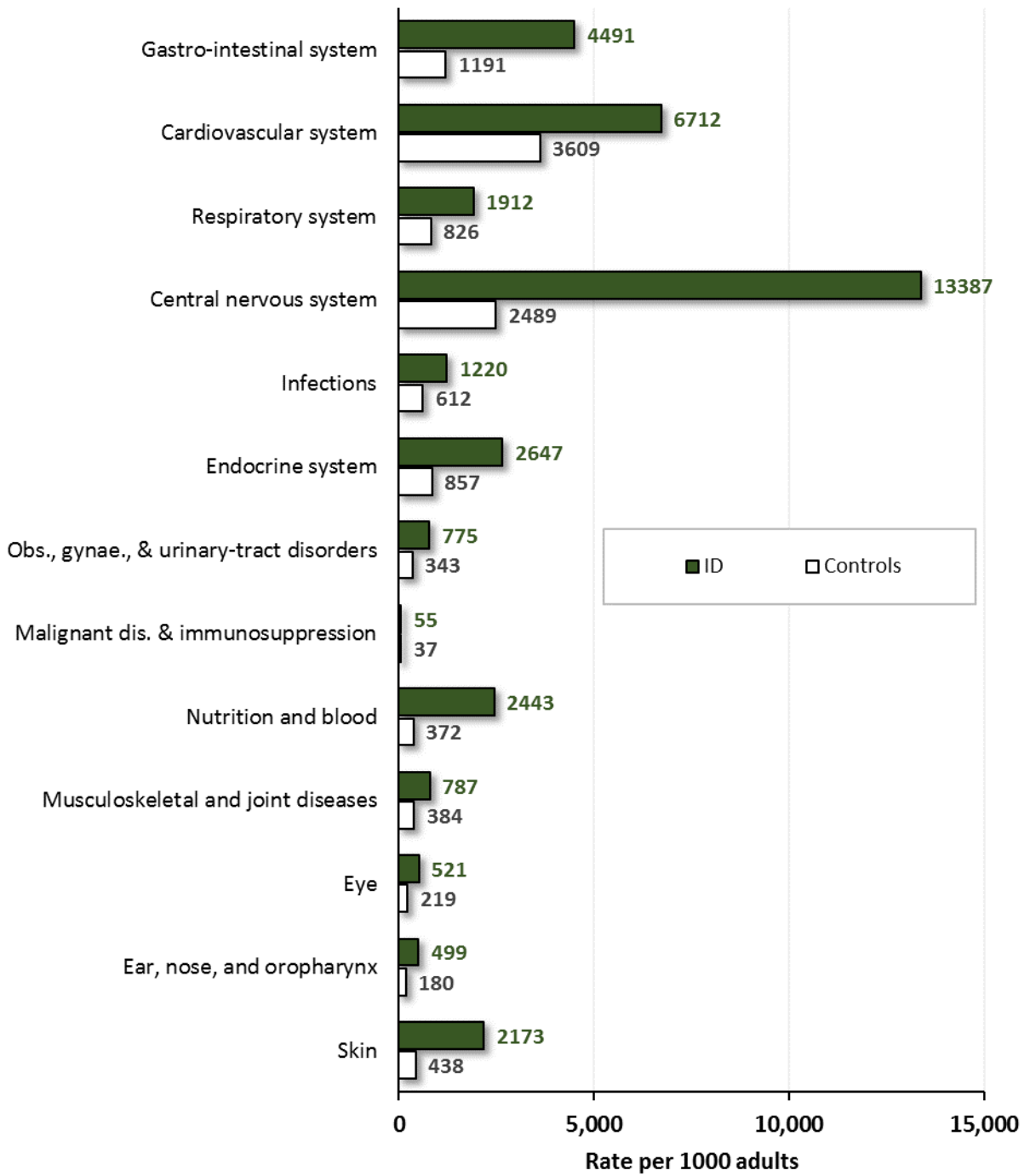
FIGURE 18: VOLUME OF PRESCRIBING IN 2011 BY BNF CHAPTER IN ID ADULTS AND CONTROLS

Prescribing of psychotropic drugs

We wanted to further summarise prescribing by analysing patterns of psychotropic medication (BNF chapters 4.1 to 4.4) between adults with ID and matched controls. Within psychotropic prescribing, we identified the following sub-groups of interest: hypnotics/anxiolytics (BNF 4.1.1-4.1.2), antipsychotics (BNF 4.2.1-4.2.2), antimanic drugs (BNF 4.2.3) and antidepressants (BNF 4.3). We excluded from antidepressants, any prescriptions for low-dose tricyclic and related antidepressants used at smaller than the minimum effective dose for depression treatment (specifically amitriptyline and nortriptyline at doses <50 mg), in line with previous analyses of primary care databases we have carried out,[69] as these may be prescribed for other reasons besides depression such as chronic neuropathic pain. We chose not to include the specific chapter of antiepileptic drugs (BNF 4.8) in our definition of psychotropic drugs, but include a separate category for this instead. We also include a category of drugs classed as benzodiazepines (which are selected hypnotics/anxiolytics and antiepileptic drugs).

Table 14 summaries the pattern of psychotropic prescribing in 2011. Adults with ID were almost three times more likely to be prescribed a psychotropic drug than controls (PR=2.73, 95% CI 2.66-2.81), with almost 4-in-10 (38.2%) receiving at least one prescription during the year. Of these, only 51.1% (n=2,874) of adults with ID prescribed a psychotropic drug in 2011 had a recorded medication review during the year.

The disparity in psychotropic prescribing was being driven by large differences in antipsychotic prescribing, where adults with ID were 9 times more likely to receive this class of drug (PR=9.19, 95%CI 8.69-9.73), and by antimanic drugs which were 16 times more likely to be prescribed to adults with ID (PR=16.05, 95% CI 13.89-18.55). Smaller differences between adults with ID and controls were seen for hypnotics/anxiolytics (PR=2.70, 95% CI 2.57-2.83) and antidepressants (PR=1.99, 95% CI 1.92-2.07) and hypnotics/anxiolytics (PR=1.84, 95% CI 1.70-1.98). While adults with ID had higher overall prescribing for psychotropic drugs, they were less likely (PR=0.73, 95% CI 0.65-0.82) than controls to receive low dose amitriptyline or nortriptyline (which were excluded from our antidepressants category). The prescribing of benzodiazepines was approximately four times higher among adults with ID than controls (PR=4.09, 95% CI 3.88-4.32).

TABLE 14: PRESCRIBING OF PSYCHOTROPIC DRUGS DURING 2011 IN ID ADULTS VERSUS CONTROLS

Drug class	ID (n=14,751)		Controls (n=86,221)		ID vs. Controls Prevalence Ratio
	n	%	n	%	PR (95% CI)
All psychotropic drugs					
- Any (BNF 4.1, 4.2, 4.3, 4.4)	5,629	**38.2%**	12,226	**14.2%**	**2.73** (2.66-2.81)
- Hypnotics and Anxiolytics (BNF 4.1.1, 4.1.2)	2,020	**13.7%**	4,457	**5.2%**	**2.70** (2.57-2.83)
- Antipsychotics (BNF 4.2.1, 4.2.2)	2,887	**19.6%**	1,875	**2.2%**	**9.19** (8.69-9.73)
- Antimanic (BNF 4.2.3)	678	**4.6%**	250	**0.3%**	**16.05** (13.89-18.55)
- Antidepressants (BNF 4.3) excluding low dose amitriptyline	2.905	**19.7%**	8,706	**10.1%**	**1.99** (1.92-2.07)
Other selected groupings					
- Benzodiazepines†	2,037	**13.8%**	2,998	**3.5%**	**4.03** (3.82-4.26)
- Antiepileptic (BNF 4.8)	3,138	**21.3%**	943	**1.1%**	**19.60** (18.26-21.03)
- Low dose amitriptyline (<50 mg)	334	**2.3%**	2,774	**3.2%**	**0.73** (0.65-0.82)
Among ID patients without epilepsy only*	12,020		69,722		
- Any Psychotropic drug	4,179	**34.8%**	9,698	**13.9%**	**2.54** (2.47-2.62)
- Antimanic (BNF 4.2.3)	245	**2.0%**	123	**0.2%**	**11.87** (9.56-14.76)
- Benzodiazepines†	1,050	**8.7%**	2,337	**3.4%**	**2.67** (2.48-2.86)

* - This analysis excludes 2,731 adults with ID and epilepsy, and is restricted to 12,020 ID adults without epilepsy and their matched controls (n=69,722 after removing n=506 with epilepsy).
† - Selected from BNF chapters 4.1.1, 4.1.2 and 4.8.

The higher prevalence of epilepsy in adults with ID compared to controls (25 times higher, Table 6) is reflected in the similarly higher prescribing of antiepileptic drugs among adults with ID (PR=19.60, 95% CI 18.26-21.03). However, the higher prevalence of epilepsy among adults with ID only explained some of the observed difference in psychotropic prescribing in Table 14. Although more than half of adults with ID and epilepsy (n=2,731) were prescribed a psychotropic drug in 2011 (n=1,450, 53.1%), a third of ID adults without epilepsy (34.8%) were

still being prescribed a psychotropic drug in 2011, which represented a two-and-half times higher rate (PR=2.54, 95% CI 2.47-2.62) higher rate than that seen in the matched control group (Table 14). By contrast, the prescribing of antimanic drugs (BNF 4.2.3) was much more common among ID adults with epilepsy (15.9% vs. 2.0%). This was primarily due to the prescribing of carbamazepine, which is listed as both antimanic and an antiepileptic drug (BNF 4.8), and is presumably being mainly prescribed to treat seizures here among adults with ID as opposed to bipolar disorder. However, excluding ID adults with epilepsy from the comparison, still resulted a large relative increase compared to their matched controls (PR=11.87, 95% CI 9.56-14.76). Benzodiazepine prescribing was also far more common among ID adults with epilepsy (37.4% vs. 8.7%), and the relative difference between adults with ID and controls fell from PR=4.03 to 2.67 when we excluded adults with ID and epilepsy (and their controls) from the comparison.

Figure 19 displays the top 20 psychotropic drug substances prescribed to adults with ID during 2011, compiled from all prescriptions issued under BNF chapters 4.1 to 4.4. These are summarised as a rate per 1,000 adults (counting a maximum of one prescription per day for each drug class), with the corresponding rates seen in the matched controls also shown on the figure.

The most commonly prescribed item was the antipsychotic risperidone (1,032 prescriptions per 1,000 adults), which was rarely prescribed across the control group (13 per 1,000). Other large relative disparities were seen for zuclopenthixol (113 per 1,000 adults with ID compared to 1.4 per 1,000 in controls), haloperidol (193 per 1,000 adults with ID compared to 3 per 1,000 in controls) and carbamazepine (421 per 1,000 adults with ID compared to 11 per 1,000 in controls). The most commonly prescribed antidepressants among adults with ID (e.g. citalopram, fluoxetine, sertraline) were prescribed at rates approximately three to four times higher among adults with ID compared to controls. While the most prescribed benzodiazepine among the psychotropic drugs in adults with ID was diazepam (378 per 1,000 adults), this was also prescribed frequently among controls (94 per 1,000 adults). By contrast lorazepam, another benzodiazepine, was frequently prescribed among adults with ID (196 per 1,000 adults), but rarely prescribed among controls (9 per 1,000 adults).
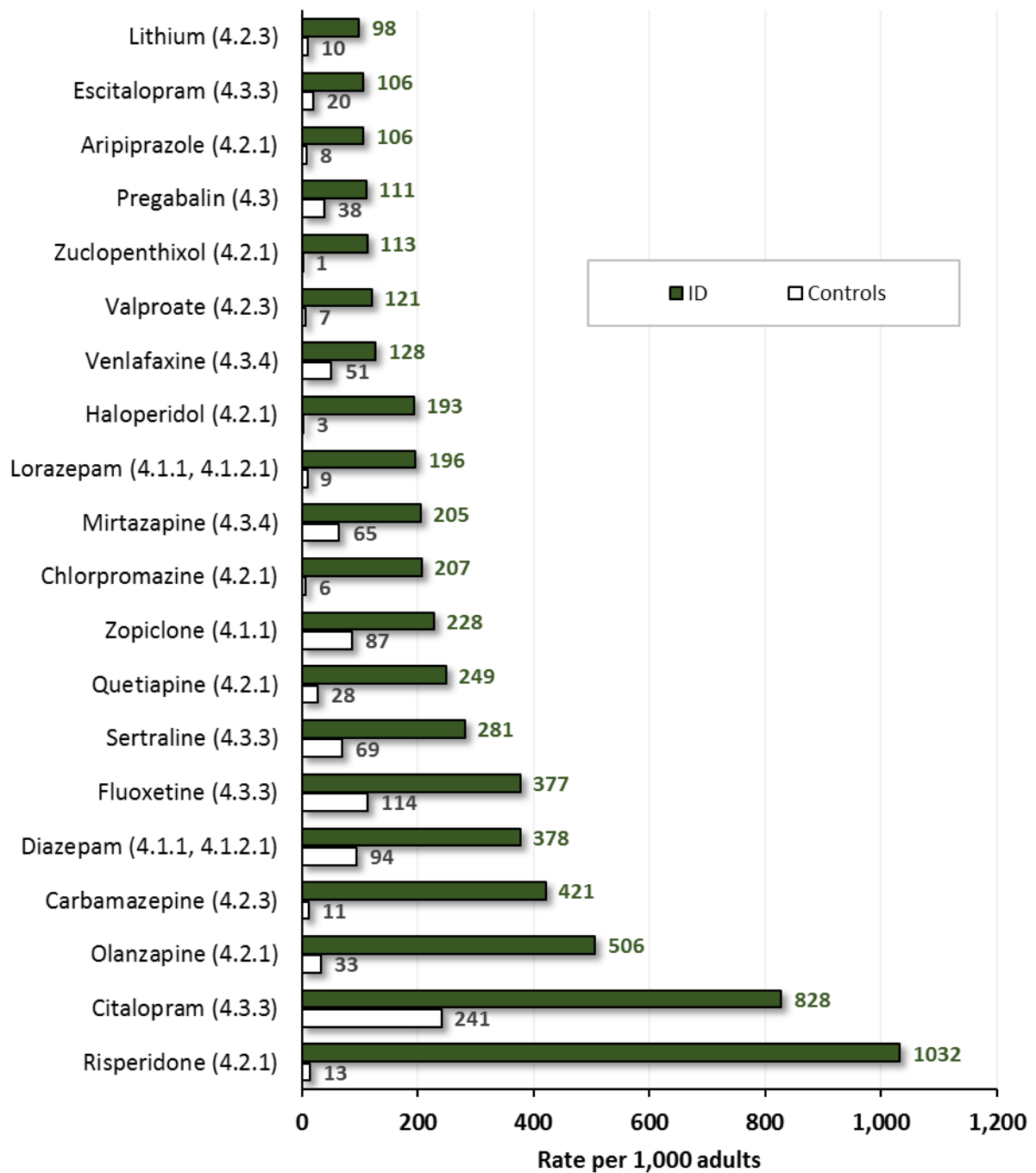
FIGURE 19: TOP 20 PSYCHOTROPIC DRUGS PRESCRIBED BY VOLUME IN 2011 AMONG ID ADULTS, WITH RATES AMONG CONTROLS SHOWN FOR COMPARISON

We summarised overall psychotropic prescribing in ID adults and controls by sub-groups of interest (Figure 20). While women with ID were marginally more likely to have received a psychotropic drug in 2011 than men with ID (41% vs 36%), this contrasted with the matched control group where women were also twice as likely (20% vs. 10%). Prescribing increased with age, for both adults with ID and controls, but the largest relative disparity was seen among the youngest ages (18-34 years). Approximately 3-in-10 younger adults (29%) with ID received a psychotropic drug in 2011, compared to 1-in-10 (9%) among the control group.

Prescribing of psychotropic drugs by socio-economic status (using the IMD) showed contrasting patterns between adults with ID and controls. While controls in more deprived areas were more likely to be prescribed a psychotropic drug during the year (18% in most deprived quintile vs. 12% in least deprived), no such pattern existed among adults with ID. Those living in the most deprived areas (IMD=5) had similar psychotropic prescribing levels in 2011 (38%) to those in the least deprived areas (38%). However, when we restricted to adults with ID not recorded as living in communal or shared accommodation there was a weak trend, where those living in the most deprived area had higher levels of psychotropic prescribing (35%) than those in the living in the least deprived category of IMD (32%).

Among ID sub-groups there were some key differences in psychotropic prescribing. Much higher rates were seen among the following: those living in communal or shared accommodation (56%), those with autism spectrum disorder (56%), those with severe health needs (48%). Adults with ID and Down's syndrome however were much less likely to be prescribed a psychotropic drug in 2011 (14% vs. 40%).

Finally, we looked further back in the patient record to summarise longer term prescribing of psychotropic drugs. Among patients who were continually registered with their practice for the last 5 years, 36.6% (3,940 of 10,769) of adults with ID averaged more than one prescription per year, compared to 14.4% of controls (10,765 of 74,784), which compares closely with what we found from the analyses based on a single year (2011). The average number of psychotropic prescriptions per year during the last 5 years was 7.6 for ID adults compared to 1.3 per year for controls.
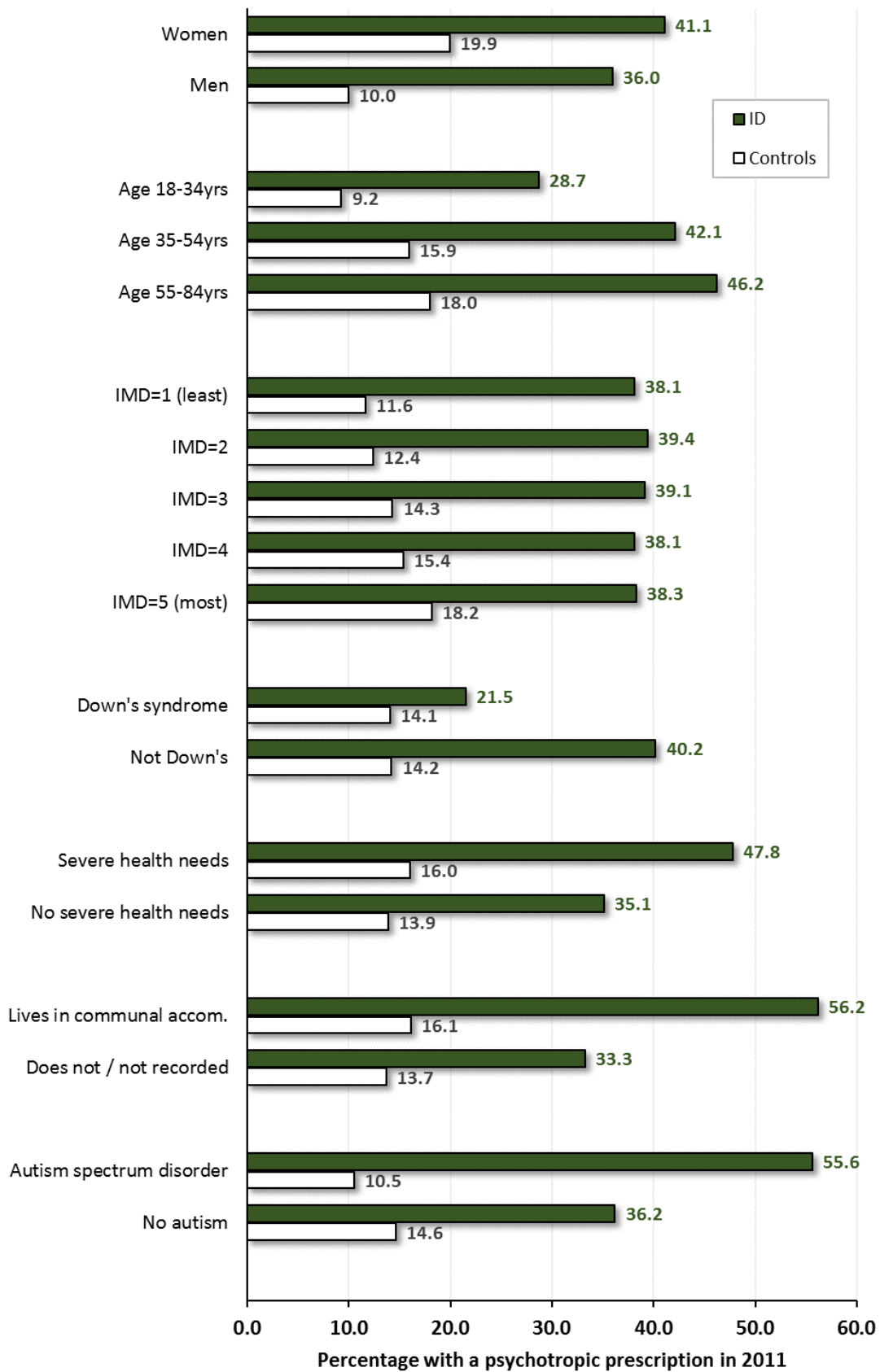
FIGURE 20: PSYCHOTROPIC DRUG PRESCRIBING IN 2011 BY IN ID ADULTS AND CONTROLS BY SUB GROUPS

Attainment of QOF indicators

We wanted to compare the achievement for a number of QOF indicators[47] between adults with ID and their matched controls. The indicators are generally disease specific and only calculated on patients who are on that particular QOF disease register, making any matched analysis here infeasible.

A summary of the age and sex characteristics of adults with ID and controls on selected QOF disease registers (chronic kidney disease, diabetes, epilepsy, hypertension, hypothyroidism, IHD and Stroke) is shown in Table 15. The prevalence of these diseases has previously been described in Table 6.

TABLE 15: SUMMARY OF ID ADULTS AND CONTROLS ON SELECTED QOF DISEASE REGISTERS

QOF Register	Adults with ID				Controls			
	n	% men	Mean age (sd)	Number excepted* (%)	n	% men	Mean age (sd)	Number excepted* (%)
Chronic kidney disease	468	39.7%	60.1 (11.9)	9 (1.9%)	1,746	44.2%	67.0 (10.9)	24 (1.4%)
Diabetes	1,017	52.9%	53.6 (14.3)	70 (6.9%)	3,786	61.5%	57.5 (13.0)	187 (4.9%)
Epilepsy	2,731	55.4%	42.4 (14.7)	141 (5.2%)	633	55.5%	47.4 (14.7)	35 (5.5%)
Hypertension	1,583	52.0%	57.1 (12.7)	29 (1.8%)	10,416	54.8%	60.4 (11.2)	150 (1.4%)
Hypo-thyroidism	1,169	34.3%	48.3 (14.7)	8 (0.7%)	2,649	19.6%	55.5 (13.2)	8 (0.3%)
Ischaemic heart disease	244	67.2%	62.5 (12.0)	14 (5.7%)	2,316	69.5%	64.2 (10.3)	72 (3.1%)
Stroke & TIA	267	52.4%	60.2 (13.6)	23 (8.6%)	944	56.6%	64.2 (12.0)	22 (2.3%)

* - Exceptions refer to disease wide specific exceptions recorded during the last year (2011) that exempt patients from all indicators related to that disease

There were some notable differences in the age-sex structure between adults with ID and controls on the QOF disease registers. Generally, adults with ID were about 5 years younger

on average. For diabetes, a greater proportion of adults with ID were women (47.1% vs. 38.5%), whereas for hypothyroidism adults with ID were more likely to be men (34.3% vs. 19.6%). Thus, any (un-matched) analysis of QOF indicators must account for age-sex differences.

Table 15 also reports on QOF exception reporting within the selected disease registers. Exception reporting is where GP's are allowed to specifically exclude patients from indicators due to patient specific clinical circumstances.[47] For example, this may arise where an indicator includes medication that cannot be prescribed due to a recorded contra-indication or side-effect. For all selected disease registers, adults with ID were more likely to be excepted from QOF indicators. For example, for Stroke (and TIA), 8.6% of adults with ID were excepted compared to 2.3% of controls.

The selected QOF indicators which we chose to compare from the 7 disease registers are shown in Table 16. These were calculated for attainment in the last 12 months on our chosen cross-sectional date (1st January 2012). This differs from QOF which will makes its annual calculations at the end of March each year.[47] We also chose to not to apply the disease exceptions from Table 15 for this comparison. As patients were no longer matched in this analyses, we fitted a log binomial model here to obtain ratios adjusted for age and sex (see Statistical analysis page 36).

Generally, there was little evidence of differences in the attainment of these QOF indicators between adults with ID and controls in our study sample. Indicators where adults with ID performed relatively poorer were: retinal screening among diabetics (48.8% vs. 56.4%, PR=0.89 95% CI 0.84-0.95), and being seizure free for 12 months among epileptics (46.9% vs. 53.7%, PR=0.91 95% CI 0.83-1.00).

TABLE 16: ATTAINMENT OF SELECTED QOF INDICATORS DURING 2011 IN ID ADULTS VERSUS CONTROLS

QOF Indicator	ID		Controls		ID vs. Controls Prevalence Ratio*
	n	%	n	%	PR (95% CI)
Chronic kidney disease					
- Last BP is ≤ 150/90 (CKD3)	340	**72.7%**	1,151	**65.9%**	**1.11** (1.03-1.19)
Diabetes					
- Last BP ≤ 150/90 (DM30)	861	**84.7%**	3,119	**82.4%**	**1.03** (1.00-1.06)
- Last Cholesterol ≤ 5 (DM17)	679	**66.8%**	2,617	**69.1%**	**1.00** (0.95-1.04)
- Last IFCCHbA1c/HbA1c ≤ 59/7.5% (DM26)	535	**52.6%**	2,011	**53.1%**	**1.01** (0.94-1.08)
- Retinal screening (DM21)	496	**48.8%**	2,137	**56.4%**	**0.89** (0.84-0.95)
- Foot examination & classification (DM29†)	658	**65.0%**	2,573	**68.1%**	**0.97** (0.92-1.02)
- Micro-albuminuria testing (DM13†)	544	**56.4%**	2,145	**60.0%**	**0.95** (0.89-1.01)
- Estimated glomerular filtration rate (eGFR) or serum creatinine testing (DM22)	903	**88.8%**	3,409	**90.0%**	**0.99** (0.97-1.01)
Epilepsy					
- Record of seizure frequency (EPIL6)	2,202	**80.6%**	501	**79.2%**	**1.03** (0.98-1.08)
- Record of seizure free (EPIL8)	1,281	**46.9%**	340	**53.7%**	**0.91** (0.83-1.00)
Hypertension					
- Last BP ≤ 150/90 (BP5)	1,249	**78.9%**	7,927	**76.1%**	**1.04** (1.01-1.07)
Hypothyroidism					
- Thyroid function test (THY2)	1,027	**87.9%**	2,355	**88.9%**	**0.99** (0.97-1.02)
Ischaemic heart disease					
- Last BP ≤ 150/90 (CHD06)	211	**86.5%**	1,934	**83.5%**	**1.02** (0.97-1.09)
- Last Cholesterol ≤ 5 (CHD08)	144	**59.0%**	1,508	**65.1%**	**0.92** (0.83-1.03)
- Aspirin, an alternative anti-platelet therapy, or an anticoagulant (CHD09)	199	**81.6%**	1.917	**82.8%**	**0.99** (0.93-1.05)
Stroke & TIA					
- Last BP ≤ 150/90 (STR6)	209	**78.3%**	746	**79.0%**	**1.00** (0.92-1.07)
- Last Cholesterol ≤ 5 (STR8)	149	**55.8%**	566	**60.0%**	**0.96** (0.96-1.08)
- Aspirin, an alternative anti-platelet therapy, or an anticoagulant (STR12)	132	**75.0%**	555	**82.8%**	**0.96** (0.89-1.03)

* - PR's derived from log-binomial model that adjusts for gender and age. Practice was included in the model assuming an exchangeable correlation structure.

† - DM29 applied to non-double amputees only (ID adults=1,013, controls=3,781). DM13 only applied to those without proteinuria (ID adults=964, controls=3,575).

† - STR12 is based on strokes shown to be non-haemorrhagic only, or a history of TIA (ID adults=176, controls=670)

Primary care consultations in 2011

The total number of primary care doctor and nurse consultations during 2011 was collated for all adults with ID and their matched controls who were registered on 1st January 2012. The resulting distribution is shown in Figure 21. 86.9% of adults with ID consulted at least once in the year compared to 72.6% of controls. Approximately 1 in 7 adults with ID (14.9%) averaged at least 1 consultation per month, more than double the rate seen in controls.
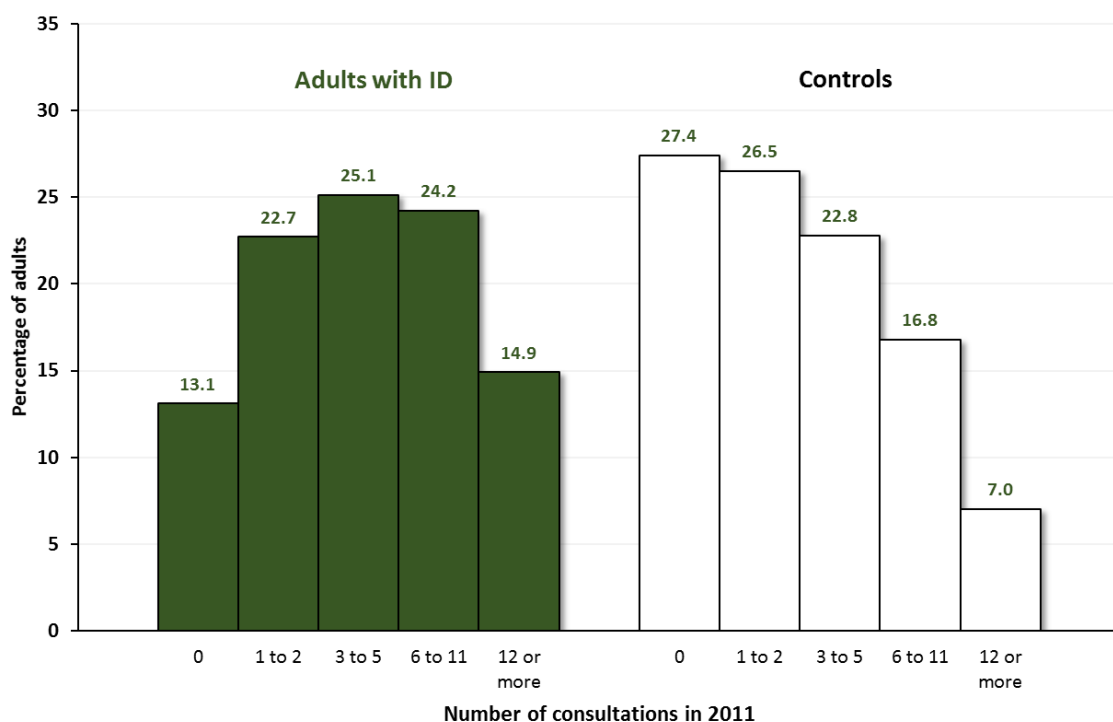
FIGURE 21: NUMBER OF PRIMARY CARE CONSULTATIONS IN 2011 IN ID ADULTS AND CONTROLS

The average number of consultations in 2011 for adults with ID was 6.29 compared to 3.89 in controls (Table 17), an overall rate which was 70% higher. Accounting for greater levels of co-morbidity among adults with ID did not explain all of this difference (RR=1.49, 95% CI 1.47-1.53). The differences in consultation levels between adults with ID and controls were slightly greater for nurse or telephone consultations and less marked for face to face doctor consultations.

TABLE 17: MEAN NUMBER OF CONSULTATIONS IN 2011 IN ID ADULTS VERSUS CONTROLS

Consultation Type	ID (n=14,751)		Controls (n=86,221)		ID vs. Control Rate Ratio*	
	Mean	SD	**Mean**	SD	**RR1** (95%CI)	**RR2** (95%CI)
- All consultations	**6.29**	8.33	**3.89**	5.20	**1.70** (1.66-1.74)	**1.49** (1.47-1.53)
- Telephone	**0.95**	2.56	**0.44**	1.32	**2.26** (2.16-2.37)	**1.87** (1.78-1.97)
- Doctor	**4.45**	5.81	**2.88**	3.91	**1.63** (1.59-1.67)	**1.45** (1.41-1.48)
- Doctor (face to face)	**3.65**	4.51	**2.52**	3.30	**1.53** (1.50-1.56)	**1.37** (1.34-1.40)
- Nurse	**1.84**	4.64	**1.01**	2.42	**1.91** (1.83-2.00)	**1.64** (1.56-1.71)

* - RR1 – Unadjusted, RR2 - Adjusted for co-morbidity score that used the following weights: Atrial Fibrillation (1), Diabetes (1), Stroke & TIA (1), Epilepsy (2), Heart Failure (2), Psychosis, schizophrenia + bipolar affective disorder (2), COPD (2), Cancer (3), Dementia (3).

The characteristics of all consultations recorded in 2011 are further presented in Figure 22. As a proportion of all consultations, face-to-face consultations were marginally lower among adults with ID (85% vs 89%), as telephone consultations were more common instead (15% vs 11%). Similarly, the proportion of all consultations with a doctor was lower in adults with ID (71% vs 74%) as nurse consultations were more common (29% vs 26%).

Consultation length was recorded and non-zero for approximately 95% of consultations in 2011, and was grouped into standard (1-10 minutes) and long length (>10 minutes). While adults with ID were more likely to have had a longer doctor consultation at any time during 2011 (51% vs. 45% for controls), the proportion of their consultations which were longer than 10 minutes was lower (35% vs 42%, Figure 22). Thus in a logistic regression model (adjusted for co-morbidity), that estimates the odds of a long consultation for ID adults vs. controls, and takes account of total number of consultations in the year, adults with ID were estimated to be less likely to receive a longer consultation (OR=0.73, 95% CI 0.69-0.77).
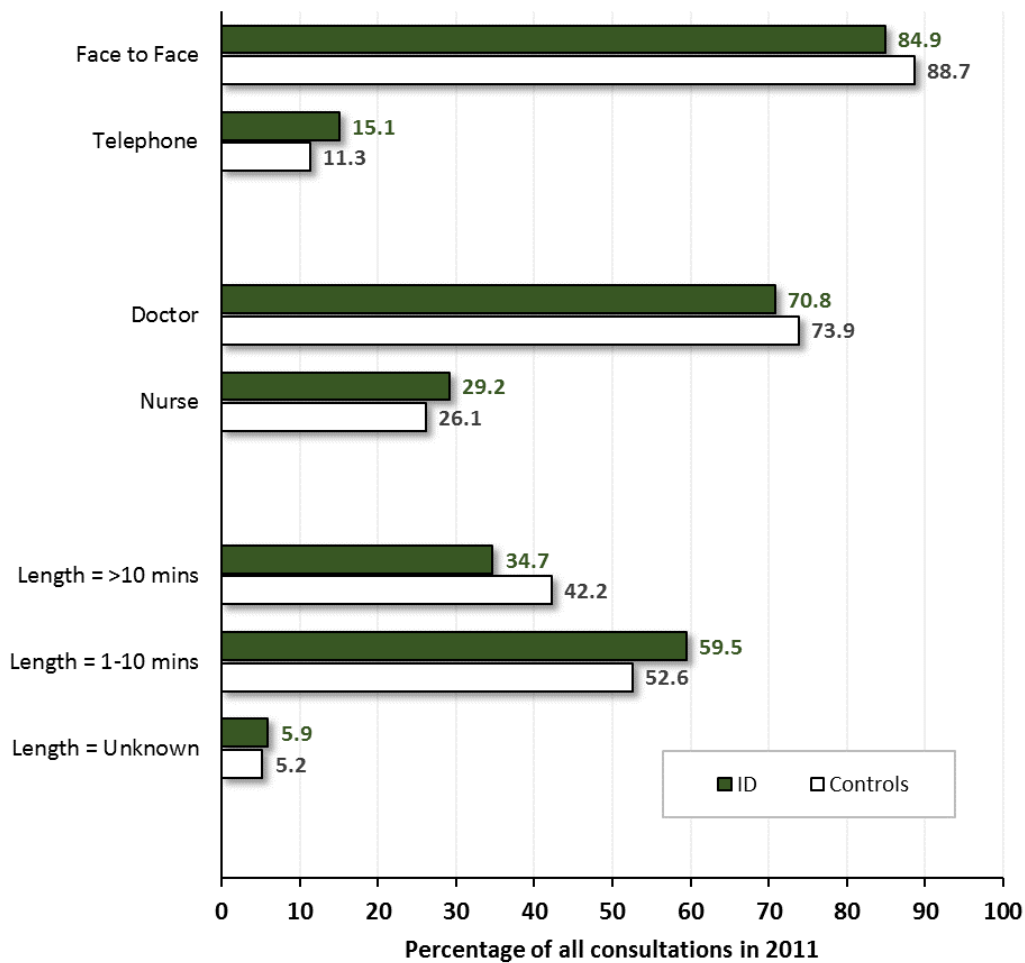
FIGURE 22: CHARACTERISTICS OF PRIMARY CARE CONSULTATIONS IN 2011 IN ID ADULTS AND CONTROLS

The mean number of primary care consultations in 2011 was further summarised by sub groups (Figure 23). Women with ID had a greater consultation rate then men with ID, though this trend was similar to that seen in the matched control group. While consultations increased with deprivation in the general population, this trend was not see within adults with ID where those living in the most and least deprived areas had similar consultation rates. Adults with ID living in communal settings had a higher mean level of total consultations during 2011 (7.51), as did those patients with severe health needs (7.46). Lower consultation rates were seen among adults with ID with autism spectrum disorder (4.98) and Down's syndrome (5.87).
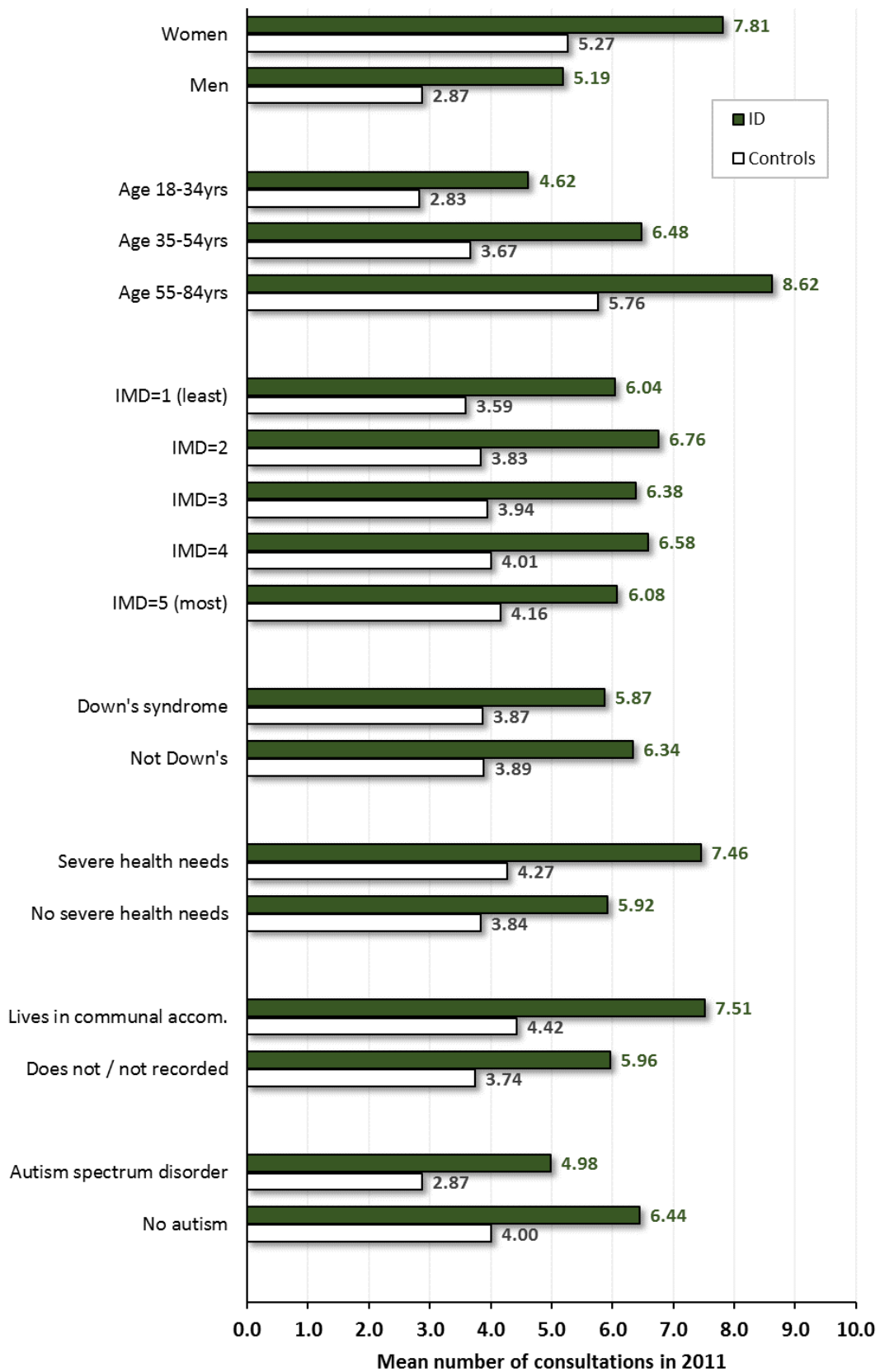
FIGURE 23: MEAN NUMBER OF PRIMARY CARE CONSULTATIONS IN 2011 IN ID ADULTS AND CONTROLS BY SUB-GROUPS

To further assess to what extent the variation in consultations during 2011 by sub groups (Figure 23) were explained by different underlying characteristics within these groups, a series of Poisson regressions were carried out on adults with ID only (Table 18). These revealed that the higher consultation rate among women was not explained by recorded health needs or other characteristics. However, the higher rate among patients with ID living in communal or shared accommodation was largely attributable to these patients being older and having more severe health needs. The lower consultation rates among ID patients with autism was explained by them being considerably younger (Table 5).

TABLE 18: ADJUSTED CONSULTATION RATE RATIOS IN 2011 BY CHARACTERISTIC OF ID ADULT

Characteristic of ID Adult	RR1* (95%CI)	RR2* (95%CI)	RR3* (95%CI)
Men vs. Women	**0.66** (0.63-0.69)	**0.68** (0.66-0.71)	**0.69** (0.67-0.72)
Down's syndrome vs. not	**0.92** (0.86-0.99)	**0.94** (0.88-1.01)	**0.94** (0.87-1.01)
Severe health needs vs. not	**1.25** (1.19-1.32)	**1.17** (1.11-1.23)	**1.15** (1.09-1.22)
Lives in communal accommodation vs. not	**1.26** (1.16-1.36)	**1.09** (1.01-1.18)	**1.06** (0.97-1.14)
Autism spectrum disorder vs. not	**0.79** (0.74-0.85)	**1.01** (0.94-1.09)	**0.98** (0.91-1.06)

* - RR1 – Unadjusted, RR2 – Adjusted for age and sex, RR3 – Further adjusted for all other characteristics listed in table.

Continuity of care among doctor consultations

To assess continuity of care, we restricted analyses to patients who had at least 2 face-to-face consultations with a doctor during 2011. For each patient we calculated a continuity of care summary measure, defined by whether they had greater than half their consultations with the same doctor (see page 34). Table 19 summarises the continuity of care for face-to-face doctor consultations during 2011.

TABLE 19: CONTINUITY OF CARE FOR FACE-TO-FACE DOCTOR CONSULTATIONS IN 2011 IN ID ADULTS VERSUS CONTROLS

Consultation Type	ID (n=14,751)		Controls (n=86,221)		ID vs. Control Odds Ratio	
	n	%	n	%	OR1* (95%CI)	OR2* (95%CI)
All adults with ≥2 doctor consultations	9,167		42,135			
- no. with >50% with same doctor‡	3,962	**43.2%**	20,611	**49.1%**	**0.77** (0.73-0.81)	**0.77** (0.73-0.82)
2-5 total doctor consultations only	5,906		30,332			
- no. with >50% with same doctor‡	2,690	**45.6%**	14,851	**49.0%**	**0.87** (0.81-0.93)	**0.86** (0.80-0.93)
6-11 total doctor consultations only	2,473		9,675			
- no. with >50% with same doctor‡	975	**39.4%**	4,713	**48.7%**	**0.64** (0.55-0.75)	**0.64** (0.54-0.75)
≥12 total doctor consultations only	788		2,128			
- no. with >50% with same doctor‡	297	**40.8%**	1,109	**52.1%**	**0.54** (0.33-0.90)	**0.62** (0.36-1.06)

* - OR1 – Unadjusted, OR2 - Adjusted for total number of doctor (face-to-face) consultations and co-morbidity score that used the following weights: Atrial Fibrillation (1), Diabetes (1), Stroke & TIA (1), Epilepsy (2), Heart Failure (2), Psychosis, schizophrenia + bipolar affective disorder (2), COPD (2), Cancer (3), Dementia (3).
‡ - Regressions restricted to match-sets (m) where there was at least one ID adult and matched control (n). These totals were: All with ≥2 (m=8,677, n=27,905), 2-5 consultations (m=5,289, n=12,411), 6-11 consultations (m= 1,305, n=2,023), ≥12 consultations (m=175, n=208).

Among the 9,167 adults with ID with at least 2 of these, 43.2% of these adults had more than half their total consultations recorded with the same GP. While this was higher among the control group (49.1%), the 20,611 controls identified here are strictly no longer a matched set

with the 9,167 adults with ID. A matched analysis, based on 8,677 match-sets where there was at least one adult with ID and a matched control (n=27,905) who both had at least 2 face-to-face doctor consultations, still suggested however that adults with ID were less likely to see the same doctor more than half the time in 2011 (OR=0.77 95% CI 0.73-0.82). This difference was consistent across different number of total of consultations. For example, among those with at least 12 face-to-face doctor consultations during 2011, 41% of adults with ID saw the same doctor for more than half of their consultations, compared to 52% of controls. This difference was confirmed in adjusted matched regressions, but these were based on very small match-sets as it became increasingly difficult to have the match sets balanced on total number of consultations.

Economic costings in 2011

Using all available data on the CPRD and HES datasets, we estimated annual NHS costings in 2011 for adults with ID and their matched controls where feasible (see Appendix 5for more details). As we wished to factor in hospital admissions into the costings, this analysis was based on a subset of the 14,751 adults registered on 1st January 2012 with linked HES data and suitable matched controls. This resulted in a subset of 11,176 adults with ID and 68,428 matched controls.

Table 20 summarises the estimated costsper patient, overall and broken into the individual components in the calculation. An estimated ratio for the costs of adults with ID compared to their matched controls was obtained by conditional negative binomial regressions (see page 36). Due to the non-symmetrical distribution of all the costing summaries (positively skewed) the model sometimes produced more conservative estimates than the relative mean differences. The estimated mean annual cost for adults with ID in 2011 (£1,445 per patient) was more than double (RR=2.05, 95% CI 2.01-2.10) the estimated costs for the control group (£640 per patient). The largest relative discrepancy was seen for primary care prescribing costs (£494 per ID adult vs. £127 per control, RR=2.48 95% CI 2.40-2.53). Most of the difference in estimated costs for hospital admissions was driven by non-elective (emergency) admissions, where adults with ID had a more than double estimated cost (£456 vs. £187 per patient).

TABLE 20: MEAN ANNUAL ESTIMATED NHS COSTS (£ PER PATIENT) IN 2011 IN ID ADULTS AND CONTROLS

Costed Source	ID (n=11,776)		Controls (n=68,428)		ID vs. Controls Rate Ratio†
	Mean	IQR‡	Mean	IQR‡	RR (95% CI)
GP consultations	193.0	37.0-255.3	115.2	0-155.4	1.71 (1.67-1.75)
Nurse consultations	22.6	0-26.5	10.9	0-12.4	1.95 (1.90-2.01)
Primary care prescribing	494.2	15.8-617.3	126.6	0-79.4	2.48 (2.42-2.55)
Other primary care initiated	5.7	0-0	3.0	0-0	1.98 (1.84-2.13)
A&E / Casualty	37.4	0-0	17.6	0-0	1.48 (1.40-1.55)
Elective hospital admissions	236.1	0-0	180.4	0-0	1.14 (1.07-1.22)
Non-elective hospital admissions	456.4	0-0	186.5	0-0	1.98 (1.86-2.10)
Total estimated mean cost	1445.4	130.0-1360.5	640.1	18.5-418.5	2.05 (2.01-2.10)

Note that costs are estimated as mean £ per patient. For more details on how these were estimated please see Appendix 5**Error! Reference source not found.**.
† - Ratios obtained from (conditional) fixed effects negative binomial regressions with bias corrected confidence intervals produced from non-parametric bootstrap estimation (1,000 simulations).
‡ - Inter quartile range

Annual economic costs were also estimated by sub-groups (Figure 24). While costs were higher for women with ID (£1,682 vs. £1,273 per patient), this gender difference was similar in relative terms in the control group. Estimated costs for the youngest (age 18-34) group of adults with ID (£1,179 per patient) still exceeded those estimated for the oldest (age 55-84) patients in the control group. Adults with ID with severe health needs had double the estimated annual costs compared to those without (£2,332 vs. £1,159 per patient).

The association between annual NHS costs and deprivation was different between adults with ID and controls. In the general population, costs steadily increase with each quintile of IMD (from £514 to £783 per patient). However, within adults with ID the trend was not repeated, such that the group with the most deprived group (£1,395 per patient) had lower costs that the least deprived group (£1,507 per patient).
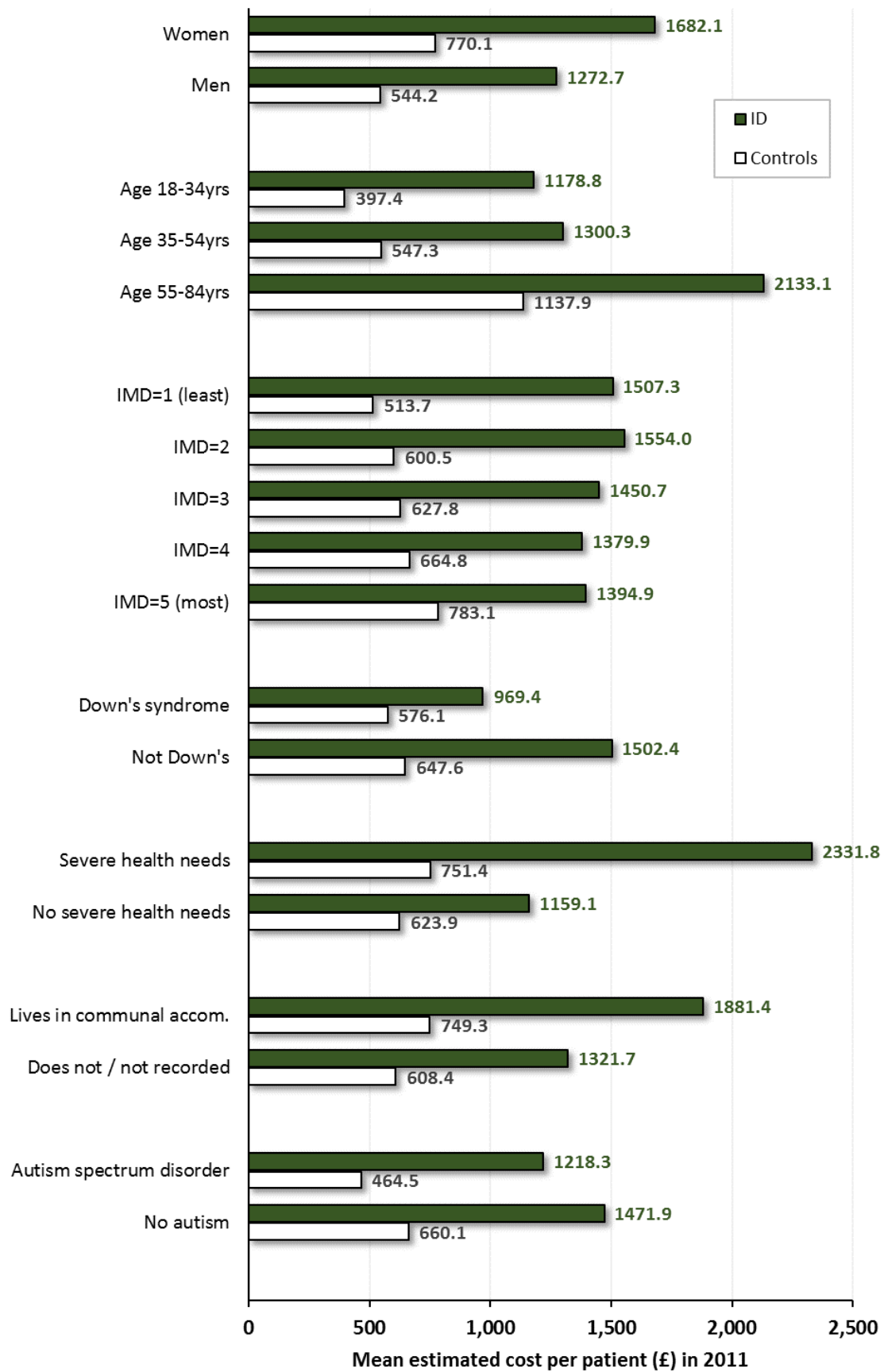
FIGURE 24: MEAN ANNUAL ESTIMATED NHS COSTS IN 2011 IN ID ADULTS AND CONTROLS BY SUB-GROUPS

The association with deprivation was further explored by stratifying by the accommodation status of the ID adult (Figure 25). The absence of the trend seen with IMD in the general population, was still apparent among ID adults estimated to be living in the community. However, a much clearer trend towards higher costs with lower levels of deprivation was now seen among ID adults living in communal accommodation.
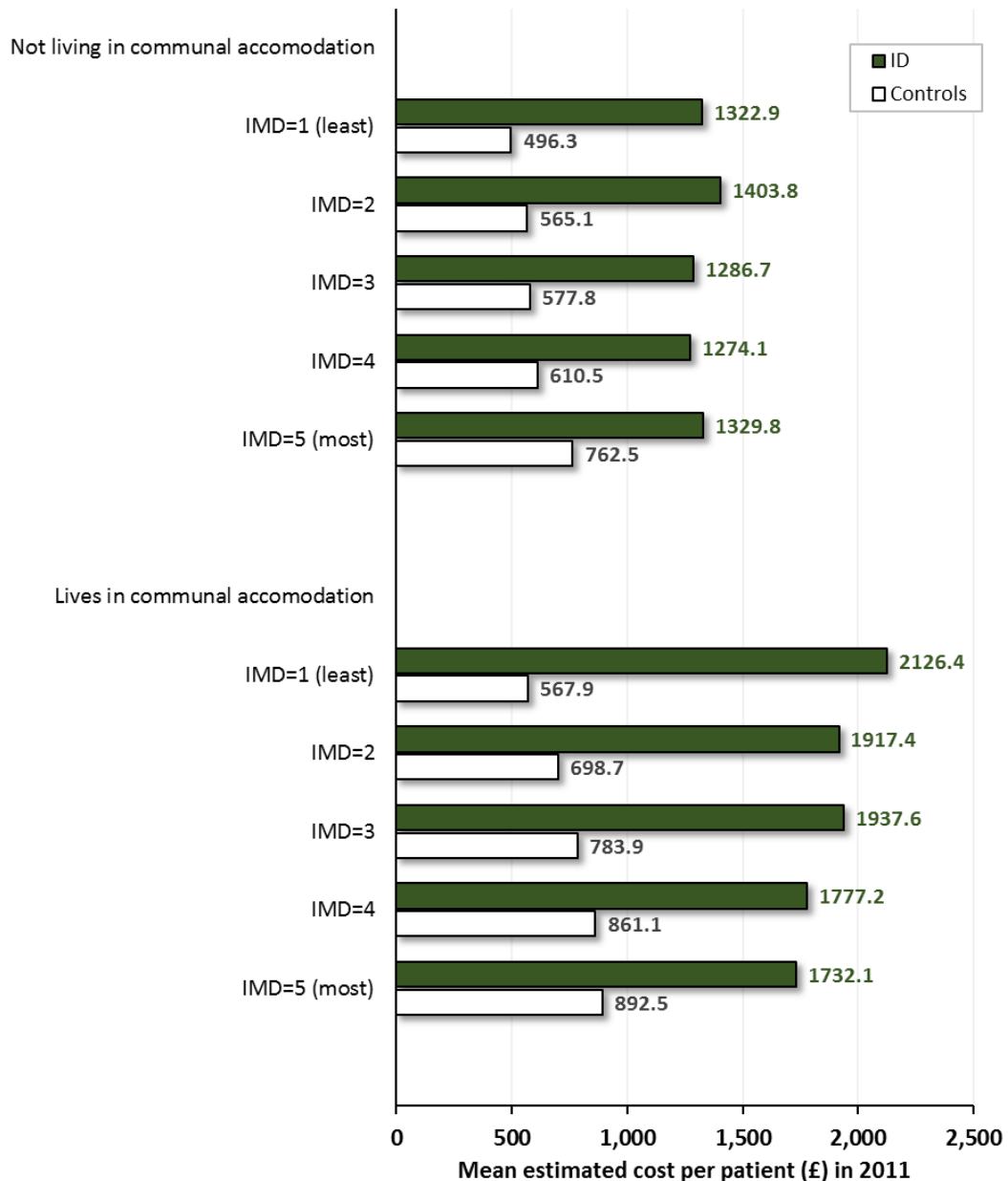
FIGURE 25: MEAN ANNUAL ESTIMATED NHS COSTS IN 2011 IN ID ADULTS AND CONTROLS BY IMD AND ACCOMMODATION STATUS OF ID ADULT

Chapter 4 Mortality

Introduction

As the CPRD dataset had been linked to ONS death registration data, it provided an opportunity to describe mortality differences between adults with ID and the age-sex matched controls in our study. While the date of death can be reasonably inferred from CPRD data, cause of death cannot be consistently identified. Therefore, we restricted mortality analyses to the 343 practices with linked data to ONS (see Figure 2). From these practices, a total of 16,666 adults with ID who were aged 18-84 years at the beginning of their follow up are included (see Figure 2), in addition to the 113,352 age-sex-practice controls without ID who were also registered at this point in time.

Please note that some of these results have already appeared in the publication by Hosking et al,[70] and are re-produced here under the terms of the Open Access license for non-commercial use with the publisher, the American Public Health Association.

Longitudinal design

More details of the longitudinal design for the analysis we devised are shown in Figure 26. All patients had to be registered for at least 30 days before being eligible for follow up. We define follow up to run from 1/1/2009 to 31/3/2013. Of the 16,666 adults with ID who are included, the majority (n=11,973) were already registered by 1/1/2009 and aged 18 years or more. To this core group we made two additions to the analysis cohort. Firstly, patients with ID registered by 1/1/2009 but who were not age 18 by then (n=1,027) were allowed entry into the cohort on 1st January of the year they turned 18 (assuming they were still registered at the practice). Secondly, adults with ID (n=3,666) who were not registered with their practice on 1/1/2009, but subsequently registered sometime during the study follow up (2009-12) were included from the point that they had spent 30 days registered with the study practice. Matched controls (n=113,352) were only included if they were registered at the defined entry point of the cohort for the adult with ID.
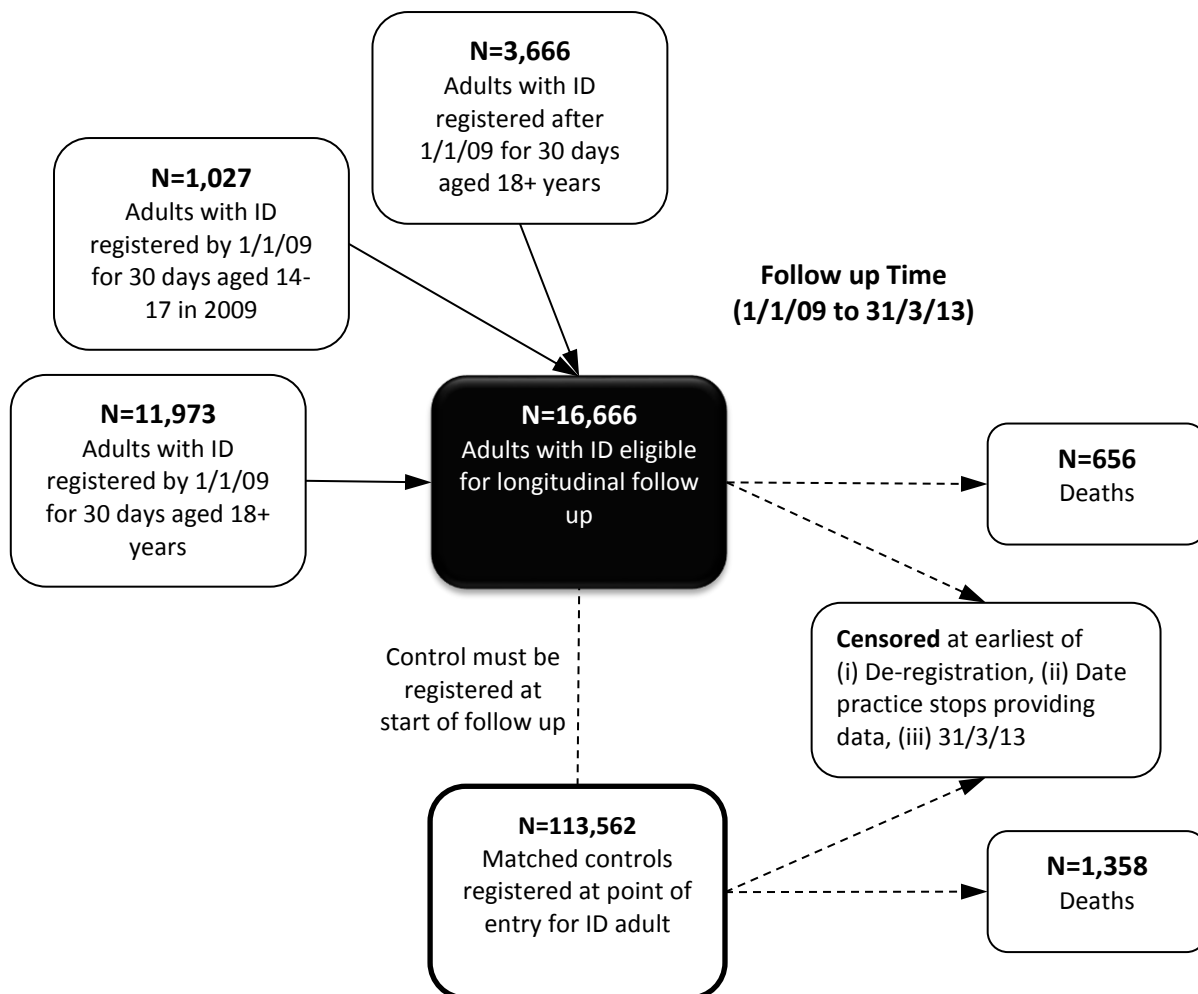
FIGURE 26: SUMMARY OF HOW THE LONGITUDINAL COHORT WAS CONSTRUCTED

All adults in the longitudinal cohort were followed to the earliest recorded event representing: (i) date of death, (ii) date of deregistration from the practice, (iii) date when their practice stopped providing data to CPRD, or (iv) 31/3/13 (Figure 26). Controls within a match-set were still followed to their end point date even if their matched adult with ID had exited the cohort earlier. The average length of follow up for all individuals was approximately 3 years (1,097 days).

The date of death recorded on the ONS record was primarily used for the majority of deaths. However, we would use the date derived from the CPRD record if it was clear that the patient had no further primary care contact from this date. This inconsistency was often only a few days, but for a small number of deaths it was approximately one year as it appeared that the year of death had been incorrectly recorded on the ONS record and was wrong by one digit (e.g. 2011 rather than 2010).

Cause of death and avoidable mortality

Underlying cause of death was derived from the ONS death registration data for patients who died during the study (656 adults with ID and 1,358 controls). For 38 (2%) of these deaths, we were unable to obtain cause of death from the ONS record. A full list of the ICD-10 codes used to group cause of death are listed in Appendix 7. When examining how often ID is recorded on death certificates, we searched all recorded main and contributory causes of death for ID associated codes, including an extended range of conditions weakly associated with ID such as cerebral palsy.[71]

Using the recorded cause of death, we further classified deaths as being potentially avoidable. We followed ONS guidelines which have used underlying cause of death to identify where there exists scope for intervention to reduce mortality.[72] Potentially avoidable deaths have been further classified as being either (i) *amenable* to good quality healthcare (treatable) or (ii) *preventable* through public health action or both. These definitions primarily include deaths under the age of 75 except for accidental deaths. For example, deaths due to asthma are identified as amenable to healthcare, through effective long-term treatment, while deaths due to lung cancer are identified as preventable, through tobacco control. As some causes of death are defined as both amenable and preventable (e.g. IHD), potentially avoidable mortality is smaller than the sum of amenable and preventable mortality.

Characteristics of ID adults in longitudinal analyses

Table 21 summarises the characteristics of the 16,666 adults with ID who are included in the longitudinal analyses. 58% were men, identical to what was seen in the cross-sectional

analyses (Table 5). What differed slightly in these analyses was how we defined a patient's age. We classified age here by their recorded age in the year of entry to the cohort, which was primarily 2009. Therefore, the average age of the longitudinal cohort is summarised as 39.9 years, whereas in the cross-sectional analysis based on a January 1st 2012 date it was 42.1 years.

TABLE 21: CHARACTERISTICS OF ID ADULTS ELIGIBLE FOR LONGITUDINAL ANALYSES

Characteristic	ID Adults			Controls
	N	% who are men	Mean age (sd)	N
All	16,666	%	39.9 (16.2)	113,562
Gender				
-Women	6,989	0%	41.3 (16.4)	47,587
-Men	9,677	100%	38.8 (15.9)	65,975
Age (at baseline)				
-18-34 years	6,981	61.2%	24.2 (5.1)	46,939
-35-54 years	6,283	57.4%	44.2 (5.4)	43,123
-55-84 years	3,402	52.9%	64.0 (7.1)	23,500
Down's syndrome*				
-Yes	1,793	55.0%	39.1 (14.4)	12,226
-No	14,873	58.4%	40.0 (16.4)	101,336
Severe health needs*				
-Yes	3,263	54.4%	41.4 (16.4)	22,298
-No	13,403	59.0%	39.5 (16.1)	91,264
Communal accommodation*				
-Yes	3,392	57.2%	47.2 (15.7)	23,117
-No	13,274	58.3%	38.0 (15.8)	90,445
Autism spectrum disorder*				
-Yes	1,532	73.2%	30.5 (13.3)	10,387
-No	15,134	56.5%	40.8 (16.1)	103,188
Epilepsy*				
-Yes	2,884	55.4%	41.0 (15.3)	19,705
-No	13,782	58.6%	39.6 (16.3)	93,857

* - Characteristic of adult with ID only. For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

All-cause mortality

During follow up from 1/1/2009 to 31/3/2013 a total of 656 (3.9%) adults with ID died compared to 1,358 (1.2%) of the matched controls. The crude mortality rate was 132.4 per 10,000 persons per year for adults with ID compared to 39.7 for controls (Table 22). Among adults with ID, there were elevated death rates among those with Down's syndrome (6.6%, 220.0 per 10,000 persons per year), high support needs (5.9%, 190.2), epilepsy (5.8%, 188.0) and those living in communal/shared accommodation (7.8%, 254.7). There were fewer deaths among the primarily younger subgroup with autism (1.0%, 36.3).

Hazard ratios (unadjusted and adjusted for co-morbidity, smoking and deprivation) for all-cause mortality are shown in Table 23. The overall hazard Ratio (HR) of 3.62 (95%CI 3.33–3.93) for ID adults versus controls was only partially explained by observed differences in co-morbidity between the groups (adjusted HR=3.05, 95%CI 2.73-3.41). While the hazard ratio for all-cause mortality was higher for men versus women, this difference was not statistically significant after adjustment (p=0.07). The higher mortality risk among adults with ID was seen at all ages. Prior to adjustment, the largest disparity between ID adults and controls was among the youngest ages (18-34 years), but the opposite was true after adjusting for co-morbidity and other factors. However, these age differences were not significant in either comparison.

Among adults with ID, those with Down's syndrome had a very high relative risk of death compared to controls (HR = 9.21, 95%CI 7.22-11.76), which was significantly different to the risk of death seen in ID without Down's (p<0.001), and not explained by further adjustment. Similarly, ID adults with severe support needs had a death rate nearly five times higher relative to their controls (HR=4.77, 95% CI 4.08-5.59), which was significantly different from ID adults without severe health needs, both before and after adjustment (p≤0.001). The same was true for ID adults recorded living in communal/shared living who had a similarly elevated death rate relative to their controls (HR=4.99, 95%CI 4.36-5.73). Epilepsy within the ID population, was a strong determinant of mortality risk, both relative to the controls (HR=6.04, 95%CI 5.04–7.24), and to other adults with ID without epilepsy (p<0.001).

TABLE 22: NUMBER OF DEATHS AND CRUDE DEATH RATES (PER 10,000 PERSONS PER YEAR) 2009-13 AMONG ID ADULTS AND CONTROLS

Characteristic	ID (n=16,666)			Controls (n=113,562)		
	n	%	Rate per 10,000	n	%	Rate per 10,000
All	656	3.94%	**132.4**	1,358	1.20%	**39.7**
Gender						
-Women	291	4.16%	**139.5**	538	1.13%	**37.5**
-Men	365	3.77%	**127.3**	820	1.20%	**41.5**
Age (at cohort entry)						
-18-34 years	48	0.69%	**25.3**	69	0.15%	**5.6**
-35-54 years	167	2.66%	**83.1**	276	0.64%	**19.6**
-55-84 years	441	12.69%	**420.0**	1,013	4.31%	**129.6**
Down's syndrome*						
-Yes	118	6.58%	**220.0**	92	0.75%	**24.9**
-No	538	3.62%	**121.8**	1,266	1.25%	**41.6**
Severe health needs*						
-Yes	194	5.94%	**190.2**	302	1.35%	**43.9**
-No	462	3.45%	**117.4**	1,056	1.16%	**38.7**
Communal accommodation*						
-Yes	265	7.81%	**254.7**	416	1.80%	**56.5**
-No	391	2.90%	**99.9**	942	1.04%	**35.1**
Autism spectrum disorder*						
-Yes	15	0.98%	**36.3**	44	0.42%	**16.0**
-No	641	4.24%	**141.2**	1,314	1.27%	**41.8**
Epilepsy*						
-Yes	167	5.79%	**188.0**	205	1.04%	**33.7**
-No	498	3.55%	**120.3**	1,153	1.23%	**41.0**

* - Characteristic of adult with ID only. For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

TABLE 23: HAZARD RATIOS FOR ALL CAUSE MORTALITY 2009-13 FOR ID ADULTS VERSUS CONTROLS

Characteristic	Base (unadjusted) model		Adjusted model†	
	HR (95% CI)	p-value‡	HR (95% CI)	p-value‡
All	**3.62** (3.33 – 3.93)	_	**3.05** (2.73 – 3.41)	_
Gender				
-Women	**4.10** (3.61 – 4.66)	0.01	**3.50** (2.94 – 4.16)	0.07
-Men	**3.30** (2.96 – 3.68)		**2.81** (2.43 – 3.24)	
Age (at cohort entry)				
-18-34 years	**4.29** (3.13 – 5.88)	_	**2.43** (1.56 – 3.77)	_
-35-54 years	**4.17** (3.52 – 4.92)	0.88	**3.22** (2.53 – 4.08)	0.25
-55-84 years	**3.39** (3.07 – 3.75)	0.21	**3.03** (2.65 – 3.46)	0.32
Down's syndrome*				
-Yes	**9.21** (7.22 – 11.76)	<0.001	**10.39** (7.13 – 15.13)	<0.001
-No	**3.19** (2.92 – 3.49)		**2.66** (2.36 – 3.00)	
Severe health needs*				
-Yes	**4.77** (4.08 – 5.59)	<0.001	**4.95** (4.03 – 6.07)	0.001
-No	**3.28** (2.98 – 3.62)		**3.15** (2.79 – 3.55)	
Communal accommodation*				
-Yes	**4.99** (4.36 – 5.73)	<0.001	**4.30** (3.52 – 5.26)	<0.001
-No	**3.05** (2.74 – 3.39)		**2.64** (2.30 – 3.02)	
Autism spectrum disorder*				
-Yes	**2.39** (1.45 – 3.96)	0.05	**2.22** (1.01 – 4.86)	0.40
-No	**3.66** (3.37 – 3.98)		**3.07** (2.74 – 3.43)	
Epilepsy*				
-Yes	**6.04** (5.04 – 7.24)	<0.001	**7.76** (6.10 – 9.86)	<0.001
-No	**3.18** (2.90 – 3.50)		**2.91** (2.60 – 3.27)	

* - Characteristic of adult with ID only. For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

† - Adjusted for nine co-morbidities (atrial fibrillation, cancer, COPD, dementia, diabetes mellitus, epilepsy, heart failure, severe mental illness and stroke) deprivation and smoking status, except for subgroup analysis for epilepsy and severe health needs where epilepsy is not included in the adjustment

‡ - P value for differences between subgroups (for age: 18-34 years is taken as baseline group)

The differences in mortality between sub-groups was further investigated in additional (un-matched) analyses that directly compared adults with ID in each sub-group (Table 24) and adjusted for age, sex and other confounders. These confirmed the earlier findings in Table 23. For example, an ID adult with Down's syndrome had a risk of death nearly three times as high (HR=2.91, 95%CI 2.31-3.66) as that for an ID adult without Down's syndrome. ID adults living in communal accommodation, or with severe health needs, or with epilepsy had risks of deaths 44%, 52% and 73% respectively higher than ID adults without each of those criteria. ID adults with autism were at lower risk of death (HR=0.56, 95%CI 0.34-0.94) than ID adults without autism.

TABLE 24: HAZARD RATIOS FOR ALL CAUSE MORTALITY 2009-13 AMONG ID ADULT SUB-GROUPS ONLY

Characteristic	ID Adults	Base model†	Adjusted model‡
	N	**HR** (95% CI)	**HR** (95% CI)
Down's syndrome			
-Yes	1,793	**2.92** (2.37 – 3.59)	**2.91** (2.31 – 3.66)
-No	14,873	1	1
Severe health needs*			
-Yes	3,263	**1.48** (1.23 – 1.77)	**1.52** (1.27 – 1.83)
-No	13,403	1	1
Communal accommodation*			
-Yes	3,392	**1.60** (1.33 – 1.92)	**1.44** (1.19 – 1.74)
-No	13,274	1	1
Autism spectrum disorder			
-Yes	1,532	**0.55** (0.34 – 0.90)	**0.56** (0.34 – 0.94)
-No	15,134	1	1
Epilepsy			
-Yes	2,884	**1.64** (1.37 – 1.97)	**1.73** (1.43 – 2.09)
-No	13,782	1	1

* - For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

† - Adjusted for age and sex only

‡ - Adjusted for age, sex, nine co-morbidities (atrial fibrillation, cancer, COPD, dementia, diabetes mellitus, epilepsy, heart failure, severe mental illness and stroke) deprivation and smoking status, except for subgroup analysis for epilepsy and severe health needs where epilepsy is not included in the adjustment

Cause specific mortality

The higher mortality risk in adults with ID produced different patterns of cause specific mortality when compared with the matched controls (Figure 27). In ID adults the most common causes of mortality were circulatory diseases (22%), respiratory diseases (18%), neoplasms (15%) and nervous system diseases (12%). This is different to the pattern in controls where neoplasms (37%), circulatory (27%), respiratory (10%) and external causes (7%) were the most common.

Cause of death is explored in more detail in Table 25, which shows the number of deaths and rate (per 10,000 persons per year) for ID adults and controls for main causes, and specific sub-groups of these where numbers allow. Notable specific contributions to mortality among people with ID in comparison to controls were dementia (n=27, rate=5.5 versus 0.5 per 10,000 persons per year), epilepsy (n=29, rate=5.9 versus 0.1 per 10,000 persons per year), pneumonia (n=67, rate=13.5 versus 1.1 per 10,000 persons per year) and aspiration pneumonitis (n=21, rate=4.2 versus 0.2 per 10,000 persons per year). On the other hand, transport accidents (n=1) and intentional self-harm (n=0) were rare or non-existent recorded causes of death among adults with ID.

While cancer (neoplasms) as a cause of death, represented a lower proportion of all deaths among ID adults (Figure 27), the death rate from cancer overall was marginally higher for ID adults (19.8 versus 14.9 per 10,000 per year). There was however some variation in types of cancer recorded as the cause of death. Colorectal (n=17) was the most common recorded cause among adults with ID, whereas among the matched controls lung (n=117) was far more frequent. Urinary tract cancers (n=2), prostate cancer (n=2), and oesophageal cancer (n=0) were rarely recorded causes of death among ID adults.

The most common underlying cause of death in ID adults with Down's syndrome (n=118) was respiratory diseases (n=24, 20%). An additional 30 deaths (25%) had Down's syndrome or other chromosomal abnormalities given as the underlying cause. Almost all of these (n=26) had respiratory disease listed as a secondary cause. If these 26 deaths were assumed to be due to respiratory disease, then the percentage of Down's syndrome deaths caused by respiratory diseases would rise to 42%.

ID ADULTS

Congenital /chromosomal abnormalities 7%
Other 5%
Not available 1%
Circulatory 22%
Neoplasms 15%
Respiratory 19%
Digestive 7%
Genitourinary 3%
Mental & behavioural 5%
Nervous system 12%
External causes 4%

CONTROLS

External causes 8%
Nervous system 3%
Other 4%
Not available 2%
Mental & behavioural 2%
Genito-urinary 1%
Circulatory 27%
Digestive 6%
Respiratory 10%
Neoplasms 37%

FIGURE 27: RECORDED CAUSE OF DEATH DURING 2009-13 IN ID ADULTS AND CONTROLS

TABLE 25: NUMBER OF DEATHS AND CRUDE DEATH RATES (PER 10,000 PERSONS PER YEAR) BY CAUSE OF DEATH 2009-13 AMONG ID ADULTS AND CONTROLS

Cause of Death	ID (n=16,666)		Controls (n=113,562)	
	n	Rate per 10,000	n	Rate per 10,000
Infectious and parasitic disorders	3	**0.6**	14	**0.4**
Neoplasms	98	**19.8**	508	**14.9**
- Oesophageal	0	**0.0**	16	**0.5**
- Colorectal	17	**3.4**	44	**1.3**
- Pancreatic	6	**1.2**	22	**0.6**
- Lung	10	**2.0**	117	**3.4**
- Breast	7	**1.4**	36	**1.1**
- Prostate	2	**0.4**	28	**0.8**
- Urinary Tract	2	**0.4**	30	**0.9**
- Lymphoma	10	**2.0**	40	**1.2**
Endocrine, nutritional & metabolic diseases	13	**2.6**	16	**0.5**
Mental and behavioural disorders	35	**7.1**	31	**0.9**
- Dementia	27	**5.5**	17	**0.5**
Diseases of the nervous system	76	**15.3**	39	**1.1**
-Epilepsy	29	**5.9**	3	**0.1**
Diseases of the circulatory system	142	**28.7**	360	**10.5**
- Ischaemic heart disease	62	**12.5**	188	**5.5**
- Cerebrovascular disease	34	**6.9**	57	**1.7**
Diseases of the respiratory system	123	**24.8**	135	**3.9**
- Pneumonia	67	**13.5**	39	**1.1**
- COPD	19	**3.8**	59	**1.7**
- Aspiration pneumonitis	21	**4.2**	6	**0.2**
Diseases of the digestive system	46	**9.3**	87	**2.5**
- Liver disease	8	**1.6**	44	**1.3**
Diseases of the musculoskeletal system	6	**1.2**	8	**0.2**
Diseases of the genitourinary system	23	**4.6**	15	**0.4**
Congenital /chromosomal abnormalities	45	**9.1**	2	**0.06**
External causes of morbidity	27	**5.5**	101	**3.0**
- Transport accidents	1	**0.2**	20	**0.6**
- Other external causes of accidental injury	20	**4.0**	31	**0.9**
- Intentional self-harm	0	**0.0**	35	**1.0**
Other (skin, blood diseases, residual codes)	10	**2.0**	13	**0.4**
Not available	9	**1.8**	29	**0.8**

Hazard ratios for selected grouped causes of death are shown in Table 26. These are presented for the unadjusted model only, which accounts for age and sex differences via the matching. These were calculated for both the main groupings (i.e. neoplasms) and where possible sub-groups (e.g. colorectal cancer). It was not possible to calculate a hazard ratio for deaths from congenital or chromosomal abnormalities due to the small number of control deaths.

The largest (estimable) relative difference in risk of death between adults with and without ID for the main groups, was seen for nervous system disorders primarily epilepsy (HR=13.79, 95% CI 9.70–19.62), followed by diseases of the genitourinary system including urinary tract infections (HR=10.89, 95% CI=6.09–19.47). Other notable disparities were seen for diseases of the respiratory system (HR=6.68, 95% CI 5.38–8.29) with aspiration pneumonitis (HR=28) and pneumonia deaths (HR=13) being key contributors, and mental and behaviour disorders (HR=7.99, 95% CI 5.19–12.31), which were influenced by the higher risk of dementia related deaths (HR=12).

While deaths from cancer represented a smaller proportion of deaths among adults with ID than the general population, the overall risk of death from neoplasms was still marginally higher (HR=1.44, 95% CI 1.18-1.76). Cancer specific estimates were imprecise due to the small number of deaths with each type, but deaths from colorectal cancer were notably higher for adults with ID (HR=2.82, 95%CI 1.71-4.63). Deaths from lung and prostate cancer both produced HR<0.7 but confidence intervals were wide.

TABLE 26: HAZARD RATIOS FOR CAUSE SPECIFIC MORTALITY 2009-13 FOR ID ADULTS VERSUS CONTROLS

Cause of death	Base (unadjusted) model
	HR (95% CI)
Infectious and parasitic disorders	**2.30** (0.70 – 7.48)
Neoplasms	**1.44** (1.18 – 1.76)
- Oesophageal	*
- Colorectal	2.82 (1.71 – 4.63)
- Pancreatic	1.92 (0.89 – 4.14)
- Lung	0.69 (0.37 – 1.28)
- Breast	1.42 (0.69 – 2.94)
- Prostate	0.54 (0.13 – 2.19)
- Urinary Tract	0.90 (0.15 – 2.37)
- Lymphoma	1.72 (0.91 – 3.26)
Endocrine, nutritional & metabolic diseases	**5.38** (2.79 – 10.07)
Mental and behavioural disorders	**7.99** (5.19 – 12.31)
- Dementia	12.18 (6.84 – 21.69)
Diseases of the nervous system	**13.79** (9.70 – 19.62)
-Epilepsy	180.6 (24.9 – 1308.2)
Diseases of the circulatory system	**3.05** (2.56 – 3.64)
- Ischaemic heart disease	2.50 (1.93 -3.23)
- Cerebrovascular disease	4.88 (3.34 – 7.12)
Diseases of the respiratory system	**6.68** (5.38 – 8.29)
- Pneumonia	13.09 (9.09 – 18.87)
- COPD	2.43 (1.52 – 3.87)
- Aspiration pneumonitis	27.73 (11.48 – 66.95)
Diseases of the digestive system	**4.02** (2.92 – 5.54)
- Liver disease	1.31 (0.65 – 2.66)
Diseases of the musculoskeletal system	**5.50** (2.22 – 13.61)
Diseases of the genitourinary system	**10.89** (6.09 – 9.47)
Congenital /chromosomal abnormalities	*
External causes of morbidity	**1.85** (1.26 – 2.71)
- Transport accidents	0.32 (0.05 -2.26)
- Other external causes of accidental injury	4.94 (3.02 – 8.07)
- Intentional self-harm	*
Other (skin, blood diseases, residual codes)	**5.03** (2.40 – 10.54)
Not available	**2.27** (1.19 – 4.43)

* - Not estimable due to insufficient numbers.

Potentially avoidable mortality

The proportion of all deaths classified as potentially avoidable (amenable and/or preventable) was similar in adults with ID (n=304, 46.3%) and controls (n=645, 47.5%). However, amenable and preventable deaths showed very different proportions in the two groups (Figure 28). Within adults with ID, the percentage of amenable deaths (n=243, 37.0%) was notably higher than seen in controls (n=305, 22.5%). This difference is reflected in a large estimated hazard ratio (HR=5.86, 95% CI 5.06–6.80) for deaths amenable to healthcare among ID adults versus controls. This may be an under estimate as standard ONS definitions do not include a number of causes of deaths in people with ID which may be considered amenable, such as deaths from UTI (n=12, 1.7%) and aspiration pneumonitis (n=21, 3.1%).

The pattern with preventable deaths was different, which represented a smaller proportion of deaths among adults with ID (n=127, 19.4%) than controls (n=543, 40.0%). However preventable deaths were still marginally more likely overall among adults with ID (HR=1.69, 95% CI 1.42–2.02).

Recording of ID on death certificates

Finally, we electronically searched the linked ONS death certification data for any mention of ID or a related condition, as either a main cause, or contributory cause of death. Only 200 (30.9%) of the linked 647 deaths had any such mention. Therefore, for 7 in 10 deaths among adults with ID there was no mention of their ID on their death certificate. For those with a recorded cause associated with ID, the most common causes listed were Down's syndrome (n=88), cerebral palsy (n=39) and developmental disorder of scholastic skills (n=50).

Adults with ID

All mortality (100%, Rate = 132.4)

Amenable
(37%, Rate=49.1)

Preventable
(19%, Rate=25.6)

Controls

Amenable
(23%, Rate=8.9)

Preventable
(40%, Rate=15.9)

Amenable
Hazard Ratio = 5.86
(95% CI = 5.06 – 6.80)

Preventable
Hazard Ratio = 1.69
(95% CI = 1.42 – 2.02)
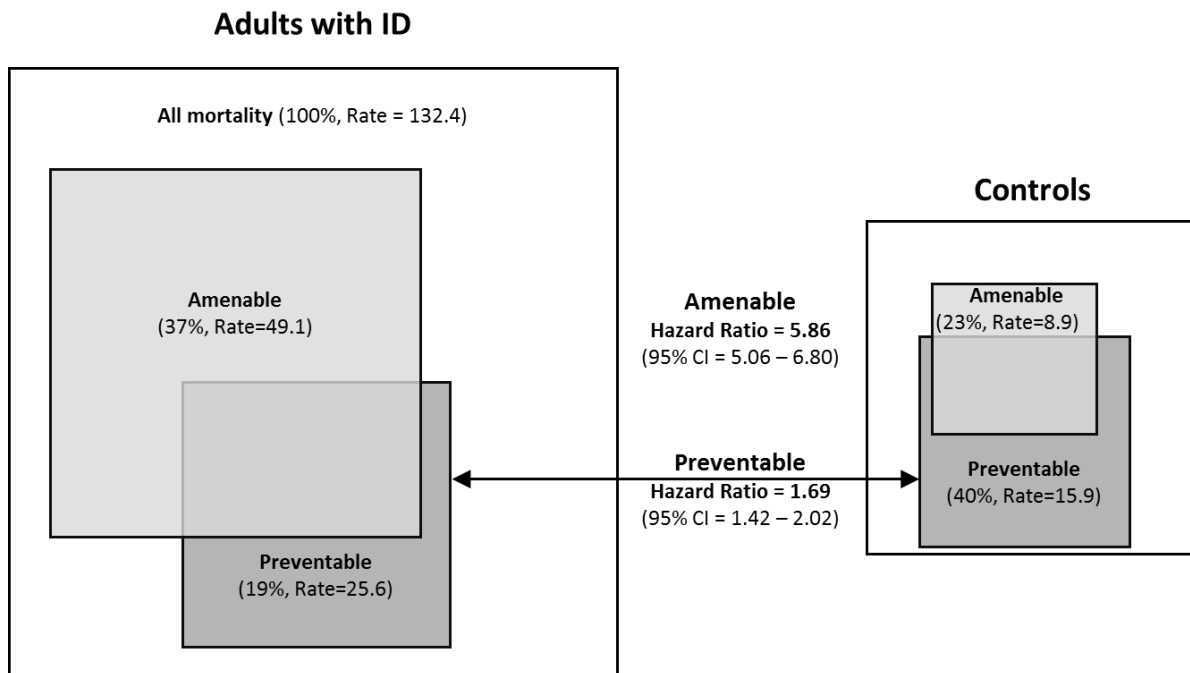
Note: Sizes of squares represent both rate and percentage of overall mortality, rates given are per 10,000 people per year. The overall sub-group of avoidable mortality is the total area covered by Amenable and/or Preventable (ID rate = 61.4 (46.3% of all mortality) and control rate =18.9 (47.5%), HR = 3.44 (3.05 – 3.89)).

Figure re-produced from Hosking et al[70]

FIGURE 28: AMENABLE AND PREVENTABLE MORTALITY DURING 2009-13 AMONG ID ADULTS AND CONTROLS

Chapter 5 Hospital Admissions

Introduction

In this section, we use the linked hospital admissions data from the HES dataset to provide a summary of hospitalisations during our study for adults with ID, and compare the volume and type of admissions with the matched controls. We also take advantage of the linkage by comparing the primary care record prior to admission for two infections, urinary tract (UTI) and lower respiratory tract (LRTI), which we suspected would be common in both ID adults and the general population[41].

Analyses are again based on 343 practices with linked data (see Figure 2). We used the same longitudinal design that was introduced for mortality analyses in Chapter 4, involving a total of 16,666 adults with ID and 113,352 age-sex-practice controls without ID (see Figure 26). Follow-up was from 1/1/2009 to a maximum date of 31/3/2013 (see page 95 for more details), with the average length for all individuals being approximately 3 years (1,097 days). The characteristics of the ID adults and controls used in the analysis have previously been described in Table 21.

Categorising admissions

The HES dataset contains information on every admission to an NHS hospital in England.[73] This includes information on the date, duration, type (e.g. elective) and the primary reason for admission (coded using ICD-10). Although multiple episodes can sometimes occur within a continuous period of hospitalisation (such as when a patient is transferred to a different consultant), we decided to focus solely on the initial episode, as we were interested in the reason for admission which it represents.[41]

We categorised admissions using the method of admission variable ADMIMETH[74] into the following groups: emergency, elective, maternity and other (such as transfers from other hospital providers). Within emergency admissions, we further identified a sub-group of admissions for ambulatory care sensitive conditions (ACSCs),[41] which represent a group thought to be potentially preventable with better clinical management. We included 20 widely used ACSCs, but also considered an additional five conditions relevant to the ID

population.[13,75] These were: constipation, aspiration, gastro-oesophageal reflux disease (GORD), osteoporosis and schizophrenia. We chose not to use osteoporosis, since it was rarely recorded as the primary reason for admission, or schizophrenia, due to the idiosyncratic recording of elective vs. emergency for many English psychiatric admissions[12]. This resulted in a total of 23 ACSCs (see Appendix 8**Error! Reference source not found.**).

For elective admissions, a small number of patients were receiving regular elective hospital procedures during the study (e.g. dialysis) and their inclusion was potentially problematic for calculating an overall rate. We made the pragmatic choice to exclude patients in our analyses of elective admission rates who averaged more than 6 elective admissions per year. This represented about 0.20% of the cohort (n=32 ID adults, n=233 controls).

Summary of overall admissions

Admissions rates (per 1,000 persons per year) by type are shown in Figure 29. The overall rate for adults with ID was 351.6 per 1,000 persons per year compared to 246.4 in controls. This difference was essentially due to the higher rate among emergency admissions (182.2 vs. 67.7 per 1,000 persons per year) as elective rates were similar between groups.
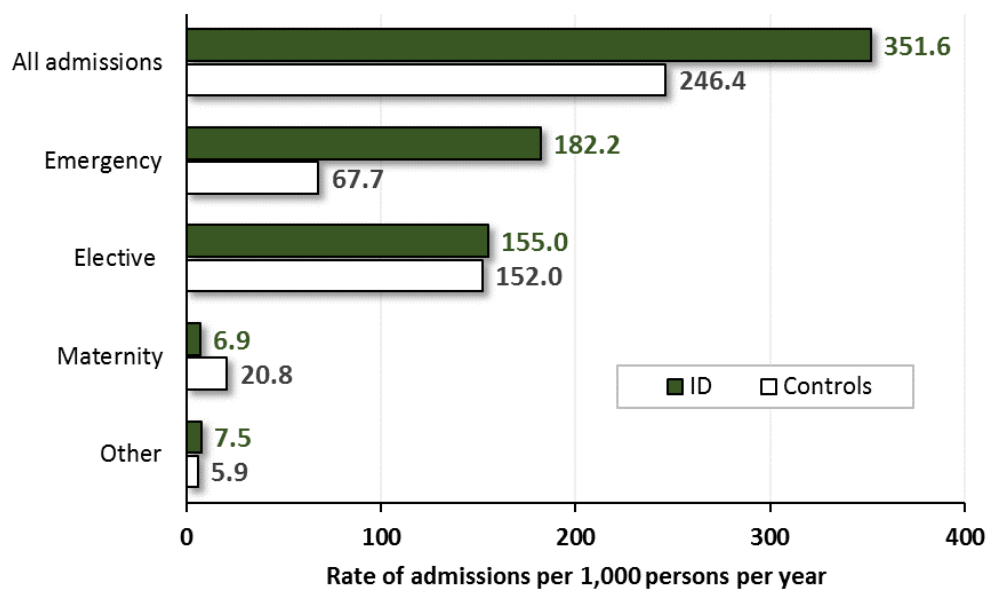
FIGURE 29: HOSPITAL ADMISSIONS RATES DURING 2009-13 FOR ID ADULTS AND CONTROLS

Of the 16,666 adults with ID, 5,924 (35.5%) had an emergency or elective admission during follow up. By comparison, among the age-, sex-, practice- matched controls (n=113,562), 30,676 (27.0%) had at least one emergency or elective admission during follow up. For emergency admissions only, 3,847 (23.1%) adults with ID had at least one admission compared to 13,496 (11.9%) of the controls. Only 2,525 (66%) of these adults with ID had any corresponding mention of ID on their hospital record. A total of 1,809 (10.9%) adults with ID had multiple emergency admissions compared to 4,326 (3.8%) of the controls.

Emergency admissions by sub-groups

A summary of emergency hospitalisation rates among sub-groups within adults with ID and matched controls is shown in Table 27. A statistical comparison of the rates is then shown in Table 28, which estimates the incidence rate ratios (IRRs) for hospitalisation for ID adults versus controls using conditional Poisson regression (see statistical methods, page 36). These are presented unadjusted (accounting only for the matching factors) and then adjusted for co-morbidities (atrial fibrillation, cancer, COPD, dementia, diabetes mellitus, epilepsy, heart failure, severe mental illness and stroke), smoking and deprivation. Sub-group comparisons used IRR's and confidence intervals derived from ID vs. control comparisons to calculate p-values for differences between them.

The overall rate for emergency hospitalisation in adults with ID (182.2 per 1,000 persons per year) represented a nearly three times increase (IRR=2.82, 95% CI 2.66-2.98) compared to their matched controls. This remained more than double (HR=2.16, 95% CI 2.02-2.30) when adjusting for co-morbidities, smoking and deprivation. While admission rates appeared higher for women with ID than men (203.8 vs. 166.5 per 1,000 persons per year), this difference was not significantly different (p=0.36). The disparity for emergency admissions between adults with ID and controls was more marked with increasing age.

Higher rates of emergency admission were seen in ID adults with severe health needs (243.9 per 1,000 persons per year) versus those without severe health needs (166.2). Compared to their matched controls, ID adults with severe health needs were at nearly four times the risk of emergency hospitalisation (IRR=3.83, 95% CI 3.42-4.28). This disparity was significantly different from the increased risk seen in ID adults without severe health needs (p<0.001).

TABLE 27: NUMBER OF EMERGENCY ADMISSIONS DURING 2009-2013 AND RATE (PER 1,000 PERSONS PER YEAR) AMONG ID ADULTS AND CONTROLS

Characteristic	ID (n=16,666)			Controls (n=113,562)		
	No. of People	Admiss-ions	Rate per 1,000	No. of People	Admiss-ions	Rate per 1,000
All	16,666	9,026	**182.2**	113,562	23,148	**67.7**
Gender						
-Women	6,989	4,250	**203.8**	47,587	10,613	**73.5**
-Men	9,677	4,776	**166.5**	65,975	12,535	**63.4**
Age (at baseline)						
-18-34 years	6,981	2,374	**125.3**	46,939	6,217	**50.5**
-35-54 years	6,283	3,201	**159.3**	43,123	7,812	**55.6**
-55-84 years	3,402	3,451	**328.7**	23,500	9,119	**116.7**
Down's syndrome*						
-Yes	1,793	804	**150.0**	12,226	2,326	**62.9**
-No	14,873	8,222	**186.1**	101,336	20,822	**68.2**
Severe health needs*						
-Yes	3,263	2,487	**243.9**	22,298	4,826	**70.2**
-No	13,403	6,539	**166.2**	91,264	18,322	**67.1**
Communal accommodation*						
-Yes	3,392	2,141	**205.7**	23,117	5,523	**75.0**
-No	13,274	6,885	**175.9**	90,445	17,625	**65.7**
Autism spectrum disorder*						
-Yes	1,532	339	**82.1**	10,374	1,459	**53.2**
-No	15,134	8,687	**191.3**	103,188	21,689	**69.0**
Epilepsy*						
-Yes	2,884	2,725	**306.8**	19,705	4,108	**67.5**
-No	13,782	6,301	**155.0**	93,587	19,040	**67.7**

* - Characteristic of adult with ID only. For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

TABLE 28: INCIDENCE RATE RATIOS FOR EMERGENCY HOSPITAL ADMISSIONS DURING 2009-2013 FOR ID ADULTS VERSUS CONTROLS

Characteristic	Base (unadjusted) model		Adjusted model†	
	IRR (95% CI)	p-value‡	IRR (95% CI)	p-value‡
All	**2.82** (2.66 – 2.98)	_	**2.16** (2.02 – 2.30)	_
Gender				
-Women	**2.90** (2.66 – 3.15)	0.36	**2.09** (1.89 – 2.30)	0.45
-Men	**2.75** (2.55 – 2.96)	_	**2.20** (2.01 – 2.41)	_
Age (at baseline)				
-18-34 years	**2.54** (2.31 – 2.80)	_	**1.81** (1.61 – 2.04)	_
-35-54 years	**2.96** (2.69 – 3.25)	0.03	**2.10** (1.87 – 2.37)	0.09
-55-84 years	**2.90** (2.63 – 3.19)	0.06	**2.43** (2.19 – 2.70)	<0.001
Down's syndrome*				
-Yes	**2.61** (2.23 – 3.05)	0.31	**2.37** (1.97 – 2.84)	0.27
-No	**2.84** (2.68 – 3.01)	_	**2.11** (1.96 – 2.26)	_
Severe health needs*				
-Yes	**3.67** (3.32 – 4.05)	<0.001	**3.83** (3.42 – 4.28)	<0.001
-No	**2.59** (2.42 – 2.77)	_	**2.32** (2.16 – 2.49)	_
Communal accommodation*				
-Yes	**2.91** (2.63 – 3.22)	0.50	**2.15** (1.88 – 2.47)	0.95
-No	**2.79** (2.61 – 2.98)	_	**2.16** (2.00 – 2.33)	_
Autism spectrum disorder*				
-Yes	**1.60** (1.32 – 1.94)	<0.001	**1.24** (0.98 – 1.57)	<0.001
-No	**2.90** (2.74 – 3.07)	_	**2.21** (2.07 – 2.37)	_
Epilepsy*				
-Yes	**4.80** (4.32 – 5.33)	<0.001	**4.98** (4.44 – 5.59)	<0.001
-No	**2.39** (2.24 – 2.56)	_	**2.15** (2.00 – 2.30)	_

* - Characteristic of adult with ID only. For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

† - Adjusted for nine co-morbidities (atrial fibrillation, cancer, COPD, dementia, diabetes mellitus, epilepsy, heart failure, severe mental illness and stroke) deprivation and smoking status, except for subgroup analysis for epilepsy and severe health needs where epilepsy is not included in the adjustment

‡ - P value for differences between sub-groups (for age: 18-34 years is taken as baseline group)

Rates of emergency admission did not significantly vary by living arrangement or by Down's syndrome, when the rate ratio between adults with ID and matched controls was compared (Table 28). However, there were significant variations in rates of emergency admission by whether the adult with ID had epilepsy or autism. Adults with ID and epilepsy had emergency hospitalisation rates approximately double that of adults with ID without epilepsy (306.8 vs. 155.0 per 1,000 persons per year). Adults with ID and autism had emergency hospitalisation rates less than half that of adults with ID without autism (82.1 vs. 191.3 per 1,000 persons per year).

Direct comparison between sub-groups among adults with ID are shown in Table 29 with IRR's adjusted for age, sex and co-morbidity. This confirmed the doubling of emergency hospitalisations among those with epilepsy (adjusted HR=2.1), as well as the higher rate among adults with severe health needs (HR=1.5) and lower rates among those with autism (HR=0.6).

Emergency admissions for ACSCs

Emergency admissions for ACSCs were much higher among adults with ID compared to controls (61.3 vs. 11.7 per 1,000 persons per year). Additionally, the proportion of emergency admissions for ACSCs among adults with ID was much higher (33.7% vs. 17.3% for controls). When this relationship with ACSCs was further explored by age (Figure 30), the proportion of emergency admissions which were ACSCs (red shading) remained constant across age for adults with ID. Within the controls however, this proportion increased from 12% in the youngest to 24% in the oldest age-group.

TABLE 29: INCIDENCE RATE RATIOS FOR EMERGENCY ADMISSIONS DURING 2009-13 AMONG ID ADULT SUBGROUPS ONLY

Characteristic	ID Adults	Base model†	Adjusted model‡
	N	**IRR** (95% CI)	**IRR** (95% CI)
Down's syndrome			
-Yes	1,793	**0.86** (0.74 – 1.00)	**1.10** (0.95 – 1.25)
-No	14,873	1	1
Severe health needs*			
-Yes	3,263	**1.40** (1.24 – 1.58)	**1.54** (1.37 – 1.74)
-No	13,403	1	1
Communal accommodation*			
-Yes	3,392	**1.03** (0.89 – 1.20)	**1.00** (0.87 – 1.16)
-No	13,274	1	1
Autism spectrum disorder			
-Yes	1,532	**0.58** (0.47 – 0.71)	**0.61** (0.49 – 0.75)
-No	15,134	1	1
Epilepsy			
-Yes	2,884	**1.95** (1.76 – 2.17)	**2.14** (1.91 – 2.39)
-No	13,782	1	1

* - For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

† - Adjusted for age and sex only

‡ - Adjusted for age, sex, nine co-morbidities (atrial fibrillation, cancer, COPD, dementia, diabetes mellitus, epilepsy, heart failure, severe mental illness and stroke) deprivation and smoking status, except for sub-group analysis for epilepsy and severe health needs where epilepsy is not included in the adjustment
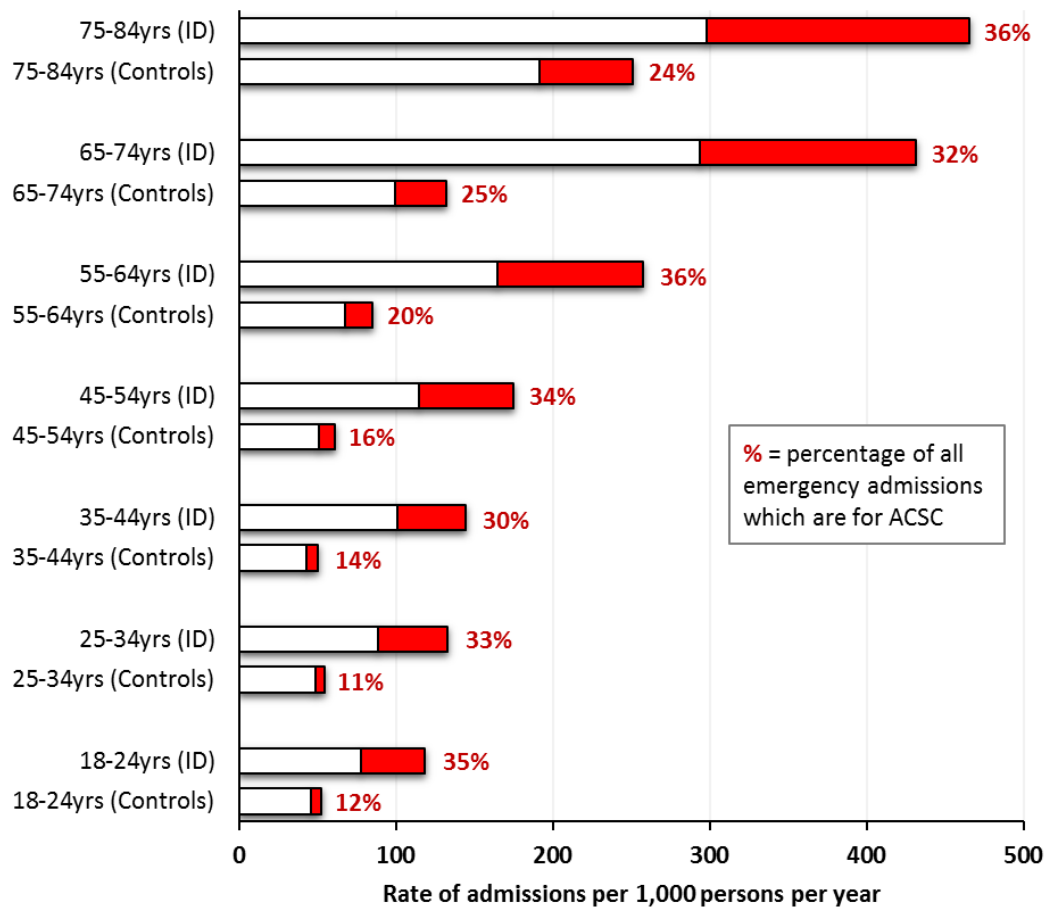
FIGURE 30: EMERGENCY ADMISSIONS, OVERALL AND FOR AMBULATORY CARE SENSITIVE CONDITIONS DURING 2009-13 BY AGE GROUP IN ID ADULTS AND CONTROLS

Emergency admissions for ACSCs are now summarised in ID adults and controls by sub-group in Table 30 (rates per 1,000 persons per year) and in Table 31 (unadjusted and adjusted IRRs). The relative difference in admission rate was over five times higher for ID adults (IRR=5.62, 95% CI 5.14-6.13). Adjusting for co-morbidity explained some of this difference, but adults with ID were still over three times more likely to have an admission for an ACSC (IRR=3.60, 95% CI 3.25–3.99).

TABLE 30: NUMBER AND RATE (PER 1,000 PERSONS PER YEAR) OF EMERGENCY ADMISSIONS FOR AMBULATORY CARE SENSITIVE CONDITIONS DURING 2009-13 AMONG ID ADULTS AND CONTROLS

Characteristic	ID (n=16,666)			Controls (n=113,562)		
	Admiss-ions	Rate per 1,000	% of all emerg.	Admiss-ions	Rate per 1,000	% of all emerg.
All	3,038	**61.3**	33.7%	4,008	**11.7**	17.3%
Gender						
-Women	1,428	**68.5**	33.6%	1,885	**13.1**	17.8%
-Men	1,610	**56.1**	33.7%	2,123	**10.7**	16.9%
Age (at baseline)						
-18-34 years	805	**42.5**	33.9%	759	**6.2**	12.2%
-35-54 years	1,041	**51.8**	32.5%	1,204	**8.6**	15.4%
-55-84 years	1,192	**113.5**	34.5%	2,045	**26.2**	22.4%
Down's syndrome*						
-Yes	392	**73.1**	48.8%	345	**9.3**	14.8%
-No	2,646	**59.9**	32.2%	3,663	**12.0**	17.6%
Severe health needs*						
-Yes	1,154	**113.2**	46.4%	830	**12.1**	17.2%
-No	1,884	**47.9**	28.8%	3,178	**11.6**	17.3%
Communal accommodation*						
-Yes	915	**87.9**	42.7%	1,032	**14.0**	18.7%
-No	2,123	**54.2**	30.8%	2,976	**11.1**	16.9%
Autism spectrum disorder*						
-Yes	116	**28.1**	34.2%	192	**7.0**	13.2%
-No	2,922	**64.3**	33.6%	3,816	**12.1**	17.6%
Epilepsy*						
-Yes	1,413	**159.1**	51.9%	723	**11.9**	17.6%
-No	1,625	**40.0**	28.8%	3,285	**11.7**	17.3%

* - Characteristic of adult with ID only. For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

TABLE 31: INCIDENCE RATE RATIOS FOR EMERGENCY ADMISSIONS FOR AMBULATORY CARE SENSITIVE CONDITIONS DURING 2009-2013 FOR ID ADULTS VERSUS CONTROLS

Characteristic	Base (unadjusted) model		Adjusted model†	
	IRR (95% CI)	p-value‡	IRR (95% CI)	p-value‡
All	**5.62** (5.14 − 6.13)	_	**3.60** (3.25 − 3.99)	_
Gender				
-Women	**5.68** (5.03 − 6.42)	0.81	**3.35** (2.87 − 3.91)	0.16
-Men	**5.56** (4.91 − 6.30)	_	**3.89** (3.39 − 4.46)	_
Age (at baseline)				
-18-34 years	**7.12** (5.96 − 8.51)	_	**3.06** (2.47 − 3.79)	_
-35-54 years	**6.34** (5.43 − 7.39)	0.34	**3.25** (2.74 − 3.87)	0.67
-55-84 years	**4.56** (4.00 − 5.20)	<0.001	**4.09** (3.52 − 4.76)	0.03
Down's syndrome*				
-Yes	**10.00** (7.54 − 13.28)	0.001	**8.28** (5.73 − 11.98)	0.002
-No	**5.26** (4.79 − 5.77)	_	**3.21** (2.88 − 3.58)	_
Severe health needs*				
-Yes	**10.31** (8.81 − 12.07)	<0.001	**11.78** (9.78 − 14.19)	<0.001
-No	**4.40** (3.95 − 4.90)	_	**4.28** (3.80 − 4.81)	_
Communal accommodation*				
-Yes	**6.86** (5.78 − 8.14)	0.01	**4.98** (4.01 − 6.20)	0.006
-No	**5.20** (4.70 − 5.76)	_	**3.35** (2.98 − 3.77)	_
Autism spectrum disorder*				
-Yes	**4.14** (2.94 − 5.83)	0.05	**2.42** (1.54 − 3.81)	0.04
-No	**5.69** (5.20 − 6.23)	_	**3.69** (3.33 − 4.10)	_
Epilepsy*				
-Yes	**14.84** (12.59 − 17.49)	<0.001	**16.77** (13.83 − 20.34)	<0.001
-No	**3.64** (3.29 − 4.03)	_	**3.46** (3.10 − 3.87)	_

* - Characteristic of adult with ID only. For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

† - Adjusted for nine co-morbidities (atrial fibrillation, cancer, COPD, dementia, diabetes mellitus, epilepsy, heart failure, severe mental illness and stroke) deprivation and smoking status, except for subgroup analysis for epilepsy and severe health needs where epilepsy is not included in the adjustment

‡ - P value for differences between subgroups (for age: 18-34 years is taken as baseline group)

The relationship of admissions for ACSCs in adults with ID varied by age, with the youngest group (18-34 years) over 7 times more likely to have an admission than their controls (IRR=7.12, 95% CI 5.96-8.51). However, once comorbidity was adjusted for, the trend by age group reversed and older adults with ID (55-84 years) were now the most likely to have an admission for an ACSC relative to their controls (IRR=4.09, 95% CI 3.52-4.76). Even after adjustment for comorbidity, ID adults with severe health needs were almost 12 times more likely to have an admission for an ACSC than their controls (IRR=11.78, 95% CI 9.78-14.19). This difference was significantly different than that estimated between ID adults without severe health needs and their controls (p<0.001). A similar observation was seen when the comparison was made between ID adults with epilepsy and their controls (IRR=16.8) versus ID adults without epilepsy (IRR=3.5).

For ID adults with Down's syndrome, almost half of emergency admissions were for ACSCs (48.8%). As a result, ID adults with Down's syndrome were estimated to be a higher risk of ACSC admission versus their controls (IRR=8.3), than ID adults without Down's versus their controls (IRR=3.2), which was significantly different (p=0.002). Similarly, adults with ID recorded living in communal accommodation were at higher risk of emergency admission for an ACSC than those not recorded as such (p=0.006).

Among all emergency admissions for ACSCs, the contribution of common conditions within ID adults and controls separately is summarised in Figure 31. For ID adults, the most common ACSCs resulting in admission were convulsions/epilepsy (36%), pneumonia/LRTI (19%) and UTI (11%). For matched controls, while pneumonia/LRTI (19%) and UTI (13%) admissions accounted for similar proportions, admissions for convulsions/epilepsy (6%) were much rarer.

ID ADULTS

(pie chart)

- Convulsions/epilepsy 36%
- Pneumonia/LRTI 19%
- UTI 11%
- Cellulitis 5%
- Aspiration 5%
- Dehydration/GE 5%
- Constipation 4%
- COPD 3%
- Asthma 3%
- Heart Failure 1%
- Angina 2%
- Diabetes 2%
- Other 4%

CONTROLS

(pie chart)

- Convulsions/epilepsy 6%
- Pneumonia/LRTI 19%
- UTI 13%
- Cellulitis 8%
- Aspiration 1%
- Dehydration/GE 6%
- Constipation 4%
- COPD 11%
- Asthma 6%
- Angina 8%
- Heart Failure 4%
- Diabetes 4%
- Other 10%

FIGURE 31: EMERGENCY ADMISSIONS FOR INDIVIDUAL AMBULATORY CARE SENSITIVE CONDITIONS DURING 2009-13 IN ID ADULTS AND CONTROLS

The rates of emergency admissions for each of the 23 ACSCs, and associated IRRs for ID adults versus controls (where estimable) are shown in Table 32. The largest relative disparities between ID adults and controls were seen for aspiration (IRR=85.9, 95% CI 45.3-162.9) and convulsions/epilepsy (IRR=31.2, 95% CI 24.6-39.5). Among emergency admissions with sufficient occurrence in both groups, only angina did not show any evidence of a higher admission rate among ID adults (IRR=1.00, 95% CI 0.60-1.68).

Primary care utilisation before admission

We sought to use the linked CPRD and HES databases to describe the primary care utilisation and management prior to admission for ACSCs. We decided to choose two infections (UTIs and LRTIs) as exemplar ACSCs since they are common in both adults with and without ID. Although epilepsy is a much larger contributor to ACSC admissions in ID adults due to its high prevalence (Table 6), the corresponding low prevalence in adults without ID makes any comparison potentially difficult.

We identified all recorded UTI and LRTI admissions during our study follow up (Table 31), and then included the first admission where there was no evidence of a prior admission for UTI or LRTI at any time previously in the patient's record. This resulted in 727 UTI admissions and 1,128 LRTI admissions. For each of these we electronically searched in the primary care record two weeks before admission to investigate whether there were any differences in primary care utilisation between adults with and without ID. Specifically, we sought whether these patients had consulted their GP during normal operating hours or if they had had an emergency encounter during this time. We included all Read codes that indicated the patient had been seen in the following locations: walk-in centre, out-of-hours service, accident and emergency department. For those that consulted their GP during the two-week period, we then searched for the following: (i) any relevant diagnosis or suspected diagnosis, (ii) an antibiotic prescription (frontline antibiotics for UTI were defined as nitrofurantoin or trimethoprim, for LRTI these were amoxicillin, clarithromycin, doxycycline or erythromycin), (iii) whether a urine test had been performed (UTI admissions only).

TABLE 32: NUMBER AND RATE (PER 1,000 PERSONS PER YEAR) OF EMERGENCY ADMISSIONS FOR INDIVIDUAL AMBULATORY CARE SENSITIVE CONDITIONS DURING 2009-13 AMONG ID ADULTS AND CONTROLS

Ambulatory Care Sensitive Condition (ACSC)	ID (n=16,666)		Controls (n=113,562)		Base (unadjusted) model
	n	Rate per 1,000	n	Rate per 1,000	IRR (95% CI)
Angina	47	1.0	329	1.0	**1.00** (0.60 – 1.68)
Aspiration	152	3.1	25	0.07	**85.9** (45.3 – 162.9)
Asthma	91	1.8	233	0.7	**2.84** (1.99 – 4.06)
Cellulitis	156	3.1	331	1.0	**3.31** (2.56 – 4.28)
COPD	105	2.1	454	1.3	**1.68** (1.04 – 2.70)
Congestive heart failure	44	0.9	156	0.5	**2.21** (1.44 -3.38)
Constipation	128	2.6	142	0.4	**6.79** (5.17 – 8.91)
Convulsions/epilepsy	1,081	21.8	256	0.8	**31.2** (24.6 – 39.5)
Dehydration & gastroenteritis	141	2.9	224	0.7	**4.71** (3.60 – 6.17)
Dental conditions	22	0.4	52	0.2	**2.80** (1.67 – 4.71)
Diabetes complications	61	1.2	140	0.4	**3.26** (1.90 – 5.58)
Ear, nose and throat	28	0.6	132	0.4	**1.42** (0.93 – 2.17)
Gangrene	1	0.02	10	0.03	*
Gastroesophageal reflux disease (GORD)	22	0.4	74	0.2	**2.22** (1.35 – 3.67)
Hypertension	3	0.06	32	0.1	*
Influenza	8	0.2	18	0.05	*
Iron deficiency anaemia	21	0.4	40	0.1	**3.97** (2.18 – 7.20)
Nutritional deficiencies	0	0	2	0.01	*
Pelvic inflammatory disease	5	0.1	26	0.08	*
Perforated/bleeding ulcer	10	0.2	20	0.06	**3.78** (1.63 – 8.75)
Pneumonia and other lower respiratory tract infections (LRTI)	566	11.4	772	2.3	**5.59** (4.85 – 6.45)
Tuberculosis and other vaccine preventable	1	0.02	11	0.03	*
Urinary tract infections (UTI)	345	7.0	528	1.5	**4.76** (3.99 – 5.68)
All ACSCs	**3,038**	**61.3**	**4,007**	**11.7**	**5.62** (5.14 – 6.13)

* - Not estimable due to insufficient numbers.

It was no longer possible to preserve any age, sex or practice matching in the comparison between adults and controls with UTI (Table 33) and LRTI (Table 34) admissions. Therefore, in the logistic regressions which estimated separate odds ratios for consultation, diagnosis or antibiotic prior to admission, we directly adjusted for age and sex differences between the two groups.

The pattern of primary care utilisation in the two weeks before a UTI admission is shown for 276 adults with ID and 451 adults without ID (Table 33). Adults with ID were more likely to be men (49% vs. 33%), older (56% were older than 55 years of age vs. 47%) and be at a high risk of a UTI (50% vs. 26%). However, both groups had a similar proportion with a primary care consultation (56%) or emergency encounter (7%) in the two-week period. The adjusted odds of a primary care consultation for ID adults was not significantly different (OR=1.04, 95% CI 0.77–1.40). For patients that did consult with their GP, adults with ID were slightly less likely to receive a UTI diagnosis (14% vs. 18%) though this wasn't statistically significant (OR=0.78, 95% CI 0.52-1.17). Similarly, adults with ID were less likely to prescribed an antibiotic (40% vs. 46%), but a statistical comparison of this difference was imprecise (OR=0.75, 95% CI 0.43-1.31).

For LRTI, 457 adults with ID with an admission were compared with 671 adults without ID (Table 34). While both groups had a similar proportion of men, ID adults were more likely to be younger (18% were aged 18-34 years vs. 12%) and far more likely to be high risk for a LRTI (24% vs. 3%). The percentage of ID adults consulting with their GP in the two weeks before admission was marginally higher than among adults without ID (61% vs. 55%) though this difference was not formally statistically significant (OR=1.26, 95% CI 0.99-1.60). Both groups had a similar proportion (6%) with an emergency consultation in the two-week period. Among patients with a consultation, an associated LRTI diagnosis during this period was similar between groups (both 22%, OR=0.99, 95% CI 0.68-1.45). Prescribing of an antibiotic was marginally lower for adults with ID (40% vs. 44%), but not significantly different from controls (OR=0.84, 95% CI 0.61-1.15).

TABLE 33: SUMMARY OF HEALTHCARE USAGE IN THE TWO WEEKS PRIOR TO HOSPITALISATION FOR ALL PATIENTS WITH A FIRST EMERGENCY ADMISSION FOR UTI DURING 2009-13

	ID (n=276)		Controls (n=451)	
	n	%	n	%
Age				
- 18-34 years	43	**15.6%**	123	**27.3%**
- 35-54 years	77	**27.9%**	115	**25.5%**
- 55-84 years	156	**55.6%**	213	**47.2%**
Sex				
- Men	134	**48.6%**	150	**33.3%**
At High Risk of UTI*				
- Yes	139	**50.4%**	117	**25.9%**
Category of Healthcare Use				
- Consulted at GP practice	156	**56.5%**	251	**55.7%**
- Had emergency encounter†	19	**6.9%**	32	**7.1%**
- Other record‡	70	**25.4%**	85	**18.8%**
- No record	31	**11.2%**	83	**18.4%**
Details of GP Consultation				
- All	156		251	
- Diagnosis recorded	22	**14.1%**	45	**17.9%**
- Urine tested°	44	**28.2%**	75	**29.9%**
- Antibiotics prescribed	62	**39.7%**	115	**45.8%**
- None of the above	76	**48.7%**	118	**47.0%**
Type of Antibiotics				
- All	62		115	
- Frontline** only	29	**46.8%**	57	**49.6%**
- Other only	28	**45.2%**	52	**45.2%**
- Frontline** and other	5	**8.1%**	6	**5.2%**
Number of Antibiotics				
- One antibiotic	55	**88.7%**	94	**81.7%**
- More than one	7	**11.3%**	21	**18.3%**

* - High risk UTI patients had a history of specific kidney operations, UTIs, catheter or incontinence.

† - Includes A&E and Out of Hours visits.

‡ - Other records are repeat prescriptions, administrative entries or routine specialist appointments.

° - Urine tests include both immediate dipstick and non-immediate urine microscopy. 37 (84%) of adults with ID and 62 (83%) of adults without ID have urine microscopy.

** - Nitrofurantoin and Trimethoprim.

TABLE 34: SUMMARY OF HEALTHCARE USAGE IN THE TWO WEEKS PRIOR TO HOSPITALISATION FOR ALL PATIENTS WITH A FIRST EMERGENCY ADMISSION FOR PNEUMONIA/LRTI DURING 2009-13

	ID (n=457)		Controls (n=671)	
	n	%	n	%
Age				
- 18-34 years	84	**18.4%**	81	**12.1%**
- 35-54 years	145	**31.7%**	194	**28.9%**
- 55-84 years	228	**49.9%**	396	**59.0%**
Sex				
- Men	260	**56.9%**	384	**57.2%**
At High Risk of Admission*				
- Yes	108	**23.6%**	23	**3.4%**
Category of Healthcare Use				
- Consulted at GP practice	277	**60.6%**	368	**54.8%**
- Had emergency encounter†	27	**5.9%**	39	**5.8%**
- Other record‡	97	**21.2%**	131	**19.5%**
- No record	56	**12.3%**	133	**19.8%**
Details of GP Consultation				
- All	277		368	
- Diagnosis recorded	60	**21.7%**	80	**21.7%**
- Antibiotics prescribed	111	**40.1%**	163	**44.3%**
- None of the above	151	**54.5%**	187	**50.8%**
Type of Antibiotics		**0.0%**		**0.0%**
- All	111		163	
- Frontline** only	65	**58.6%**	113	**69.3%**
- Other only	32	**28.8%**	34	**20.9%**
- Frontline** and other	14	**12.6%**	16	**9.8%**
Number of Antibiotics				
- One antibiotic	88	**79.3%**	130	**79.8%**
- More than one	23	**20.7%**	33	**20.2%**

* - High risk pneumonia/LRTI patients had a history or recurrent chest infections, pneumonitis, PEG feeding, prescriptions for food thickeners or having 2 or more chest infections in the preceding year.

† - Includes A&E and Out of Hours visits.

‡ - Other records are repeat prescriptions, administrative entries or routine specialist appointments.

** - Amoxicillin, Clarithromycin, Doxycycline and Erythromycin.

Chapter 6 Health Checks and Hospital Admissions

Introduction

In this chapter we present a robust observational methodology, using practice and individual level designs, to assess whether the introduction of health checks in 2009 reduced emergency hospitalisation for adults with ID. Firstly, we compare practices with high with low participation in the DES, evaluating change in admission rates for all adults with ID, controlling for underlying differences between practices. However, the possibility remains that practices participating in the DES improved the care of their ID patients independent of introducing the health checks. Therefore, we also present a matched cohort study (Figure 32) comparing the change in admission rates of 7,487 individual adults with ID who had health checks to the change seen in the matched population controls without ID. This will account for any secular trends in practice care or hospital admissions that may have taken place.

2009 → **2013**

FIRST HEALTH CHECK

| R_{i1} = Pre-check admission rate | **N=7,831** ID adults | R_{i2} = Post-check admission rate | → | Change in admission rate = R_{i2} / R_{i1} |

Matched on age, sex & practice

Impact of health check adjusted for temporal trends in admissions

| R_{c1} = Pre-check admission rate | **N=46,408** Controls | R_{c2} = Post-check admission rate | → | Change in admission rate = R_{c2} / R_{c1} |
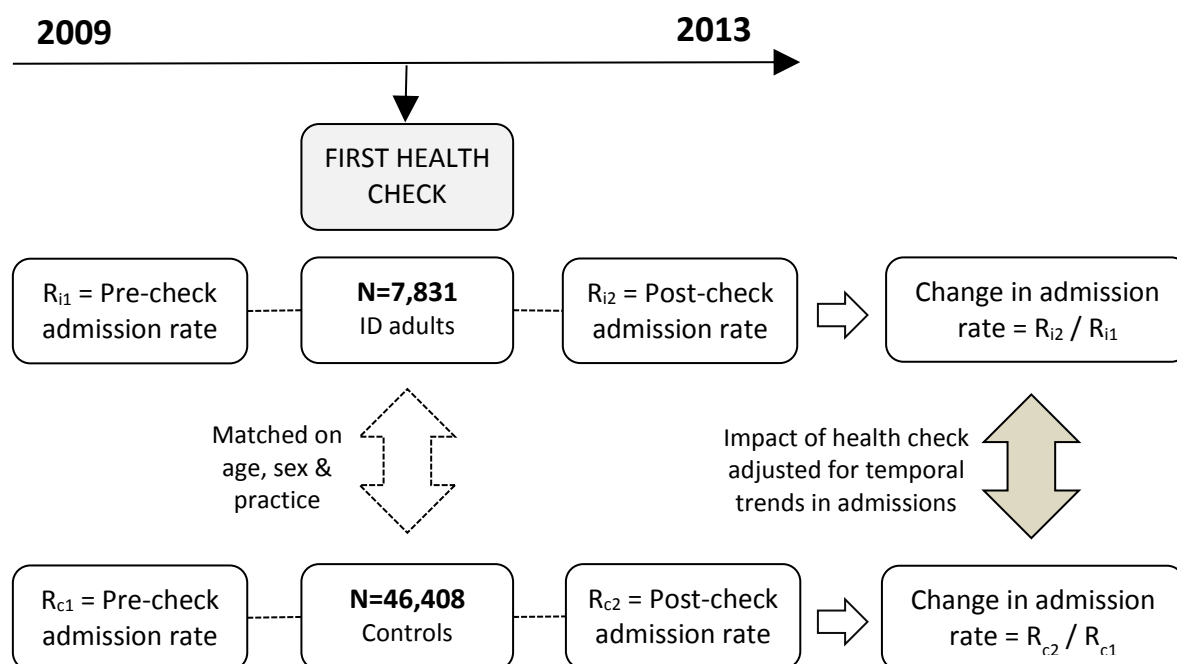
FIGURE 32: MATCHED COHORT DESIGN FOR INDIVIDUAL HEALTH CHECK ANALYSES

However, the possibility remains that during our study there may have been underlying trends in admissions specific to all patients with ID in England. Therefore, a second matched cohort study for adults with ID not receiving health checks is used to confirm the specificity of findings to those having a health check only. In Figure 32 the date of health check is replaced with a random index date based on the known distribution of health check dates (Figure 4).

Please note that some of these results have already appeared in the publication by Carey et al,[76] and are re-produced here under the terms of the Creative Commons Attribution License (CC-BY 4.0).

Classification of practices

For this analysis carried out at practice level, we restricted to 289 practices with complete data from 1/1/2009 to 31/12/2012 (Figure 33). We then classified practice participation in the DES by calculating the percentage of patients registered on 1/1/2009 on the QOF learning disability register that subsequently received a health check by the end of 2010 or 2012. We defined full practice participation as practices with ≥50% of their ID adults having a health check by the end of 2010. A total of 126 of 289 (43.6%) practices were classed as fully participating. Non-participating practices were defined as practices with <25% of their ID adults having a health check by 2012, and 68 (23.5%) practices satisfied this criterion. Finally, 95 practices satisfied neither criteria and were classed as partially participating, having participation rates of 25-50%. 72 of the 289 practices had zero participation by 2010, which fell to 35 by 2012.

We were able to compare some practice characteristics of fully participating practices versus non- or partial participating ones. Practices located in the north or midlands of England were marginally more likely to be classified as fully participating in health checks (48/102, 47.1%) versus those located in the south (78/187, 41.7%). Practices located in the most deprived fifth of IMD, were similarly more likely to be a fully participating practice (25/60, 41.7%) than practices located in the least deprived fifth (15/44, 34.1%).

N=126
Participating Practices
with >50% of ID adults with
health check by end of 2010

N=289
Only practices with
complete data
1/1/2009 to
31/12/2012[1]

N=68
Non Participating Practices
with <25% of ID adults with
health check by end of 2012

N=95
Partially Participating
Practices[2]

Practice Level
Analyses
Pages 131-134

N=7,487
Health Check Patients
ID adults[3] with first health
check during 2009-13 &
46,408 matched controls[5]

N=343
CPRD Practices
with HES data
active on 1/1/2009

N=6,922
Non Health Check Patients
ID adults[4] with no health check
during 2009-13 & 47,662
matched controls[5]

Individual Level
Analyses
Pages 135 - 141

[1] 14,080 total adults with ID with ≥1 registered day in these practices during 2009-12

[2] Practices with 25-50% of ID adults with health check by end of 2010, or only achieves >50% during 2011-12

[3] ID adults must have been registered for 90 days prior to health check and be alive for at least 90 days after it

[4] ID adults without health checks were assigned index date using the distribution of known health check dates

[5] Controls subject to same criteria as above using their case's health check date as index date

FIGURE 33: SUMMARY OF HEALTH CHECK ANALYSES

We then compared the patient characteristics of practices fully participating in health checks compared to those not participating, by first calculating the mean for a summary measure in each practice, and then calculating the median value across all practices in each participation group (Table 35). For example, calculating the mean percentage of ID adults registered on 1/1/2009 who had a health check by the end of 2010, reveals that the median fully participating practice had 69.5% of its ID adults with a health check by then. This compared with 0.0% in non-participating and 22.2% in partial participating. Although the median percentage rose to 58.3% for partial participating practices for health checks by the end of 2012, we chose to keep these practices apart from the fully participating ones as we wanted to assess any effect from early adoption of the scheme.

The median of the mean number of ID adults registered on 1/1/2009 was higher among all participating practices (38.0 patients) than non-participating ones (26.5 patients). This may be attributed to them having a higher mean percentage of patients recorded living in shared or communal establishments (median 15.8 vs. 5.9%). Practices fully participating in health checks tended to have more ID patients with severe health needs than those non-participating (median 22.2 vs. 15.2%). However, it may be that each of these measures may reflect higher recording levels on the GP systems by more engaged staff in these participating practices.

Characteristics of ID Adults summarised at practice level†	All Practices (N=289)	Non Participating* (N=68)	Partial Participating* (N=95)	Fully Participating* (N=126)
	Median (IQR)	Median (IQR)	Median (IQR)	Median (IQR)
Total registered during 2009-12‡	43.0 (25.0-64.0)	36.0 (16.0-50.0)	46.0 (31.0-64.0)	45.0 (24.0-79.0)
Number registered on 1/1/09 only	34.0 (19.0-52.0)	26.5 (12.5-39.5)	34.0 (31.0-64.0)	38.0 (19.0-61.0)
% with health check by end of 2010	43.1 (1.6-65.8)	0.0 (0.0-0.0)	22.2 (4.3-41.7)	69.5 (60.0-80.0)
% with health check by end of 2012	66.7 (28.6-81.8)	0.0 (0.0-0.0)	58.6 (41.0-68.8)	81.8 (74.2-87.9)
% who are men	57.6 (50.0-64.3)	55.6 (50.0-64.5)	58.3 (50.0-63.2)	57.5 (50.0-65.0)
Mean age (in 2009)	41.6 (38.7-44.8)	41.9 (38.9-45.8)	40.5 (37.5-43.8)	42.6 (39.4-45.0)
% with severe health needs**	18.8 (10.5-27.0)	15.2 (8.2-21.6)	17.4 (10.2-27.8)	22.2 (14.0-30.0)
% living in communal establishment residence**	9.7 (0.0-26.4)	5.9 (0.0-23.1)	8.6 (0.0-21.4)	15.8 (2.3-34.2)
% with epilepsy	17.1 (12.2-22.1)	16.3 (9.4-24.4)	16.7 (11.1-21.1)	18.3 (13.5-22.2)

* - Fully participating practices had >50% of their ID adults with a health check by end of 2010. Non-participating practices had <25% of their ID adults with a health check by end of 2012. 95 partial participating practices did not meet either criterion.

† - Medians calculated among all ID adults registered on 1/1/2009, except for "Total registered during 2009-12". First, a mean is calculated at practice level, and then a median of the practice means is calculated.

‡ - Patients who spent at least one day registered during 2009-12 (n=14,080).

** - For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

Practice participation in health checks and hospital admissions

A summary of hospital admissions (all emergency, emergency ACSCs, elective) among adults with ID during 2009-12 is shown in Figure 34. In each plot the admission rate per quarter has been calculated by the total admissions during that quarter divided by total registration time

from those patients. Unlike analyses presented elsewhere in this report, these plots include patients with no minimum registration period, and include a total of 14,080 ID adults who were registered at any time during 2009-12 irrespective of whether they received a health check or not. For elective admissions, we excluded the small number patients who had abnormally high elective admissions rates in any period (see page 110). The data is then analysed in Table 36, where two periods are now considered: 2009-10 and 2011-12, and annual rates have been calculated. The effect of practice participation on hospital admissions has been estimated by the interaction IRR between practice participation (fully versus none) and period (2011-12 vs. 2009-10) in conditional Poisson model (see Statistical methods page 36).

Emergency admission rates calculated in each quarter (Figure 34) tended to fall over time in all practice participation categories. This is summarised annually in Table 36 as a fall from 191.1 per 1000 adults per year in 2009-10, to 176.7 in 2011-12. Non-participating health check practices had consistently higher emergency admission rates throughout than practices which were fully participating (Figure 34), with both groups of practices experiencing a similar fall over time (IRR=0.97, 95% CI 0.78-1.19).

When emergency admissions for only ACSCs were considered the pattern was different (Figure 34, Table 36). While these admissions had fallen among those fully participating in health checks (69.2 in 2009-10 to 56.3 in 2011-12 per 1,000 adults), this was not replicated in practices not participating in health checks (70.1 in 2009-10 to 77.1 in 2011-12 per 1,000 adults). A statistical comparison of the difference in this change showed an overall benefit of greater practice participation (IRR=0.74, 95%CI 0.58-0.95). There was no evidence of any difference in the change over time in elective admissions between fully- and non-participating practices (IRR=1.02, 95% CI 0.84-1.25).

Alternative modelling approaches provided similar findings. For example, a fixed effects (conditional) negative binomial showed no trend with all emergency (IRR=0.98, 95% CI 0.82-1.18), but reduced change with emergency ACSCs (IRR=0.76, 95% CI 0.59-0.98).

(a) All emergency admissions

(b) Emergency ACSCs admissions only

(c) Elective admissions
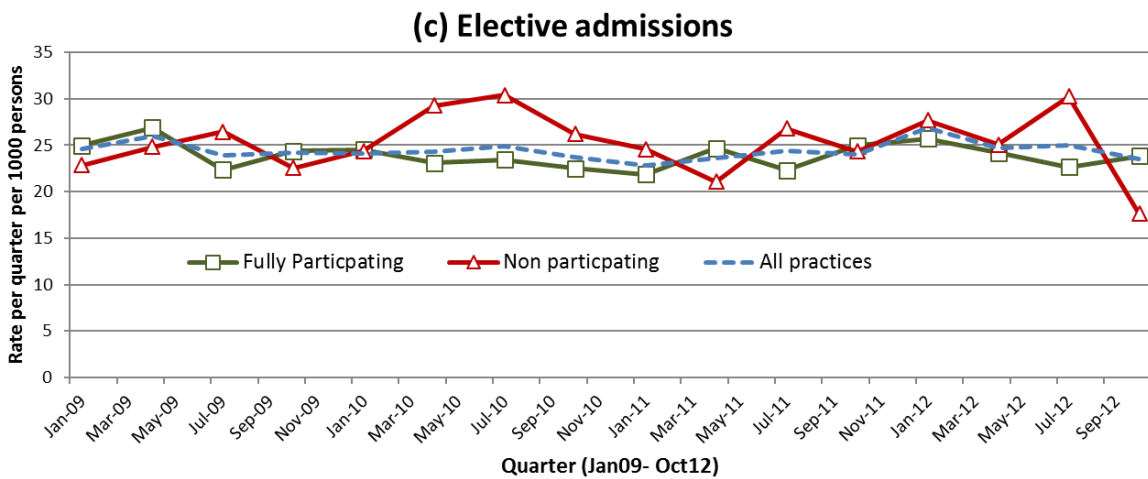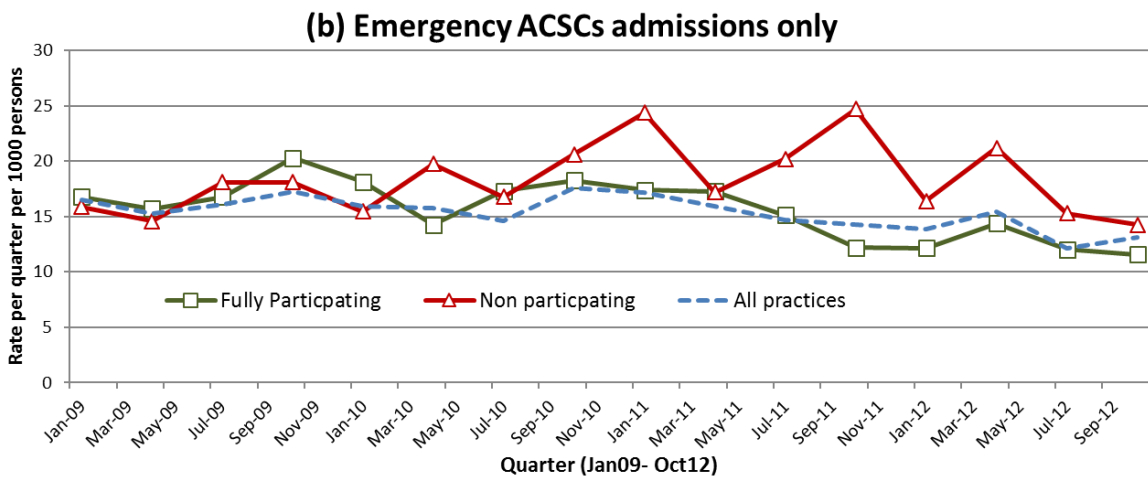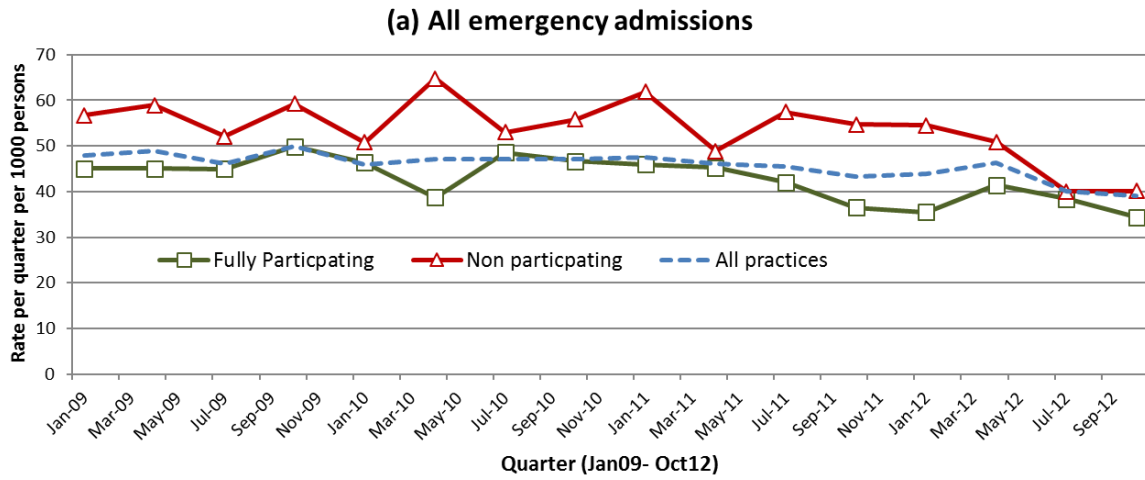
FIGURE 34: HOSPITAL ADMISSIONS IN EACH QUARTER DURING 2009-12 BY PRACTICE LEVEL OF PARTICIPATION IN HEALTH CHECKS

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TABLE 36: HOSPITAL ADMISSIONS IN 2011-12 VS. 2009-10 BY PRACTICE LEVEL OF PARTICIPATION IN HEALTH CHECKS

	2009-10 Admissions	2011-12 Admissions	Period Change	Fully vs. Non Participation Period Change
	Rate per 1,000 person years	Rate per 1,000 person years	IRR† (95% CI)	IRR‡ (95% CI)
All practices (N=289)				
- All Emergency Admissions	191.1	176.7	**0.92** (0.86-0.99)	–
- Emergency ACSCs Only	64.9	58.6	**0.91** (0.82-1.00)	–
- All Elective Admissions*	117.1	119.2	**1.02** (0.95-1.09)	–
Fully participating practices (N=126)				
- All Emergency Admissions	183.6	160.6	**0.88** (0.80-0.96)	**0.97** (0.78-1.19)
- Emergency ACSCs Only	69.2	56.3	**0.82** (0.72-0.92)	**0.74** (0.58-0.95)
- All Elective Admissions*	112.4	114.0	**1.02** (0.92-1.14)	**1.02** (0.84-1.25)
Non participating practices (N=68)				
- All Emergency Admissions	226.9	205.3	**0.90** (0.75-1.09)	**1.00** _
- Emergency ACSCs Only	70.1	77.1	**1.10** (0.89-1.36)	**1.00** _
- All Elective Admissions*	125.9	127.3	**1.00** (0.85-1.19)	**1.00** _

† - This represents the within practice change in admission post health check compared to pre health check estimated from conditional Poisson model

‡ - This represents the within practice post health check change in admissions between the fully participating practices versus the non-participating practices estimated from conditional Poisson model

* - Patients with abnormally high elective rates were excluded (average > 6/year)

Assigning an index date to ID adults without health checks

We now consider analyses based on 7,487 individuals with a first health check between 1/4/2009 and 31/3/2013. As explained previously on page 29, we also include in our analyses 6,922 adults with ID who did not receive a health check during this period (Figure 3) but were assigned a random index date. We could then analyse this group in a complementary analysis to ensure any findings from our study are specific to ID adults with health checks and not due to underlying trends in hospital admissions in the ID population that may have taken place during our study period.

Briefly, this matching involved assigning a random date based on the known distribution of health checks between 1/4/2009 and 31/3/2013 in our data (Figure 35). For this we used the dates from 7,831 individuals with health checks we originally identified (344 of these individuals had subsequently been excluded due to age, registration or data criteria). These dates were then randomly assigned to the 7,751 adults without health checks, who we had identified as being potentially eligible for our analyses. This was achieved by iteratively sampling (without replacement) from the pool of 7,831 dates. For a date match to be successful, the adult without the health check had to be alive and registered for at least 90 days on potential index date. Unsuccessful date matches were returned to the pool of matching dates, until no more matches were possible.

At the end of this process 7,050 (91%) successful date matches were assigned. Among this group 58% of index dates were in 2009 or 2010, compared to 59% among the 7,487 individuals with health checks. Most rejections were due to the patient only being registered for a short period, or only being age eligible (18 years old) in 2013. A further 128 patients were rejected after the date assignment, mainly due to insufficient follow up of 90 days which we required. This left 6,922 adults without a health check with an assigned index date which we could use in the complementary analyses of health checks, which also uses their 47,622 matched population controls.

PATIENTS WITH HEALTH CHECKS

PATIENTS WITHOUT HEALTH CHECKS

N=7,831
All ID adults with first health check 1/4/2009 to 31/3/2013

Randomly assign date of health check

N=7,751
All ID adults aged 18-84 years without first health check 1/4/2009 to 31/3/2013

N=344
Excluded

Fails data, age, or registration criteria

N=701
Non matches

All possible date matches exhausted

N=7,050
Matched

Assigned an index date

N=128
Excluded

Fails data, age, or registration criteria

N=7,487
Health Check Patients

Aged 18-84 years at time of check & registered for 90 days prior to health check and alive at least 90 days after it

N=6,922
Non Health Check Patients

ID adults with no health check during 2009-13 and still registered on index date of health check

FIGURE 35: SUMMARY OF DATE MATCHING BETWEEN ID ADULTS WITH AND WITHOUT HEALTH CHECKS

Individual analyses of health checks and hospital admissions

A comparison of ID adults with (n=7,487) and without (n=6,922) health checks is summarised in Table 37. While the two groups had a similar gender distribution (58% men), ID adults with

health checks were notably younger (mean=42.6 versus 39.0 years). More than 1 in 4 ID adults with a health check were classed as having severe health needs (27.2%) or living in a communal establishment (25.6%). This was much higher than what was recorded in those without health checks (12.9% and 11.7% respectively). Mean follow up time was similar in both groups (ID adults with health check = 560 days (pre) and 1081 days (post); ID adults without health check = 521 days (pre) and 1059 days (post)).

TABLE 37: CHARACTERISTICS OF ID ADULTS WITH AND WITHOUT HEALTH CHECKS BETWEEN APRIL 2009 AND MARCH 2013 USED IN HOSPITAL ADMISSIONS ANALYSIS

Characteristic	ID with health check (N=7,487)		ID without health check (n=6,922)	
	n	%	n	%
Gender				
-Women	3,183	**42.5%**	2,889	**41.7%**
-Men	4,304	**57.5%**	4,033	**58.3%**
Age (at health check)				
-18-34 years	2,579	**34.5%**	3,159	**45.6%**
-35-54 years	3,136	**41.9%**	2,432	**35.1%**
-55-84 years	1,772	**23.7%**	1,331	**19.2%**
Down's syndrome				
-Yes	914	**12.2%**	639	**9.2%**
-No	6,573	**87.8%**	6,283	**90.8%**
Severe health needs*				
-Yes	2,035	**27.2%**	891	**12.9%**
-No	5,452	**72.8%**	6,031	**87.1%**
Communal accommodation*				
-Yes	1,913	**25.6%**	811	**11.7%**
-No	5,574	**74.5%**	6,111	**88.3%**
Autism spectrum disorder				
-Yes	743	**9.9%**	499	**7.2%**
-No	6,744	**90.1%**	6,423	**92.8%**
Epilepsy				
-Yes	1,552	**20.7%**	975	**14.1%**
-No	5,935	**79.3%**	5,947	**85.9%**

* - For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

Hospital admission rates (all emergency, emergency ACSCs, elective) before and after the health check are summarised in Table 38. Four groups are shown: ID adults with and without health checks (using their random index date), and the matched controls for each of these two groups. Conditional Poisson models were used to estimate the IRR for period and interaction effects (see statistical methods page 36). This model was first fitted to ID adults and controls separately, estimating the individual change in hospital admission rate after as compared to before health check (or index date). A combined model of ID adults and controls with a case-period interaction then provided an estimate for the effect of health checks (or index dates) on admission rates among adults with ID, adjusted for any temporal trends in admissions.

For the 7,487 adults with a health check, all emergency admissions rose by 22% from 145.7 to 173.2 annually per 1,000 persons (IRR=1.22, 95% CI 1.11-1.34). By contrast, in their 46,408 matched controls the rate for all emergency admissions increased by 27% from 58.6 to 70.1 (IRR=1.27, 95% CI 1.20-1.34). Therefore, in the combined Poisson model, the interaction for the impact of health checks on adults with ID is estimated to be under 1 (IRR=0.96, 95%CI 0.87-1.07). ID adults without health checks had higher overall admission rates for emergency admission (e.g. 186.0 versus 145.7 annually per 1,000 persons pre index date), and a slight subsequent increase in admission rate post index date relative to their controls (IRR=1.05, 95% CI 0.94-1.17).

While emergency admissions for ASCs among ID adults with health checks also showed a rise post health check (52.4 to 59.3 per 1,000 persons per year), this change was smaller than that seen in the control group (11% versus 35%). The combined Poisson model produced a statistically significant interaction (IRR=0.82, 95%CI 0.69-0.99), which represents the change in admission rate post health check compared to controls. This interaction effect and trend was not replicated in ID adults without a health check (IRR=1.11, 95% CI 0.92-1.36).

For elective hospital admissions, the estimated post health check was similar between ID adults with health checks and controls (IRR=0.96, 95% CI 0.87-1.06). There was some evidence that elective admissions among ID adults without health check, had shown a reduced change compared to their controls (IRR=0.90, 95% CI 0.81-1.00) after their assigned index date.

TABLE 38: COMPARISON OF HOSPITAL ADMISSION RATES DURING 2009-13 IN ID ADULTS AND CONTROLS PRE AND POST HEALTH CHECK, OR INDEX DATE FOR THOSE WITHOUT HEALTH CHECKS

	Pre Health Check	Post Health Check	Period Change	Fully vs. Non Participation Period Change
	Rate per 1,000 person years	Rate per 1,000 person years	IRR† (95% CI)	IRR‡ (95% CI)
ID adults with health check (N=7,487)				
- All Emergency Admissions	145.7	173.2	**1.22** (1.11-1.34)	**0.96** (0.87-1.07)
- Emergency ACSCs Only	52.4	59.3	**1.11** (0.95-1.29)	**0.82** (0.69-0.99)
- All Elective Admissions*	115.9	122.4	**1.11** (1.01-1.21)	**0.96** (0.87-1.06)
ID adults without health check (N=6,922)				
- All Emergency Admissions	186.0	212.2	**1.20** (1.09-1.32)	**1.05** (0.94-1.17)
- Emergency ACSCs Only	52.7	66.7	**1.35** (1.14-1.60)	**1.11** (0.92-1.36)
- All Elective Admissions*	119.1	128.4	**1.02** (0.93-1.12)	**0.90** (0.81-1.00)
Controls for ID with health check (N=46,408)				
- All Emergency Admissions	58.6	70.1	**1.27** (1.20-1.34)	–
- Emergency ACSCs Only	9.5	12.9	**1.40** (1.24-1.58)	–
- All Elective Admissions*	102.4	121.3	**1.15** (1.11-1.20)	–
Controls for ID without health check (N=47,662)				
- All Emergency Admissions	56.9	66.1	**1.15** (1.09-1.21)	–
- Emergency ACSCs Only	8.5	11.0	**1.28** (1.14-1.44)	–
- All Elective Admissions*	88.4	106.2	**1.13** (1.09-1.18)	–

† - This represents the within person change in admission post health check compared to pre health check estimated from conditional Poisson model

‡ - This represents the within person post health check change in admissions between the ID patients and their respective controls estimated from conditional Poisson model

* - Patients with abnormally high elective rates were excluded (average > 6/year)

We carried out sensitivity analyses using a different statistical modelling approach that directly compared the change in admissions between adults with ID with health checks, with those without health checks (see Statistical analysis, page 36). The models accounted for underlying differences between the two un-matched groups, by adjusting for age, sex, and co-morbidity. The Poisson and negative binomial models produced similar findings to our previous approach. For example, for the negative binomial models the interaction IRR's were: all emergency admissions (IRR=1.04, 95% CI 0.90-1.19), emergency ACSs (IRR=0.80, 95% CI 0.66-0.99) and elective admissions (IRR=1.03, 95% CI 0.90-1.17).

Table 39 summarises the estimate of the impact of health checks on emergency hospital admissions stratified by individual characteristics, both for ID adults with and without health checks. These are the case-period interaction IRR's from the conditional Poisson models fitted to each group separately. A significant rise in admissions was seen among Down's syndrome adults with health checks compared to their population controls (IRR=1.55, 95% CI 1.15-2.08). However, this increase was replicated among Down's adults without health checks (IRR=1.55) compared to their controls, suggesting a trend specific to adults with Down's syndrome. By contrast, while health checks were associated with a smaller change in emergency admissions among ID adults with severe health needs compared to their controls (IRR=0.80, 95% CI 0.67-0.95), this trend was not replicated in ID adults without health checks with severe health needs compared to their controls (IRR=1.07, 95% CI 0.85-1.35). A further analysis of ID adults with severe support needs receiving health checks also suggested a decrease in their emergency admissions for ACSCs compared to controls (IRR=0.76, 95% CI 0.56-1.01).

TABLE 39: INTERACTION INCIDENCE RATE RATIOS COMPARING THE CHANGE IN EMERGENCY HOSPITAL ADMISSION RATES DURING 2009-13 POST HEALTH CHECK BETWEEN ID ADULTS AND MATCHED CONTROLS STRATIFIED BY INDIVIDUAL CHARACTERISTICS

Characteristic	ID with health check (N=7,487)	ID without health check (n=6,922)
	IRR (95%CI)	IRR (95% CI)
Gender		
-Women	**1.07** (0.92-1.25)	**1.13** (0.95-1.34)
-Men	**0.88** (0.76-1.01)	**0.98** (0.85-1.13)
Age (at health check)		
-18-34 years	**1.01** (0.81-1.25)	**0.97** (0.80-1.16)
-35-54 years	**0.95** (0.80-1.13)	**1.12** (0.92-1.34)
-55-84 years	**0.96** (0.81-1.14)	**0.96** (0.78-1.18)
Down's syndrome		
-Yes	**1.55** (1.15-2.08)	**1.55** (1.08-2.22)
-No	**0.91** (0.82-1.02)	**1.01** (0.90-1.14)
Severe health needs*		
-Yes	**0.80** (0.67-0.95)	**1.07** (0.85-1.35)
-No	**1.06** (0.93-1.22)	**1.03** (0.90-1.17)
Communal accommodation*		
-Yes	**1.13** (0.92-1.38)	**1.22** (0.92-1.62)
-No	**0.91** (0.80-1.03)	**1.02** (0.90-1.15)
Autism spectrum disorder		
-Yes	**1.18** (0.76-1.82)	**1.25** (0.75-2.08)
-No	**0.95** (0.85-1.05)	**1.04** (0.93-1.16)
Epilepsy		
-Yes	**0.88** (0.73-1.07)	**1.17** (0.91-1.49)
-No	**1.03** (0.90-1.17)	**1.01** (0.89-1.15)

* - For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

Chapter 7 Who Gets Health Checks and What Is Recorded?

Introduction

The final part of the analysis in the report considers two further questions: (1) What gets recorded on a patient's electronic record during a health check? and (2) What predicts who gets a health check?

To answer these questions, we focused on health checks that took place during 2009-11, only including 274 practices that had a minimum involvement (20% of registered ID patients with a health check) in the DES (Figure 3). We also required patients to be registered at the beginning of follow up (1/1/2009) for at least a year, thus ensuring that these health checks were not being performed on recently registered patients. This identified 5,583 first health checks on established patients with ID, from which we summarised what was being electronically recorded on their record around the time of the check (Figure 36).

We then estimated what difference the health check had made to the overall recording of some selected process measures, by further restricting to the 5,026 patients with health checks who were still registered at 31/12/2011. This allowed a comparison of two distinct periods (Figure 36) - one before health checks were introduced (2006-08), and one during the period when the check took place (2009-11). The change in their records between these two periods was then contrasted with the records of 2,728 adults with ID from the same practices who did *not* get a health check during 2009-11. Lastly, we present an analysis that investigates which factors, if any, predict from this combined group of 7,754 ID adults, who received a health check during 2009-11.

The characteristics of the three groups of adults with ID used in the analyses described above are given in Table 40. As described previously (Table 37), patients with and without health checks differ significantly with respect to severe health needs, epilepsy and living arrangements.
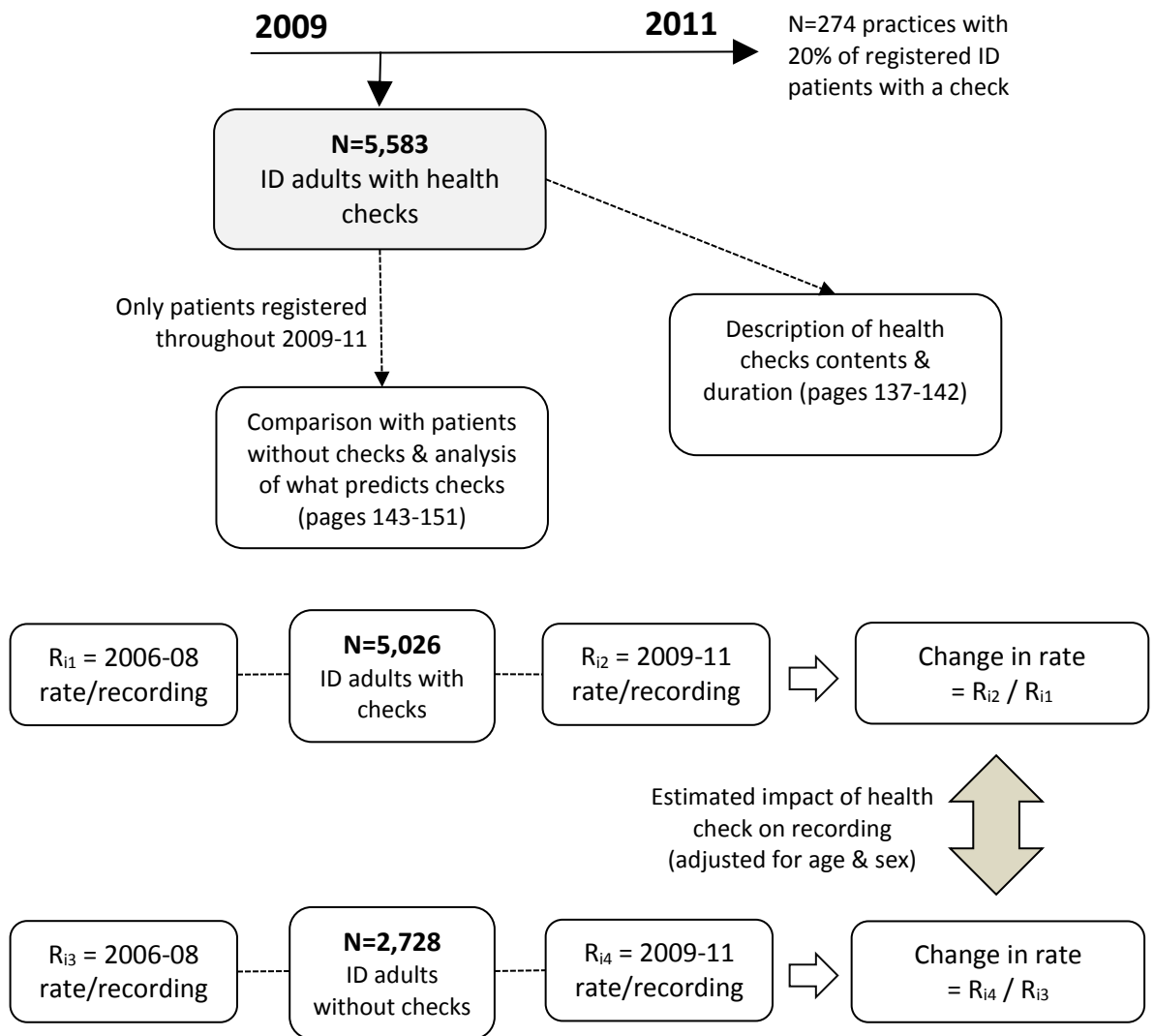
FIGURE 36: SUMMARY OF COHORT DESIGN FOR ANALYSES INVESTIGATING IMPACT OF HEALTH CHECKS ON RECORDING OF HEALTH MEASURES

TABLE 40: CHARACTERISTICS OF ID ADULTS WITH AND WITHOUT HEALTH CHECKS BETWEEN JANUARY 2009 AND DECEMBER 2013 USED IN DESCRIPTIVE ANALYSIS

Characteristic	First health check during 2009-11				No health check during 2009-11	
	All patients		Registered 2009-11		Registered 2009-11	
	n	%	n	%	n	%
All	5,583	**100%**	5,026	**100%**	2,783	**100%**
Gender						
-Women	2,404	**43.1%**	2,153	**42.8%**	1,116	**40.9%**
-Men	3,179	**56.9%**	2,873	**57.2%**	1,612	**59.1%**
Age (at health check)						
-18-34 years	1,578	**28.3%**	1,489	**29.6%**	1,053	**38.6%**
-35-54 years	2,555	**45.8%**	2,351	**45.8%**	1,127	**41.3%**
-55-84 years	1,450	**26.0%**	1,186	**23.6%**	548	**20.1%**
Down's syndrome						
-Yes	725	**13.0%**	644	**12.8%**	219	**8.0%**
-No	4,858	**87.0%**	4,382	**87.2%**	2,509	**92.0%**
Severe health needs*						
-Yes	1,485	**26.6%**	1,336	**26.6%**	388	**14.2%**
-No	4,098	**73.4%**	3,690	**73.4%**	2,340	**85.8%**
Communal accommodation*						
-Yes	1,766	**31.6%**	1,551	**30.9%**	245	**9.0%**
-No	3,817	**68.4%**	3,475	**69.1%**	2,483	**91.0%**
Autism spectrum disorder						
-Yes	457	**8.2%**	401	**8.0%**	127	**4.7%**
-No	5,126	**91.8%**	4,625	**92.0%**	2,601	**9.5%**
Epilepsy						
-Yes	1,201	**21.5%**	1,080	**21.5%**	372	**13.6%**
-No	4,382	**78.5%**	3,946	**78.5%**	3,946	**86.4%**

* - For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details.

What gets recorded during a health check?

To investigate what was being recorded during the 5,583 first health checks carried out between 2009 and 2011, we extracted all information 14 days either side of the recorded date of the health check (see page 28). While the majority of information was being recorded

on the date of the health check, by allowing two weeks either side of it, we were able to account for (i) health checks that took place across multiple days, (ii) results of tests that were only apparent on the system after the check had taken place.

We then attempted to summarise the total information recorded, by identifying common categories that were being used (Table 41). These categories were defined to be as broad as possible to try and capture whether a specific health area or concern had been addressed during the check. So for example, the category "Alcohol" would count Read codes estimating alcohol consumption as well as any codes around lifestyle advice in relation to alcohol. "Ears" would cover hearing tests and assessments, examination or symptoms of the ears or whether they had been seen by an audiologist. In the end we identified 22 common categories (Table 41) which we thought were applicable to all adults with ID. A further 5 categories (medication review, breast exam, cervical smear, epilepsy, influenza vaccination) were summarised on specific sub-groups only. A listing of the Read codes used is given in Appendix 9**Error! Reference source not found.**.

We also observed a pattern associated with health checks in some practices where there was consistently little or no recorded information on the electronic patient record around the time of the check. We think these checks are probably being performed away from the GP surgery, as this absence of informative recording was more common in practices with large clusters of ID adults living in communal or shared accommodation. We do not necessarily believe that no tests or examinations are being carried out in these checks, but can only summarise them as being "non-informative" based on what was recorded in the patient electronic record. We automated identification of these as those where none of the top 10 categories listed in Table 41 were being recorded. A total of 458 (8.2%) checks were identified as "non-informative".

TABLE 41: MOST FREQUENTLY RECORDED HEALTH CATEGORIES IDENTIFIED AT TIME OF FIRST HEALTH CHECK BETWEEN JANUARY 2009 AND DECEMBER 2011

Category Identified	Details	n	%
Top 10 Categories			
Weight/BMI	measured, gain/loss, BMI measured, health education/weight management/advice	4,323	**77.4%**
Blood pressure	measured	4,279	**76.6%**
Alcohol	consumption, advice/counselling, screen, intervention	3,952	**70.8%**
Smoking	tobacco consumption, health education/advice	3,334	**59.7%**
Mobility	how mobile, assessment, walking aid	3,099	**55.5%**
Ears	hearing, blocked/waxy ears, seen by audiologist	3,060	**54.8%**
Eyes	visual symptoms, wears glasses, examination, ophthalmological monitoring, normal vision	2,949	**52.8%**
Carer	details, paid/voluntary, does not have carer	2,535	**45.4%**
Pulse	measured/examined	2,396	**42.9%**
Height	measured	2,385	**42.7%**
Other common categories			
Health action plan	offered, declined, reviewed or completed	2,269	**40.6%**
Behaviour	problems, change, assessment	2,056	**36.8%**
Dental	dental exam, advice, seen by dentist	2,027	**36.3%**
Communication	speech, writing, responding	1,733	**31.0%**
Exercise	how much, able to exercise, health education/advice	1,522	**27.3%**
Diet	diet, allergies, appetite, advice/health education	1,512	**27.1%**
Blood test	taken, requested or results recorded	1,503	**26.9%**
Urine test	obtained, sent to lab, dipstick, results recorded	1,393	**25.0%**
Mental health	symptoms/none, mood, depression screening, mental health review	772	**13.8%**
Bowels & bladder	health education, continence, catheter, assessment	739	**13.2%**
Respiratory	examination, rate of respiration, breath sounds, respiratory flow rates	664	**11.9%**
Sexual related	sexually active, contraception, health education	587	**10.5%**
Specific sub-groups*			
Medication review (on repeat medication)	medication monitoring, medication review, epilepsy (and others) medication	1,123	**26.1%**
Breast exam (women)	examination/self-exam, mammography	493	**20.5%**
Cervical smear (women)	given, offered, refused, not indicated	404	**16.8%**
Epilepsy (epilepsy prior to 2009)	monitoring, fit frequency, last fit, seizure free	537	**44.7%**
Flu vaccination (health check Sep-Jan only)	given	387	**19.1%**

* - Denominators for sub-groups: Medication review n=4,297, Breast/Cervical smear n=2,404, Epilepsy n=1,201, Flu vaccination n=2,028.

The most common category of recorded information during the health check was weight or BMI related, where 4,323 health checks had related information (Table 41). This represented 77.4% of all 2009-2011 health checks, or 84.4% of the 5,125 "informative" health checks only. This was followed by blood pressure, alcohol, smoking and mobility, as being the most frequent which had related information in more than half of the health checks. Only 4 in 10 health checks (40.6%) had a record of a health action plan being offered, declined, reviewed or completed. Only a small proportion (<15%) of health checks had recorded information relating to mental health and bowels or bladder.

Across practices, there was considerable variation in the volume of recorded information around the time of the health checks. Among the 22 common categories identified from Table 41, 49 (18%) of the 274 practices had health checks which averaged less than 6 categories. By contrast, 53 (19%) had health checks which averaged more than 12 different categories being recorded.

Recorded length and GP involvement in health check

We sought to determine the length of the health check and summarise who was involved in carrying out the health check. In order to do this, we first excluded the 458 non-informative health checks, as our assumption was that the lack of electronic information on the system reflected that these checks that were primarily taking place outside of the GP surgery. From the remaining checks, we further excluded 179 with missing or zero duration length, resulting in 4,946 health checks. We then identified the singular day on which the majority of the top 10 categories listed in Table 41 appeared. In the rare event of a tie, we used the date on which the Read code for the health check appeared.

Of the 4,946 health checks recorded during 2009-2011 containing informative electronic information on duration, approximately half (n=2,464, 49.8%) appeared to be conducted solely by the GP. A further 686 (13.9%) had information indicating both GP and nurse involvement, while 1,287 checks (26.1%) had only nurse involvement indicated. For about 1 in 10 checks (n=509, 10.3%) neither a GP nor nurse was directly recorded, with "administrator" being the most common role indicated. Across sub-groups (Figure 37), the

percentage with GP involvement in the health check remained around 6 in 10 for most categories.

Of the 4,946 health checks with duration recorded, about 3-in-10 (n=1,399, 28.3%) were estimated to be greater than 30 minutes in duration, for the singular day which contained the most information recorded. Across sub-groups (Figure 37), the largest variation in duration was by living arrangement. Here, ID adults in communal or shared accommodation were recorded as less likely to have a check lasting 30 minutes (19.3%) versus those not recorded as such (32.2%).
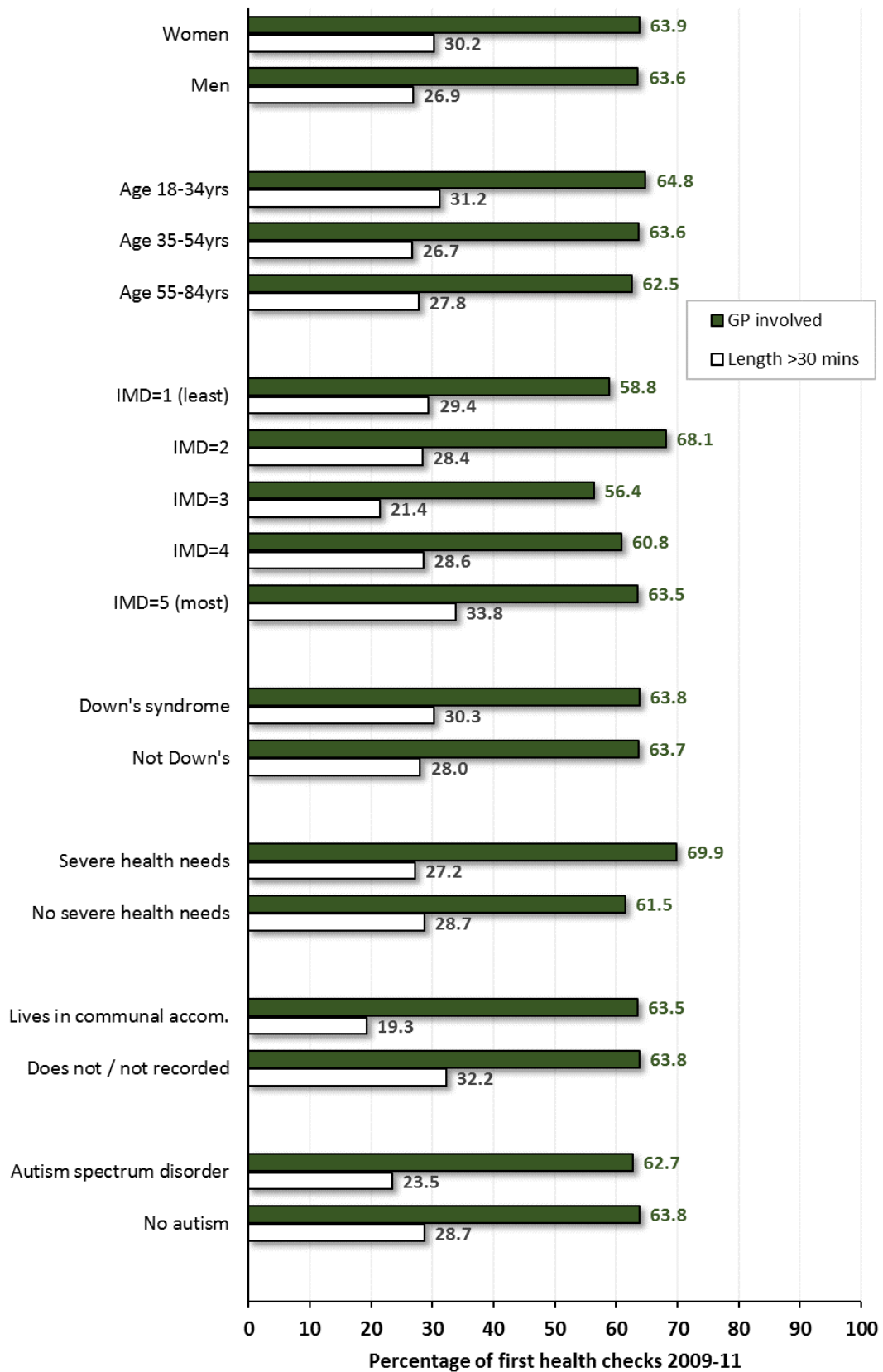
FIGURE 37: PERCENTAGE OF FIRST HEALTH CHECKS DURING 2009-11 THAT INVOLVE GP AND ARE GREATER THAN 30 MINUTES DURATION BY SUB-GROUPS

Process measures before and after health checks

Using the identified categories from Table 41, we now wished to summarise the added benefit of health checks in reference to how the information was recorded prior to the introduction of health checks. To do this we compared the recording of these categories during 2006-08 versus 2009-11 for the 5,026 ID adults who received a health check during 2009-11 in practices which had a minimum level (20%) of participation in the DES. We contrasted the absolute change in recording with the corresponding one seen in the 2,728 ID adults from the same set of practices who did not receive a check during this time (Figure 36). This is summarised in Table 42.

The biggest impact that health checks had was on the recording of health issues regarding mobility (+67.3% difference), eyes (+60.1%), carer details (+59.8%) and ears (58.3%). Prior to health checks there had been minimal information on mobility or carer details with less than 5% of patients having any associated information for these categories. While adult patients who did not receive a health check up to the end of 2011 had significant increases in all these categories (+9-10% differences), the level of change was much smaller than for patients with the health checks. Other categories where the observed change differed notably between these groups of patients were: alcohol, pulse, dental, behaviour and communication.

Categories where the health check appeared to have minimal impact on recording over time were mental health and medication review. During 2009-11, only 1 in 3 (35.7%) ID adults that received a health check had any recording concerning mental health. While we have identified data issues regarding the completeness of medication reviews on the system (page 35), the observed change in recording was similar (+4%) between patients with and without health checks.

Vaccination rates for influenza among ID adults with health checks improved from 49.7% to 60.6%, an increase (+10.9%) that was not notably different from those without checks (+7.2%). However overall coverage was much higher among those with health checks (60.6% versus 37.7% in 2009-11) due in part to greater health needs among those with checks (e.g. 27% vs 14% for severe health needs in Table 40).

TABLE 42: CHANGE IN FREQUENTLY RECORDED HEALTH CATEGORIES BETWEEN 2006-08 AND 2009-11 IN ID ADULTS WITH AND WITHOUT HEALTH CHECKS BETWEEN JANUARY 2009 AND DECEMBER 2011

Category Identified	ID Adults with health check 2009-11 (n=5,026)			ID Adults without health check 2009-11 (n=2,728)		
Top 10 Categories	% 2006-08	% 2009-11	+/- change	% 2006-08	% 2009-11	+/- change
Weight/BMI	59.9	95.3	+35.4	50.7	54.8	+4.1
Blood pressure	69.8	95.3	+25.6	60.3	64.4	+4.1
Alcohol	38.8	89.9	+51.1	34.3	40.2	+5.9
Smoking	73.8	92.4	+18.5	69.9	72.4	+2.5
Mobility	4.8	72.1	+67.3	3.3	12.2	+8.9
Ears	17.3	75.6	+58.3	11.1	20.7	+9.6
Eyes	14.4	74.6	+60.1	11.1	21.0	+9.9
Carer	3.4	63.2	+59.8	2.6	11.6	+9.0
Pulse	16.1	67.4	+51.3	14.0	25.6	+11.7
Height	35.4	65.4	+30.0	30.6	27.6	-3.1
Other common categories						
Health action plan	1.8	60.0	+58.2	1.5	13.5	+12.0
Behaviour	4.6	53.5	+48.9	2.3	8.9	+6.6
Dental	1.6	53.6	+52.0	0.8	8.7	+7.9
Communication	0.9	44.5	+43.6	0.5	5.3	+4.8
Exercise	21.9	46.4	+24.6	20.2	20.7	+0.5
Diet	24.2	47.1	+22.9	19.0	21.5	+2.5
Blood test	62.3	77.6	+15.4	51.8	58.7	+6.9
Urine test	39.0	58.7	+19.6	30.8	32.4	+1.6
Mental health	29.2	35.7	+6.6	22.5	26.3	+3.8
Bowels & bladder	15.3	30.2	+14.9	11.7	13.4	+1.7
Respiratory	11.6	25.0	+13.4	12.9	15.0	+2.1
Sexual related	7.9	21.0	+13.1	8.8	10.7	+1.9
Specific sub-groups*						
Medication review	60.7	65.1	+4.4	46.6	50.8	+4.2
Breast exam	8.6	41.8	+33.2	9.1	14.0	+4.9
Cervical smear	52.7	65.5	+12.8	50.0	54.7	+4.7
Epilepsy	96.9	98.6	+1.7	97.3	96.8	-0.5
Flu vaccination	49.7	60.6	+10.9	30.5	37.7	+7.2

* - Denominators for sub-groups: Medication review and Flu vaccination are now based on all patients. However cervical smear and breast examination are based on n=2,153 women with health checks and 1,116 women without health checks. Epilepsy based on n=1,080 patients with health checks and n=372 without health checks.

Diagnoses, consultations and prescribing before and after health checks

We now investigated whether the introduction of health checks had impacted the diagnosing of common QOF conditions over time. This was done by comparing the change in prevalence rates for selected QOF conditions from 2006-08 to 2009-11 for the 5,026 ID adults who received a health check during 2009-11 (which by definition has to be positive) with the change in prevalence in the 2,728 ID adults without a health check during this time (Figure 36). There was no consistent pattern in the increase in prevalence between the groups, with both groups showing an absolute increase of 1-2% for most conditions (Table 43). The most notable disparity was for a diagnosis of depression where patients with ID without health checks had a greater increase (+2.4%) than those with health checks (+1.6%).

TABLE 43: CHANGE IN PREVALENCE OF SELECTED QOF CONDITIONS BETWEEN 2006-08 AND 2009-11 IN ID ADULTS WITH AND WITHOUT HEALTH CHECKS BETWEEN JANUARY 2009 AND DECEMBER 2011

Category Identified	ID Adults with health check 2009-11 (n=5,026)			ID Adults without health check 2009-11 (n=2,728)		
	% 2006-08	% 2009-11	+/- change	% 2006-08	% 2009-11	+/- change
Diabetes	6.03	7.54	+1.51	5.61	7.29	+1.68
Hypertension	10.07	12.14	+2.07	11.07	12.83	+1.76
Chronic Kidney Disease	2.43	3.94	+1.51	2.27	3.48	+1.21
Hyperthyroidism	8.81	10.27	+1.46	5.50	6.67	+1.17
IHD	0.99	1.49	+0.50	2.02	2.46	+0.44
Osteoporosis	1.37	2.03	+0.66	1.25	1.72	+0.47
Depression	15.10	16.69	+1.59	17.16	19.57	+2.41
Severe mental illness	7.86	8.50	+0.64	6.23	6.78	+0.55
Epilepsy	26.34	27.12	+0.78	18.15	18.73	+0.58
COPD	0.44	0.80	+0.36	1.32	1.80	+0.48

Figure 38 shows the percentage of patients in 2008 and 2011 with a consultation, a prescription (any, repeats only, psychotropic only) and any referrals made in primary care in 2008 and 2011, by whether they received a health check during 2009-11.
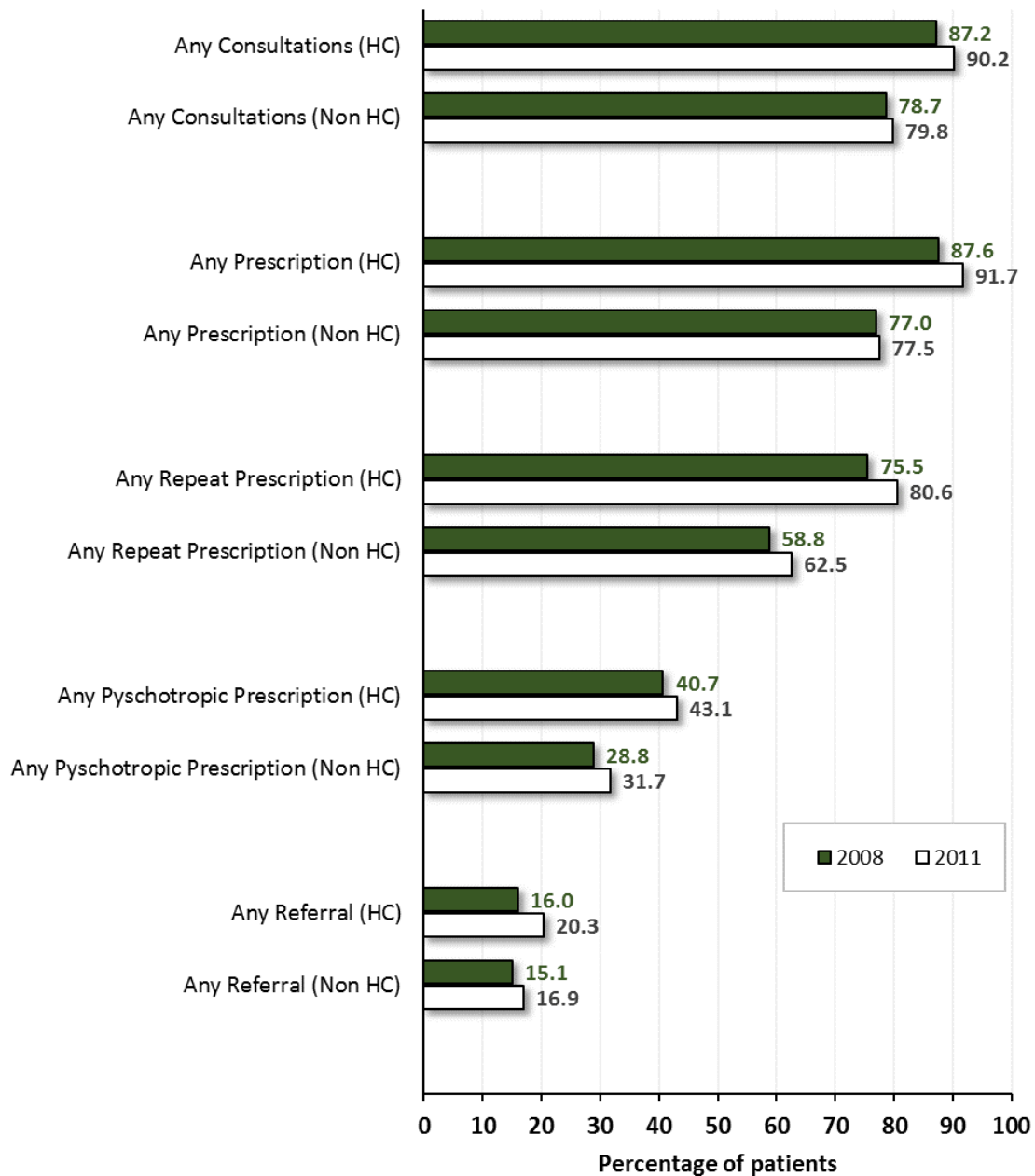
FIGURE 38: PERCENTAGE OF PATIENTS WITH CONSULTATIONS, PRESCRIPTIONS AND REFERRALS IN 2008 AND 2011 IN ID ADULTS WITH AND WITHOUT HEALTH CHECKS 2009-11

There were clear baseline differences between the two groups in 2008, where adults with ID who would go on to receive a health checks were already more likely to consult in the year (87% vs. 79%) or receive any prescription (88% vs. 77%). By 2011, both groups showed small increases over time, which were generally higher in the health checks group. For example, the percentage of patients with a consultation (not counting the health check itself) increased from 87% to 90% in the health checks group, compared to 79% to 80% in the non-health checks group. The percentage of patients with a referrals rose from 16% to 20% for those with health checks, compared to an increase from 15% to 17% for those without health checks.

We also compared the recording of being seizure free for ID patients with epilepsy before and after health checks. During 2006-08, 632 of 1,080 (58.5%) were seizure free, which rose to 694 of 1,080 (64.3%) during 2009-11. This absolute increase of 5.8%, compared with a 2.7% increase in 372 epilepsy patients without health checks over the same period (which rose from 55.9% to 58.6%).

Finally, we compared the mean level of consultations, prescribing and referrals (made within primary care) in 2008 and 2011, and the associated absolute change, for ID adults with and without health checks (Table 44). To assess if the change in mean level of each outcome differed between groups we carried out a conservative test based on the change in outcome for each individual. The changes were ranked and a Wilcoxon rank sum test was carried out to see if they differed between groups.

TABLE 44: CHANGE IN MEAN NUMBER OF CONSULTATIONS, MEDICATIONS AND REFERRALS BETWEEN 2008 AND 2011 IN ID ADULTS WITH AND WITHOUT HEALTH CHECKS

Category Identified	ID Adults with health check 2009-11 (n=5,026)			ID Adults without health check 2009-11 (n=2,728)			Difference in change*
	2008	2011	+/- change	2008	2011	+/- change	p-value
Consultations	5.38	5.93	+0.55	4.64	5.38	+0.74	0.71
Drug classes	5.09	5.90	+0.81	4.04	4.54	+0.50	<0.001
Drug classes (repeats only)	3.02	3.62	+0.60	2.23	2.66	+0.43	<0.001
Psychotropic prescriptions	0.65	0.69	+0.04	0.45	0.50	+0.05	0.44
Referrals (made in primary care)	0.23	0.30	+0.07	0.21	0.25	+0.04	0.08

* - p-value for Wilcoxon rank sum text between with individual change between groups.

While there was no evidence that health checks had led to any significant change in the mean level of consultations over time (p=0.71), there was some evidence that the change in the overall mean level of prescribing was greater among patients with health checks (p<0.001), though not for psychotropic prescribing.

Change in estimated economic costs before and during health checks

We also revisited our estimates of annual NHS costs in relation to health checks. Here we use the costings identified for 2011 (see Appendix 5**Error! Reference source not found.**) and apply these to both 2008 and 2011 for the groups of ID adults with and without health checks. To assess if the change in costs differ between groups we again ranked the changes for each individual, and carried out a Wilcoxon rank sum test to see if they differed between groups (Table 45).

TABLE 45: CHANGE IN MEAN NHS COSTS (£ PER PERSON) BETWEEN 2008 AND 2011 IN ID ADULTS WITH AND WITHOUT HEALTH CHECKS

Category Identified	ID Adults with health check 2009-11 (n=5,026)			ID Adults without health check 2009-11 (n=2,728)			Difference in change*
	2008	2011	+/- change	2008	2011	+/- change	p-value
Primary Care							
- Mean consultations	£159.4	£216.7	**+£57.3**	£146.1	£180.4	**+£34.3**	<0.001
- Mean prescribing	£455.3	£559.7	**+£104.4**	£310.2	£399.5	**+£89.3**	<0.001
Secondary Care†							
- Elective admissions	£204.0	£194.8	**-£9.2**	£197.9	£196.1	**-£1.8**	0.80
- Non-elective admissions	£292.7	£429.6	**+£136.9**	£311.2	£472.4	**+£161.2**	0.90

Note that costs are estimated as mean £ per patient based on fixed 2011 costings. For more details on how these were estimated please see Appendix 5.

* - p-value for Wilcoxon rank sum text between with individual change between groups.

† - Analyses restricted to patients with linked HES data only: n=4,218 with health checks, n=2,179 without health checks.

Primary care costs for consultations and prescribing rose for both groups, both the mean change within individual patients was greater for ID adults with health checks (p<0.001). However, this difference was not replicated when we looked at secondary care costs among patients with linkage to the HES data. While the cost of elective admissions (based on 2011 costings) remained flat over time for the two groups, there were large increases of approximately 50% for non-elective admissions. While the overall mean increase was higher for ID adults without health checks (+£161 vs £137 per patient), there was no statistical difference of the comparison of the within individual change using the Wilcoxon rank sum test (p=0.90).

Predictors of first health check during 2009-11

We now investigate what factors were predictors of receiving a first health check during 2009-11 among 7,754 adults with ID registered throughout in practices with a minimum level (20%)

of participation in the DES. A logistic model with practice fitted as a random effect (see statistical methods, page 36) was used to produce mutually adjusted odds ratios for all factors investigated. We carried out sensitivity analyses excluding patients from practices with exceptionally high participation in the DES (>90%), but this made no material difference to our conclusions.

Table 46 summarises what baseline factors were important in predicting the receipt of a first health check between 2009 and 2011. Older patients (aged 35 years or more at the beginning of follow up) were more likely to get a health check than younger ones (68.0% vs 58.7%). The strongest associations were seen among patients with pre-existing epilepsy (87.6%) and those in communal or shared accommodation (86.4%). Patients who were already being seen in primary care frequently prior to the introduction of health checks (6 or more consultations in 2008), were subsequently more likely to get a health check during 2009-11 (69.3%). There was no evidence of a trend with level of area deprivation (p=0.85).

TABLE 46: BASELINE PREDICTORS OF HEALTH CHECKS FOR ID ADULTS BETWEEN JANUARY 2009 AND DECEMBER 2011

Characteristic	Total	With a health check	%	Adjusted OR† (95% CI)
All	7,754	5,026	**64.8%**	_
Gender				
-Women	3,269	2,153	**65.9%**	_
-Men	4,485	2,873	**64.1%**	**1.01** (0.90-1.13)
Age (in 2009)				
-18-34 years	2,669	1,567	**58.7%**	_
-35-54 years	3,483	2,370	**68.0%**	**1.33** (1.17-1.51)
-55-84 years	1,602	1,089	**68.0%**	**1.19** (1.01-1.39)
Down's syndrome				
-Yes	863	644	**74.6%**	**2.11** (1.75-2.55)
-No	6,891	4,382	**63.6%**	_
Severe health needs*				
-Yes	1,338	1,117	**83.5%**	**2.39** (2.00-2.86)
-No	6,416	3,909	**60.9%**	_
Communal accommodation*				
-Yes	1,796	1,551	**86.4%**	**4.35** (3.61-5.23)
-No	5.958	3,475	**58.3%**	_
Autism spectrum disorder				
-Yes	528	401	**76.0%**	**1.63** (1.28-2.09)
-No	7,226	4,625	**64.0%**	_
Epilepsy				
-Yes	1,052	921	**87.6%**	**3.46** (2.79-4.28)
-No	6,702	4,105	**61.3%**	_
Deprivation*				
- 1 (Least Deprived Fifth)	802	483	**60.2%**	_
- 2	1,126	790	**70.2%**	**1.33** (1.04-1.69)
- 3	1,240	848	**68.4%**	**1.22** (0.96-1.56)
- 4	1,519	993	**65.4%**	**1.07** (0.84-1.36)
- 5 (Most Deprived Fifth)	1,661	1,073	**64.6%**	**1.12** (0.88-1.43)
Test for trend				**p=0.85**
Consultations (during 2008)				
- 0 to 1	2,219	1,284	**57.9%**	_
- 2 to 5	2,958	1,955	**66.1%**	**1.17** (1.03-1.34)
- 6 or more	2,577	1,787	**69.3%**	**1.30** (1.12-1.51)

* - For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details. Deprivation was defined as IMD quintile[46].

† - Logistic model with random effect fitted for practice. OR mutually adjusted for all characteristics listed in table.

Predictors of repeated health check during 2010-11

Finally, we investigated the influence of baseline factors on a repeated health check. To do this, we focused on the 3,995 patients who received a first health check during 2009 or 2010 from Table 46. For patients with a health check during 2009 (n=1,900), we looked to see if they received another one during 2010. For patients with a health check during 2010 (n=2,095), a subsequent one during 2011 was searched for. Overall, 2,425 patients (60.7%) with a first health check during 2009 or 2010 received a second health check during the following calendar year.

Table 47 summarises what baseline factors were important in predicting a repeated health check between 2010 and 2011. The factors which predicted a first health check showed smaller associations here, with communal living (68.6%) and epilepsy (64.6%) again showing higher attainment. This time, there was a significant trend with deprivation (p<0.001) with patients living in more deprived areas being less likely to get a repeated check (54.2%).

TABLE 47: BASELINE PREDICTORS OF A REPEATED HEALTH CHECK BETWEEN JANUARY 2010 AND DECEMBER 2011 AMONG ID ADULTS WITH A FIRST BETWEEN JANUARY 2009 AND DECEMBER 2010

Characteristic	Total	With 2nd health check	%	Adjusted OR† (95% CI)
All	3,995	2,425	**60.7%**	_
Gender				
-Women	1,729	1,063	**61.5%**	_
-Men	2,266	1,362	**60.1%**	**0.94** (0.81-1.09)
Age (in 2009)				
-18-34 years	1,207	681	**56.4%**	_
-35-54 years	1,910	1,186	**62.1%**	**1.30** (1.09-1.54)
-55-84 years	878	558	**63.6%**	**1.41** (1.13-1.76)
Down's syndrome				
-Yes	511	325	**63.6%**	**1.24** (0.99-1.56)
-No	3,484	2,100	**60.3%**	_
Severe health needs*				
-Yes	593	325	**64.6%**	**1.03** (0.86-1.24)
-No	3,077	1,832	**59.5%**	_
Communal accommodation*				
-Yes	1,368	938	**68.6%**	**1.60** (1.32-1.94)
-No	2,627	1,487	**56.6%**	_
Autism spectrum disorder				
-Yes	329	205	**62.3%**	**1.20** (0.91-1.58)
-No	3,666	2,220	**60.6%**	_
Epilepsy				
-Yes	748	483	**64.6%**	**1.19** (0.98-1.45)
-No	3,247	1,942	**59.8%**	_
Deprivation*				
- 1 (Least Deprived Fifth)	336	203	**60.4%**	_
- 2	649	446	**68.7%**	**1.36** (0.97-1.90)
- 3	720	482	**66.9%**	**1.08** (0.77-1.51)
- 4	803	443	**55.2%**	**0.79** (0.57-1.09)
- 5 (Most Deprived Fifth)	840	455	**54.2%**	**0.71** (0.50-1.00)
Test for trend				**P<0.001**
Consultations (during 2008)				
- 0 to 1	984	560	**56.9%**	_
- 2 to 5	1,566	950	**60.7%**	**1.12** (0.93-1.36)
- 6 or more	1,445	915	**63.3%**	**1.23** (1.01-1.51)

* - For definition of severe health needs see page 28 and Figure 5 for further details. For definition of communal accommodation see page 33 for further details. Deprivation was defined as IMD quintile[46].

† - Logistic model with random effect for practice. OR mutually adjusted for all characteristics listed in table.

Chapter 8 Discussion

Introduction

In this final section, we now summarise the results from the study (Chapters 3-7), and discuss them further, including strengths and limitations, placing them in context with the existing literature. Finally, we highlight implications that we have identified. To recap, the study originally had two overall aims (Table 1).

- **Aim 1:** To describe the health, healthcare quality, equity of healthcare, mortality rates and NHS costs for adults with ID in a national sample. This is discussed on pages 161-179.

- **Aim 2:** To evaluate the process and outcome effectiveness of annual health checks for adults with ID in primary care. This is discussed from page 179 onwards.

Aim 1: Health, healthcare quality, mortality and NHS costs - Summary of findings

We used data from 408 English general practices to show that, compared to an age-sex-practice matched group of patients without ID, adults with ID

- Had higher overall levels of most chronic diseases and multi-morbidity, though recording was lower for CHD and cancer

- Had greater overall primary and secondary care utilisation and costs, particularly prescribing

- Had higher levels of psychotropic prescribing, particularly antipsychotics and benzodiazepines

- Were less likely to have longer doctor consultations and had lower continuity of care with the same doctor

- Were estimated to contribute approximately double the amount of NHS costs across primary and secondary care

- Did not demonstrate the same pattern of greater disease prevalence and prescribing with increases in area deprivation

We then used data from national hospital admissions and mortality datasets linked to primary care records in 343 practices to create a retrospective longitudinal study between 2009 and 2013, and show that, compared to an age-sex-practice matched group of patients without ID, adults with ID

- Had a risk of death more than three times higher, even after adjusting for differences in co-morbidity
- Had more than a third of their deaths classed as potentially amenable to health care interventions
- Were three times as likely to be admitted to hospital for an emergency admission, five times as likely for admissions classed as potentially preventable (ACSCs)
- Had a third of their emergency admissions classed as potentially preventable
- Did not appear to differ in the primary care utilisation and management before admissions for two common ACSCs (urinary tract and lower respiratory tract infections) despite being at increased risk of complications

Aim 1: Health, healthcare quality, mortality and NHS costs - Strengths and limitations

We have provided a systematic description of the health needs and consultation patterns of adults with ID in English primary care, which has addressed a variety of data gaps that have been highlighted for this group including chronic disease prevalence.[77] By primary care, we specifically mean healthcare delivered through the GP practice, and thus other types of primary care (e.g. dentistry, optometry) will not be covered in our summary analyses. The inclusion of controls without ID, or conditions related to ID such as autism, enabled direct age-sex comparisons within the same English population, which is an advantage over approaches which have relied on whole external populations for comparable estimates of chronic disease in the general population.[78] By matching on GP practice, we were able to overcome potential variations in the practice recording of health promotion and chronic conditions that is likely to exist in our data, in addition to dissimilarities in consultation access between different practices.

Another potential strength of our approach was the inclusion of a large unselected group of patients with ID identified as such in primary care. As ID (as "learning disability") has been

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included in QOF since 2006, and the associated prevalence has stabilised (see Appendix 1**Error! Reference source not found.**), it seems reasonable to presume we have included most adults with severe ID in our study. However, our reliance on primary care data to identify ID could be viewed as a limitation too, as there are noted concerns about the under recording of ID on primary care systems (page 20).[39,50] Thus, our results must be viewed in the context of ID identified and recorded by GPs, which will represent the most important group of adults with ID. However, we think it is unlikely that any under-recording of ID could explain away any of the key differences in health care utilisation that we have observed and detailed here.

There are other limitations that relate to under- or incomplete recording of other characteristics in primary care that we sought to measure in our study. We detailed issues regarding the recording of medication reviews in CPRD (page 35), which suggested we may be underestimating these; but this would not invalidate comparisons between adults with and without ID. Key characteristics such as living arrangements or severity of ID were not routinely recorded, so we had use additional information where available to bolster these measures. For example, for severity of ID we created a proxy measure of severe health needs that would capture severity through a combination of other recorded health needs (Figure 5). However, the evidence from the systematic review of health checks for people with ID in 2014[12] has suggested that the identification of some chronic conditions and health needs is incomplete in adults with ID and so, our results should be interpreted as conservative estimates of the true extent of need. For living arrangements, we were restricted to identifying only patients who were recorded as living in shared or communal accommodation by either a specific Read code or clustering of address flag. This approach, while crude, still allowed us to identify large differences between patients with ID classified this way or not. Patients who were not classified this way however will have heterogeneous living arrangements, in terms of carers or family support.

Our study attempted to summarise consultation length by using the recorded duration on the underlying computer system that the CPRD practices use (Vision).[79] This however must be viewed as an approximation, as the system may be recording the period where the GP views the record before and after the relevant face-to-face consultation with the patient. We also observed that some duration entries were implausibly zero or overlong presumably due to user error. We attempted to mitigate this by summarising length into binary categories (1-10

versus >10 minutes). Despite some uncertainty over consultation length, we do not believe that the aforementioned errors would be disproportionate between adults with ID and controls, and thus our relative comparisons and observed differences are valid.

We also estimated continuity of care, by anonymously identifying the GP or nurse during the recorded consultation from their unique system ID on the Vision system.[79] While this simplistic approach addresses continuity of care with the same clinician, known as relational continuity, it does not address measures of management continuity. These would include the consistency of clinical management or co-ordination of care, which will also make a significant contribution to a patient's experience of care over time.[80]

We also presented a comparison of estimated NHS costs between adults with and without ID during a single calendar year (2011) using published costings to allocate costs to recorded events. While events taking place at the GP surgery such as consultations and prescribing are on the whole clearly identified on the patient record and could be costed accordingly, events outside the practice such as outpatient attendance or visits to A&E were inconsistently recorded, and as a result could not always be identified. Further, we were unable to ascertain the costs of other primary care activities such as laboratory tests. Thus, our estimates of cost must be acknowledged as a significant underestimate, although we do not believe that the under-recording of events would differ disproportionally between patients with and without ID. For this reason, we chose to compare relative differences in costs as opposed to absolute differences. The doubling of estimated costs compared to the general population appeared to be primarily driven by a similar relative difference in the underlying admission rate. Despite our caveat about our NHS costs estimates, we were still able to highlight an association of falling costs with increasing levels of area deprivation among adults with ID living in shared or communal accommodation, which is the inverse of what is observed in the general population.

We also provided a comprehensive description of the patterns in mortality and emergency hospital admissions for a large cohort of adults with ID in England between 2009 and 2013. The linkage of primary care data to routine data sources of mortality and secondary care use, directly addresses a key data gap that has been recently highlighted in a 2015 review of mortality for people with ID in England,[25] and featured as a recommendation (number 16) in

the CIPOLD.[22] Our detailed comparison of emergency hospitalisation rate for adults with ID with the general population extends an area of limited research.[81] Our work makes a significant contribution by quantifying mortality and hospitalisation disparities for adults with ID compared to the general population, where accurate and detailed information is essential for future planning and policy making.[82]

This study's utilisation of linked primary care data allows for better ascertainment of adults with ID, which in the UK has been historically been poor in mortality data[25] and thought to be low among hospital admissions data.[13] In our study, we found a low proportion (31%) with a recording of ID or associated condition as a secondary cause on their death certificates, similar to that found by others.[25] Likewise, only 66% of adults with ID with a hospital admission in our study had ID recorded on their record, emphasising the limitation of studies based on hospitalisation records or death certificates alone. The linked primary care records in our study also allows for control and stratification by factors not routinely available in hospital or mortality data such as co-morbidity and smoking.

For the mortality analyses, one of the main limitations of our study is the potentially incomplete and inaccurate recording in death certification data. For example, in our study many patients with Down's syndrome had this condition recorded as the underlying cause of death, with respiratory diseases as a secondary cause, which was probably the more appropriate underlying cause of death. This miscoding would have had no impact in our analyses of avoidable mortality, as either condition would still have been classified as an amenable, and hence avoidable, death. However, it could also be argued that some deaths among adults with ID are ultimately less avoidable due to the conditions associated with ID. For example, immune defects common in adults with Down's syndrome may make them more prone to infection,[83] and subsequently less amenable to treatment.

In our analysis of hospital admissions, a small number had an uninformative primary diagnosis of ID, so we were unable to determine a more specific reason for admission. In our comparison of primary care utilisation prior to hospitalisation for two common infections, we suspected that urine dipstick tests were poorly recorded across both groups and likely to be underestimated. This analysis was unmatched, and although we adjusted for age and sex differences between ID patients and controls in those presenting, we cannot be sure how

comparable the scenarios are for the two groups. Similarly, although epilepsy was a common reason for admission, we chose not to compare epilepsy admissions between adults with and without ID as we had reservations about how comparable the severity of the condition would be between groups. In addition, epilepsy management, such as drug and dose changes, are mostly initiated and managed by non-primary care specialists.

Aim 1: Health, healthcare quality, mortality and NHS costs - Comparison with other studies

(i) Disease prevalence

A number of studies in the UK and internationally have described the prevalence of health problems in people with ID.[19,20,78,84-88] These have shown high levels of co-morbidity, although direct comparisons of estimated prevalence to the general population has generally been difficult due to population selection and disease definition. Only a recent Scottish study in primary care of 8,014 adults with ID has been able to provide comprehensive standardised prevalence rates by age-groups,[88] and produced similar findings for 2007 to our own published findings for 2012.[63]

In addition, the recent studies in Scotland,[88] Ireland[78] and the Netherlands[87] have all considered multi-morbidity in adults with ID. These studies considered a wider range of conditions than our study, and as a result reported higher levels of multi-morbidity than we did. This makes any direct comparison difficult, however the relative doubling of multi-morbidity (defined as two or more conditions) between adults with and without ID in the Scottish study[88] were similar to our findings where adults with ID were 1.8 times more likely to have multiple QOF conditions. The Dutch study finding of greater multi-morbidity among Down's adults[87] was the opposite to what we found, presumably due to their study being among older adults only (≥50 years) whereas our Down's patients were primarily of younger age (73% were less than 50 years old).

Looking at individual conditions, our estimate of the prevalence of epilepsy in adults with ID (18.5%) compared favourably with an estimate of 18.8% found in the recent Scottish primary care study.[88] Both are lower than an estimate of 26% found in Leicestershire from a regional based register in 2006,[18] but this may reflect regional and methodological differences. There

has also been a concern that epilepsy has been historically over diagnosed in people with ID, estimated at around 3 in 10 from a review in 2011,[89] and so our more recent findings may represent an improvement in diagnosis.

We also demonstrated an excess of recorded mental health problems among patients with ID, which require good access to specialist services and present a challenge to primary care in managing such patients, where GPs may lack sufficient support.[90] Our high prevalence of recorded mental health problems such as schizophrenia (6.8%) is similar to what was found in the Scottish primary care study (5.6%),[88] and consistent with an earlier population-based survey undertaken in Glasgow in the early 2000's, which found 4.4% of 1,023 adults with ID received a clinical diagnosis of a psychotic disorder including schizophrenia.[91] Although the recording of depression ever in the patient record was similar for adults with ID (18%) to that reported in the Scottish primary care study (16%),[88] we found no difference compared to our matched controls, whereas in Scotland adults with ID were significantly more likely to have a diagnosis than population controls.[88] When we restricted to diagnoses made in the last year, we actually found adults with ID were less likely to receive a depression diagnosis. This may have reflected the reluctance of some GPs to make a diagnosis, which during 2011 would have required further use of assessment tools in QOF[47], which may not be appropriate for some patients with ID (and would not have been the case for the Scottish study reported in 2007).[88]

There has been limited information on the physical and sensory disability prevalence among adults with ID from UK. The Scottish study of primary care data estimated hearing loss at 8.2% and visual impairment at 3.2%,[88] which compares favourably with our estimates of deafness (8.3%) and bilateral visual loss or low vision (4.7%). Internationally, our estimates of severe visual problems was close to the prevalence of blindness (5.0%) reported in a detailed Dutch study of visual impairment among adults with ID.[20] Similarly, our recorded prevalence of behavioural problems was similar to those reported in earlier regional studies in England[92] and Norway.[93]

The lower recording of cancer, IHD and COPD in adults with ID was surprising, especially given the high prevalence of co-morbid risk factors for IHD such as diabetes, obesity, hypothyroidism, chronic kidney disease and stroke. However, any apparent higher risk may be offset by the much lower recorded rates of smoking and alcohol use among adults with ID.

The lower prevalence of these conditions was also observed in comparisons with the general population in Scotland with age-sex standardised OR's of 0.69 for cancer, 0.43 for coronary heart disease and 0.84 for COPD,[88] that compare with our prevalence ratios of 0.65 (cancer and IHD) and 0.84 for COPD. Internationally, a recent Dutch longitudinal study of older adults with IHD estimated the incidence of coronary heart disease to be 6.5 per 1,000 person years, compared with 7.3 from general population estimates.[94] Besides the noted difference in lifestyle factors there are two other possible explanations for the lower prevalence of these conditions. One would be that the data reflects inadequate identification among adults with ID,[95] and the recorded prevalence is a poor estimate of the true underlying prevalence. For cancer for example, a diagnosis may be delayed through communication difficulties regarding symptoms with their carers or family members.[96] Alternatively, the data correctly reflect reality, but due to the premature mortality among adults with ID there is a survivor type effect within the ID population. If a significant proportion of younger adults with ID who would have gone on to develop cancer or IHD in later life never reach the advanced age that these diseases are typically diagnosed within the general population, then the prevalence of these conditions in later life would be lower. This argument is given some credence by the observation that a higher prevalence of both cancer and ID was seen when the comparison was restricted to younger adults only, though numbers with the conditions were small (Table 7).

We also showed that compared to the general population, adult patients with ID were more likely to be recorded both as obese (BMI>30), and underweight (BMI<20). Our estimate that 36.4% of ID adults measured were obese, is similar to other UK findings,[97,98] but far exceeds a pooled prevalence estimate of 15% among adolescents with ID from several countries.[99] Though the association between ID and being underweight in adulthood is generally accepted due to poor feeding and swallowing,[17] we were not aware of any population estimates of its prevalence. Older patients with ID are known to suffer an earlier onset of frailty than the general population,[100] and our higher prevalence of recorded osteoporosis reflects the high prevalence of low bone quality that has been measured among older patients with ID. [101] A recent Dutch study showed that a low BMI among older patients with ID was predictive of 3-year mortality. [94]

(ii) Consultations

Our overall estimate of a 70% higher rate in GP consultations between adults with and without ID of the same age and sex, matched what was found in a Dutch study of 71 general practices during 2001.[19] We were able to further demonstrate that this higher consultation rate was not explained by the higher prevalence of conditions included in the QOF.

This finding of higher consultations contrasted with two small earlier UK studies, one in London that sampled 187 adults with ID from 40 practices,[102] and another based on 142 adults in the East of England.[103] Neither found an increase in consultation among their ID adults when the authors compared their study results to expected consultation levels estimated using national data (General Household Survey, QRESEARCH). Our study has the advantage of directly comparing consultation behaviour within practices, accounting for any practice variations or trends. Besides the methodological differences, these older studies may also reflect temporal changes in consultation behaviour for adults for ID that may have taken place in the UK.

Our analysis of recorded consultation length showed that while adults with ID had more consultations of a long length (more than 10 minutes) overall with a GP or nurse during the year than their matched controls, there were less likely to have a longer one when their higher overall consultation level was taken into account. In other words, any given consultation with a GP or nurse is likely to be shorter on average for an adult patient with ID. For continuity of care, patients with ID were consistently less likely to see the same doctor, no matter how many consultations they had during the year. This may partly reflect a greater propensity for these patients to consult for acute problems where an urgent appointment is more important than continuity per se. While this may be true, the ability to see their regular GP was highlighted by our patient group in the study as important factor in their healthcare (Table 3). Discussions with the patient group also found that allotted appointment times were not always adequate to discuss their health issues. Both increased consultation times through double appointments and enhanced continuity of care have been highlighted as reasonable adjustments that GP practices could be expected to make in improving the access of healthcare for people with ID.[104]

(iii) Prescribing

The prescribing of psychotropic medication for challenging behaviour in adults with ID is much discussed and controversial in nature, with concerns of over prescribing within this group.[105] Additionally, there has been observed a low level of recorded ancillary information in the electronic GP records of patients with ID to justify the level of prescribing observed.[106] In the UK, the scale of the prescribing of psychotropic drugs to patients with ID nationally has been previously described in the CPRD data between 2009 and 2012,[107] and more recently in another primary care database (THIN) from 1999-2013.[106] The study based on CPRD data found that 41.3% of person days for adults with ID were exposed to a psychotropic drug (including antiepileptic drugs). We provided an alternative summary (and did not count antiepileptic drugs), describing instead the proportion of adults with ID who received a psychotropic drug at any time during single year (2011), and found a similar 4-in-10 proportion. This was lower than what was reported in Scotland during 2002-4 (49.5%)[91], but more similar to other international cross-sectional findings from The Netherlands (32%)[108] Norway (37%)[109] and Australia (35%).[110] While these studies generally showed antipsychotics were the most frequent type of psychotropic medication being prescribed to this group, in our study antipsychotics and antidepressants were equally likely to be prescribed.

The most comprehensive comparison of prescribing trends between adults with and without ID in a primary care setting we are aware of is a 2001 Dutch primary care study.[19] This study of 868 patients with ID, found that 82% received any prescription during the year, compared to 69% of age-sex-practice controls. By contrast we found 86% and 67% respectively, and similarly found antipsychotic drugs to be the most common class of drug prescribed to this group.

Among antipsychotics, the most common drugs being prescribed to adult patients with ID in 2011 were the atypical/second generation antipsychotics risperidone and olanzapine, which are effective in reducing aggressive behaviour in ID patients in comparison to typical/first generation ones.[111] However typical/first generation antipsychotics such as chlorpromazine and haloperidol were still widely prescribed to adults with ID, while almost non-existent in the general population. Many patients with ID are treated long term with antipsychotics for many years,[112] and the prevalence of adverse effects resulting from them is thought to be high. A recent Dutch study reported associations between psychotropic drugs and quality of

life, with a large majority of ID patients (>90%) on psychotropic drugs experiencing an adverse event during a two-year follow up.[113]

The greater prescribing of benzodiazepines among adults with ID will be partly attributable to the higher prevalence of epilepsy in this group, where benzodiazepines such as clobazam are licenced for the prevention and treatment of fits in epilepsy.[114] While we found the rate of antidepressant prescribing to be double that for adults with ID compared to the general populations, the prescribing of low dose amitriptyline was an exception, being lower in adults with ID. Since these are often prescribed for neuropathic pain,[115] our finding may indicate that patients without ID are more often prescribed amitriptyline for this important indication.

(iv) Mortality

Our finding of an increased overall risk of death associated with ID is consistent with numerous contemporary findings both in the UK and internationally showing premature mortality for this group.[14] In the UK, studies of mortality among people with ID have used a number of data sources including local registers, death certification data alone or national registers.[25] The largest existing UK study to date, was based on follow up of a regional disease in Leicestershire between 1993 and 2006,[116] identifying 503 deaths among adults with ID, and found an increased risk of death of just under three (2.77) compared to the general population.[117] This was slightly lower than our age-sex adjusted HR=3.62, which may be attributable to regional as well as period and other methodological differences. Internationally, a recent large retrospective longitudinal study in New South Wales, Australia used linked health data for 817 deaths among people with ID aged 5-69 to produce a SMR of 3.15.[118]

Gender differences that may impact on mortality within the ID population are not well understood.[119] In our study we observed higher age-sex adjusted mortality rates for women (139.5 per 10,000 persons per year) than in men (127.3), though no statistical difference remained when adjusted for differences in co-morbidity between the genders. This was similar to a recent US study,[119] utilising information from four state level disability service systems, which found higher mortality rates for ID women than men (18.9 versus 16.2 per 1,000). However, simply comparing overall mortality rates could hide any potential gender

disparity, as males of a similar age in the general population may have a higher underlying mortality rate than females from being more likely to engage in higher risk lifestyles or behaviours, a difference that may not exist within the ID population.[119]

Therefore, although more deaths are observed among adult men with ID in many studies, when their analyses compare their observed mortality with *expected* deaths in their control populations, using standardised mortality ratios (SMRs), they observe much higher expected mortality for females with ID.[77,117,118,120] For example, in the New South Wales study, they reported a SMR=4.26 for females versus a SMR=2.52 for males,[118] while the Leicestershire study produced a similarly higher SMR for women (3.24) compared to men (2.28).[117] A comparable gender disparity was also seen for SMRs in all ages in a recent study in Ireland using national databases of people with ID and census data.[121] In our study, we also observed more deaths among adult men with ID than women (365 vs. 291,Table 22), but a greater relative mortality risk for women (HR=4.10, Table 23) relative to their general population controls than the corresponding estimate for men (HR=3.30). While our analysis seemingly has the advantage of directly comparing adults with ID with age-sex-practice matched controls, rather than to a larger reference population, a potential drawback is that it is then based on a smaller number of deaths within its control population as we only have a sample of all adults without ID. This may account for differences in the estimated mortality in the general population, especially at younger ages, and why our gender difference was not as notable as that found previously in the Leicestershire study.[117] Regardless of these methodological differences, the gender relationship between ID and mortality is complex and warrants further investigation.[118]

We found an elevated risk of mortality in adults with Down's syndrome, which was approximately three times higher than for adults with ID without Down's. Mortality in people with Down's syndrome has been widely studied.[120,122-125] A large Danish study of 3,530 persons with Down's syndrome, found a HR=8.94 for standard trisomy 21 versus the general population for mortality between 1968 and 2009,[124] which compares closely to the HR=9.21 (Table 23) we found before any adjustment for co-morbidity. A smaller American study of 169 adults with Down's syndrome residing in the community found an adjusted risk of death almost four times as high (3.77) compared to other adults with ID without Down's

syndrome.[125] A recent study in Ontario of 172 deaths among people of all ages with ID also found an elevated risk for Down's syndrome, but only among those over aged 60 years.[120]

Among ID patients with autism spectrum disorder we found some evidence that their risk of mortality was lower than other ID patients without autism (HR=0.56, Table 24), even after adjusting for the age differences between the groups. However, we are cautious about over interpreting this finding as very few of this younger sub-group died during our study (n=15, 1.0%). Their risk of death was still estimated to be twice that of their matched controls without ID (HR=2.2, Table 23). A doubling of mortality risk with autism spectrum disorder compared to the general population has been shown in several population cohorts worldwide,[126] however this risk increases in studies that were able to further restrict the comparison to subjects with a co-existing ID [126] or neurologic disorders.[127] While a recent large Swedish case-control study reported an OR=5.8,[126] the median age of death for the group with co-existing ID (40 years) suggests insufficient follow-up in our study (3 years) may account for our imprecise findings among the younger sub-group of ID adults with autism, who had an average age of only 30.5 years at beginning of follow-up.

We also estimated a higher risk of mortality for adults with ID and epilepsy compared to adults with ID without epilepsy. There is established concern over epilepsy as a condition more commonly associated with death for people with ID,[71] particularly the contribution of sudden unexpected death associated with epilepsy (SUDEP).[128,129] A Swedish study of 1,478 people with ID, found associations between epilepsy and mortality between 1987 and 1992, with an estimated SMR of 5.0 for those with epilepsy compared to 1.6 for those without epilepsy.[130] This compares to the HRs we found of 6.0 and 3.2 before adjusting for mortality (Table 23). In the Leicestershire study,[128] elevated SMR's for adults with ID and epilepsy were seen in both men (SMR=3.2) and women (SMR=5.6), with both rising dramatically when the outcome was restricted to SUDEP, identified from case notes and post-mortem reports. In Ontario, elevated mortality with epilepsy for people with ID was about 1.8 times higher for ages 20-60[120] compared to our estimate of 1.6-1.7 (Table 24).

Our description of cause-specific mortality by comparison of ICD-10 categories is broadly similar to findings from the Leicestershire study,[117] with the smaller number of deaths within some categories accounting for some variation. No association with cancer was found in the

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earlier studies in Lecistershire,[117] nor a large 35-year follow up study in Finland.[15] While we found a small excess of mortality from cancer in adults with ID in our study, it varied by type, and was notably smaller for lung and prostate. Cancer is thought to be a less prominent cause of death for people with ID, perhaps due to the premature mortality within this group.[71] However, we still demonstrated increased associations with some cancers (particularly colorectal, Table 25) which suggests the associations with different neoplasms are more nuanced. Our findings may also highlight an important change resulting from an ageing population of people with ID due to increases in life expectancy.[131]

A high proportion of deaths amenable to healthcare intervention was described in CIPOLD.[132] However, the inquiry was only able to compare this proportion to the national UK average, and could not quantify either the absolute or relative risks. Our study extends this work, and provides quantitative estimates of this risk for adults with ID (Figure 28), with the rate of such deaths being almost 6 times higher among adults with ID than they were for adults of the same age and sex within the general population without ID. However, existing definitions of amenable mortality do not include some important treatable causes of deaths among people with ID, including UTIs and aspiration, and so are likely to underestimate the true burden of amenable mortality. However, at the same time it may be that some causes of death are less preventable or amenable in adults with ID due to the underlying cause of the ID itself. For example, the immune defects observed in people with Down's syndrome may lead to infections being more common, more severe, and less amenable to treatment.[125]

The difference in the relative contribution of preventable and amenable deaths to avoidable mortality compared to the general population may be partly explained by differences in lifestyle exposures. For example, we found adults with recorded ID in primary care were also far less likely to be recorded as smokers or consumer of alcohol on their electronic patient record. Adherence to current medical guidelines may also differ due to communication difficulties with patients with ID.[95] However, the high absolute risk of deaths amenable to healthcare intervention reflects established concerns over difficulties accessing healthcare, delays in diagnosis and poorer management experienced by people with ID.[8,22]

(v) Hospital Admissions

There are few recent studies about emergency hospital usage by adults with ID.[133] In England, the only previous national study by Glover et al[13] used earlier hospital data from 2005-9 and while large, it relied solely on the identification of ID from hospital data. Using the linked datasets in our study, we estimated that approximately 1 in 3 adults with ID who have an emergency admission in England do not have their ID recorded anywhere on their hospital record. This may explain the small difference in crude admission rates for emergency ACSCs between our study (61 per 1,000 per year), and what was found in the earlier 2005-9 study by Glover et al[13] (76 per 1,000 per year), as less severe cases of ID are presumably less likely to be recorded in hospital data. However, when Glover et al[13] compared admission rates for ACSCs to the general population, they also found a similar five times relative difference to what we found (Table 31).

In terms of different ACSCs involved, the findings in Glover et al[13] were broadly similar to what we observed, with emergency admissions for epilepsy and convulsions accounting for 41% of ACSCs compared to 36% in our study. Both studies found much higher emergency admissions for constipation and pneumonia, but we did not observe the same rates of admission seen for complications of diabetes, though they were still higher for adults with ID compared to the general population.

There are three other large scale studies on hospitalisations of adults with ID that we are aware of, but non-differentiated between emergency and planned admissions.[134-136] Our focus on preventable emergency admissions means that any comparison is difficult, as we would not expect good primary care management to decrease planned admissions for ACSCs. However, the large Canadian study from Manitoba found elevated hospitalisation rates during 1999-2003 for both epilepsy (RR=54) and constipation (RR=7.9) compared to the general population,[137] both of which will be dominated by emergency admissions, and as a result gave a similar picture to the pattern of emergency admissions in our study.

(vi) Costs

We are not aware of any other studies that have compared NHS costs between same age-sex patients with and without ID.

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Aim 1: Health, healthcare quality, mortality and NHS costs - Implications

We have identified the following implications from our cross-sectional analysis of disease prevalence, consultations and prescribing and NHS costs:

- Our findings on prevalence of chronic disease raise concern over inadequate identification of some conditions such as cancer or IHD. The lower prevalence of cancer in particular needs further exploration as this may indicate late diagnosis or poorer survival. A particular focus could be colorectal cancer where higher mortality rates were observed.

- The main burden of excess chronic disease for adult patients with ID is provided by epilepsy and severe mental illness such as schizophrenia. Ways to address these challenges for primary care and to improve access to specialist services need consideration.

- While psychotropic prescribing was much higher for adults with ID, this was not the case for the prescribing of low dose amitriptyline which was lower. As this is often prescribed for neuropathic pain, one interpretation might be that patients with ID are having diagnoses for pain missed, and less likely to communicate their symptoms well.

- The high burden of obesity among adults with ID is a concern, but presents an ongoing opportunity to build on weight loss interventions for patients with ID.[138] Additionally, adults with ID are more likely to be underweight, which also needs recognition and action.

- The higher level of chronic disease in adults with ID compared to the general population is not adequately captured by the Charlson index, emphasising this is not an appropriate measure of co-morbidity and mortality risk for this group.

- As higher consultation levels for adults with ID were not explained by co-morbidity, this implies that the resource implications of caring for adult patients with ID are unlikely to be met through present remuneration systems developed for QOF. Additionally, the high levels of need and utilisation by patients in communal establishments will lead to variable demands on practices depending on local variations in the density of communal establishments.

- Practices could take steps to improve access to longer consultations and continuity of care for patients with ID, as part of a reasonable adjustment.[104] This may be achieved by simple flags on computerised primary care records which prompt receptionists to offer double appointments where possible and bypass on call doctor arrangements for specific patients.

- The higher levels of prescribing and prescribing costs in primary care for adults with ID combined with the low levels of recorded medication reviews for this group, suggests that there is potential for changes to practice that could improve quality of care and potentially reduce NHS prescribing costs. In particular, the higher prescribing of psychotropic drugs among adults with ID is a concern and warrants further investigation.

- The high excess costs for adults with ID for emergency hospital admissions confirms the importance of examining emergency hospital admissions as an outcome for the effectiveness of health checks.

- The inverse association of NHS costs with increasing deprivation among ID adults living in communal or shared accommodation needs further explanation as it may represent inequitable healthcare of these patients living in poorer areas.

- The lack of comparable data in the literature on NHS costs for adults with ID suggests that more research is needed in this important area, which is vital for planning services and resources.

We have identified the following implications from our longitudinal results of mortality and hospital admissions:

- The consistently higher mortality risk for adults with ID seen at all ages reiterates the overall greater healthcare need of people with ID. Consistent guidance on the recording of ID as a contributory, but not underlying cause, on death certificates would be helpful for ongoing surveillance of the health of people with ID in all countries.[139]

- The higher burden of respiratory deaths among adults with ID is important to highlight, as national strategies in developed countries often give lower a priority to respiratory health. The large contribution of pneumonia and aspiration represents a potential focus for improving healthcare for people with ID.

- The much greater risk of death from urinary and neurological causes among adults with ID, highlights further potential opportunities to improve care for people with ID through better management of urinary tract infections and by optimising seizure control in people with ID.

- Our findings that more than a third of deaths among adults with ID were amenable to healthcare emphasises that strategies for improving health among people with ID need to prioritise access to and quality of healthcare as well as preventive interventions. Existing population wide strategies for working age adults in high income countries focus on cardiovascular risk and lifestyle factors, which although important for people with ID, do not address their different healthcare needs. Addressing the health and mortality disparities experienced by adults with ID is a key challenge for healthcare systems and a potentially important indicator of healthcare system equity and effectiveness.

- The higher emergency admission rate for adults with ID, which is even more marked for preventable admissions, highlights a specific area where improvements could be made. As the life expectancy of adults with ID increases,[131] it is essential that preventable admissions are fully described, so that appropriate interventions, specific to adults with ID, can be developed.

- We observed that 1-in-3 adults with a diagnosis of ID from primary care, had no mention of their ID on their hospital record. Inadequate flagging of these patients is seen as barrier to effective and safe hospital care.[40] Improving the sharing of information about ID diagnoses across NHS services, particularly from GP systems, should continue to be part of a reasonable adjustment to improve the healthcare needs for these patients.[40]

- Although the primary care utilisation and management prior to an admission for a UTI or LRTI for an adult patient with ID was not noticeably different from patients without ID, their primary care records did identify them as being at higher risk of UTI or LRTI. Since integrated risk stratification software is increasingly available in primary care,[140] these could be reasonably extended to better incorporate patients with ID, thereby facilitating the most appropriate initial management and follow-up monitoring.[141]

Aim 2: Health checks and effectiveness of health checks - Summary of findings

We used several methodological approaches to investigate the impact of health checks for adults for ID and found

- There was no evidence that the introduction of health checks was associated with a fall in overall emergency hospitalisation, except for adults with severe health needs.

- However, the change in the rate of potentially preventable emergency admissions was lower than expected after health checks, both within individuals and at a practice level.

- There were large variations in recorded information on the patient record around the time of the health check, both between different individuals and practices.

- Adults with ID who would go on to receive health checks were already consulting more and had higher prescribing levels and NHS costs than other adults with ID who did not go on to have health checks.

- Adults with ID who received health checks had larger increases in prescribing levels and costs than adults with ID without health checks; but patterns with consultation levels were less clear.

- Among practices carrying out health checks, adults with ID who have more severe health needs or who were living in communal establishments were more likely to receive a health check.

- Practices in the most deprived areas were more likely to offer health checks during 2009-12 than those in the least deprived areas. However, among patients who received a health check during 2009-10, those living in more deprived areas were less likely to receive a follow up health check in 2010-11.

Aim 2: Health checks and effectiveness of health checks - Strengths and limitations

We believe that our study is the first to report on the health outcome benefits of health checks for adults with ID rather than just process measures.[86] While the systematic reviews by Robertson et al[12,142] have shown the effectiveness of health checks in detecting unrecognised health needs in people with ID, they highlighted the lack of evidence regarding whether their provision translated into important longer term benefits, such as a reduction

in avoidable hospitalisations or mortality. For health checks among the general population (for 40-74 year olds), a recent study using CPRD data showed that their introduction increased the identification of cardiovascular risk factors,[143] but an earlier Cochrane systematic review for similar general health checks failed to find evidence that they reduce mortality, hospitalisation or disability.[144]

A strength of our analysis of health checks and hospital admissions was that we reached a similar conclusion from two different approaches, one based on practice level comparisons and the other based on individuals. As these two strategies used slightly different patient groups and definitions of time, the same conclusion would not necessarily be expected. An example of how the different groups behaved in the analyses could be seen in the trends in emergency hospital admissions over time. In the analyses on individual patients with ID, emergency hospital admissions were rising post health check for those with checks, or index date for those without health checks (Table 38). On the other hand, the practice level analyses showed an apparent fall in admissions during 2011-12 (Table 36). The observed rise in admissions in the same individuals is partly explained by their ageing over time, plus the fundamental requirement for them to be alive at the time of health check (or index date). This means that any deaths during the study for this group of patients can only occur post health check, and these would likely be associated with a rise in admissions beforehand. By contrast, the observed practice trends were based on an open cohort of all patients with ID aged 18-84 years in each calendar year, keeping average age effectively constant and allowing mortality within patients during each year.

Our analysis of health checks and hospital admissions has some limitations. The analysis at practice level was unmatched, and would likely be subject to residual confounding from unmeasured factors and characteristics at both practice and individual level. We observed that practices that regularly performed health checks were more likely to have adults with ID recorded with severe health needs, or who were recorded as living in communal establishments, than practices who did not participate (Table 35). However, this may reflect different levels of recording in these practices, as the group of practices that went on to regularly carry out health checks in our study already had lower emergency hospital admissions rates among their patients with ID at the outset in 2009 (Table 36). These practices

might have further reduced admissions anyway, and subsequent adoption of health checks may simply be a marker of other improvements in their care over the study period.

In order to control for any practice level changes over time, we matched individual adults with ID receiving health checks to population controls in the same practice. This analysis now adjusts for any temporal change, be it artefact or real, across practices or hospitals that may have taken place during the study. However, this adjustment would still fail to account for any changes specific to people with ID that may have happened. These could feasibly have occurred in the UK as a result of two high profile independent inquiries which have occurred during the last decade.[8,22] Therefore, our analysis also crucially included ID patients without health checks as a second control group not exposed to health checks. Instead, we assigned them a random health check date based on the distribution of observed dates for health checks. Since this group of patients showed no similar reduction in ACSCs compared to their matched controls, it provided additional evidence for the effectiveness of health checks. On the other hand, since our finding that adults with Down's syndrome increased emergency admissions by 55% post health check was also replicated in Down's adults without health checks, we concluded that this trend was *specific to Down's syndrome patients* and not health checks. This increase in emergency admissions for Down's patients may reflect the premature ageing associated with Down's such as early onset Alzheimer's disease,[145] combined with better survival into middle age, in part due to advances in childhood cardiac surgery.[123]

Although we have provided a description of what was recorded on the electronic patient record at the time of the health check, this may not represent all the important events that actually took place. It also cannot be assumed that the amount of information recorded directly correlates with the overall quality of the health check. There may be reasons specific to certain practices why some features of the health check are not regularly recorded electronically. For example, we observed a cluster of practices that featured a high proportion of patients living in communal establishments, recorded zero information besides the system flag to facilitate payment. We do not believe that these health checks were truly empty in their content. Therefore, our findings need to be seen in the context of the limitations of recorded electronic information.

Our analysis comparing changes in specific recorded process measures between ID adults with and without health checks was unmatched, and has limitations due to the potential non-comparability of the two groups. Before health checks were introduced, patients who would go on to receive health checks in our study, already had higher levels of recording for many process measures, as well as higher levels of prescribing. Additionally, they were also more likely to have severe health needs or be resident in communal accommodation. This makes any comparison between the two groups of ID patients difficult to interpret. As a result, we kept the statistical approach austere, focusing on change within individual, and using non-parametric tests to compare the change between the groups. Sensitivity analyses, investigating the change in consultation and prescribing levels comparing to the matched population controls, in the same manner as the analysis of hospital admissions in Chapter 6, produced similar findings as the un-matched analyses.

Whilst we did not attempt a formal economic costing of the effectiveness of the health check scheme, we estimated annual NHS costs before and after health checks. As already noted, there were already cost disparities before the scheme began, with patients who would go on to receive health checks already having higher primary care costs. Our comparison of within person changes in costs showed higher increases for both primary care consultation and prescribing costs for patients with health checks. Although mean overall costs for non-elective hospital admissions appeared to have increased less for health check patients, our statistical comparison of within patient cost showed no evidence of a difference, due to the majority of patients having zero costs in both periods.

Aim 2: Health checks and effectiveness of health checks - Comparison with the literature

(i) Health checks and hospital admissions

Reducing emergency hospital admissions to contain healthcare costs is a major international concern, but evidence for successful community interventions has been limited.[146] While our primary outcome of overall emergency hospital admission showed no change after the introduction of health checks for adults with ID, the evidence for a reduction in potentially preventable admissions was more consistent, and plausible. Given that admissions for ACSCs

represent less than 1 in 5 emergency admissions in the UK,[41] it is perhaps not surprising that we failed to detect a change among the broader group of all emergency admissions.

Within the general population, there has been a lack of evidence to support case management as an effective intervention for reducing emergency admissions.[146] Similar to the DES for annual health checks, GPs in England have been recently incentivised to case manage patients identified as high risk (approximately 2%) as part of UK policy to reduce emergency admissions. [29] Despite this, it has been argued that the focus should move towards admissions for conditions that are more amenable to prevention in the community,[146] such as ACSCs. While we were not able to determine what proportion of adults with ID were being classified as high risk by GPs, we have confirmed their higher overall emergency admission rates to hospital, and estimated that about 1-in-3 of these are for ACSCs. Admissions for epilepsy contributed about 4-in-10 emergency admissions for ACSCs for adults with ID, so one possible explanation is that health checks are facilitating better overall management of epilepsy and seizures among patients with ID. Similar to earlier findings from CPRD data from 2007,[24] our cross-sectional analysis during 2011 showed that adults with ID had lower recorded rates of being recorded as seizure free during the year compared to adults with epilepsy from the general population. This difference may be attributable to differences in disease severity and seizure types which are harder to manage.[24] Our longitudinal analysis suggested minor improvements in seizure free recording since health checks had been introduced. However, any such benefit would be important, as improved service provision of ID patients with epilepsy has been identified as a mechanism for reducing excess mortality among all people with ID.[147]

It has been argued that regular health checks for adults with ID are an efficient way of closing the health inequality gap that this group may experience, however this may also be widened if more easily managed patients are more likely to get health checks.[148] It is therefore reassuring that we found that those with more complex health needs were more likely to receive a health check, In our study, the decrease in emergency admission rates for ACSCs was more marked (27%) when we directly compared participating with non-participating practices, which suggests that there may be a "practice level benefit" of health checks, where changes in care have benefited all ID patients within the practice irrespective of whether they have the health check. However this may be an over simplification, as a recent serious case

review in the UK into the deaths of two adults with ID found that they had been invited to a health check but had failed to attend.[149] Interestingly, our analysis of individuals suggested that health checks produced the greatest benefit in reducing emergency admission to hospital in those with more severe and complex needs.

(ii) Health checks and process measures

The systematic review by Robertson et al[12] identified many worldwide studies showing that similar health checks for adults with ID have had meaningful impacts on health promotion and screening activity in primary care. In the UK for example, a small Scottish trial of an annual intervention for adults with ID[32] reported large increases in vision and hearing tests performed,[150] similar to our findings of increased recording in these areas for patients with health checks compared to those without. Many of the studies in the review however are now 10-20 years old, and the additional beneficial gains seen historically may not necessarily apply to English primary care where the recording of such conditions is now incentivised.

Post-introduction of the DES for annual health checks in England (2009), there are two large studies which have investigated their effect on process measures further. The study by Chauhan et al[151] used data from 171 practices in 6 Primary Care Trusts to identify approximately 4,000 adults with ID in both 2010 and 2011. The study by Buszewicz et al[86] used English data from the THIN database to compare recording during 2009-11 among 4,645 ID patients with health checks from 222 incentivised practices with 611 ID patients in 48 non-incentivised practices. Both studies found increased recording of a wide range of health assessments such as sight and hearing.[86,151]

We found that while health checks appeared to have increased prescribing levels among adults with ID over time, there was little impact on medication reviews over time. This contrasted with the study by Buszewicz et al[86] which found more reviews among patients with health checks. We acknowledge that the recording of medication reviews on CPRD may not be complete (page 35), and this may explain the discrepancy seen in reviews recorded during 2009-11 in our study (65%) and that seen in Buszewicz et al[86] (84%) over the same period. The 3-year recording of any medication review in our study was much higher than what we observed recorded during the checks themselves (26% for patients on repeat medication).

Since medication reviews are incentivised elsewhere in QOF,[47] it may be that many patients already have had a relevant review at the time of the check.

The systematic review by Robertson et al[12] also concluded that health checks had been effective in detecting a range of previously undetected conditions such as cancer and heart disease. While Chauhan et al[151] found that health checks were associated with an increased identification of conditions incentivised by QOF such as diabetes, Buszewicz et al[86] only found increases in post 2009 diagnoses for conditions likely to be a focus of health checks for patients with ID such as constipation or gastrointestinal disorders. We found little evidence to suggest that health checks were associated with increased diagnoses during 2009-11 for a range of QOF conditions. The lower prevalence of recorded cancer in adults with ID in our study suggests improvements in timely diagnoses of cancer in people with ID may still be possible.[152]

Our finding of increased prescribing levels and associated costs in adults with ID who had health checks compared to those who did not, is novel, and needs further investigation to confirm whether the checks are driving this increase. The pattern with consultations in primary care was less clear. The suggestion was that the checks had led to greater costs associated with consultations, with no change in the number of consultations themselves.

While we estimated annual NHS costs from available data, we did not attempt to estimate the costs of health checks themselves, and thus assess the cost effectiveness of the health check scheme. The large variation in recording procedures across practices for health checks needs to be better understood, to enable better cost estimates of health checks on a large scale. Both in the UK[153,154] and internationally,[155] small trials of health check intervention have suggested there were no associated higher costs in terms of service use compared to standard care.[153,154] However these studies may not have fully accounted for longer term hospitalisation costs, which in turn could have led to an underestimation of any potential economic savings.[154] Therefore, costs implications and benefits of health checks remain unclear and require further evaluation.

A few studies have recently investigated factors influencing uptake and attendance of health checks. A 3-year study in Northern Ireland[156] explored variations in uptake, where overall uptake of their DES of health checks has been higher than in England (64% of eligible patients

had received a check by 2013/14). Similar to our findings, they found higher uptake with age, and that patients living in nursing or residential homes (82%) were significantly more likely to have a health check than those living independently (63%). They also found that patients living in more deprived areas were less likely to have had a check, whereas we only found a relationship with deprivation when we focussed on repeated checks over time.

Attendance at health checks, once a check has been offered was investigated in a recent Australian meta-analysis of three community trials,[157] and showed that Down's syndrome was the only consistent characteristic associated with health check attendance. By comparison, the recent study of English primary care data found that non-attendance was associated with being younger and living in more deprived areas.[86] Our analysis of repeated health checks, could be thought of as a proxy attendance measure, and similarly found repeated checks were less likely with younger age and deprivation.

Aim 2: Health checks and effectiveness of health checks - Implications

We have identified the following implications from our analysis of health checks and hospital admissions.

- Annual health checks for adults with ID can improve access to care and may be influential in reducing preventable admissions to hospital, which make up a third of all emergency hospitalisations for adults with ID. Whilst the evidence has been weak for community initiated case management interventions in reducing preventable admissions in the general population, our results argue for the continued implementation of annual health checks for all patients with ID. As we did not undertake a formal cost analysis in this study, future research could helpfully estimate whether the cost of health checks is offset by savings from fewer emergency hospitalisations.

- Ensuring that all eligible adults, especially those with the most severe or complex needs, receive an annual health check will continue to address key issues of health inequality and discrimination for adults with ID. This can be achieved, both within practices already participating in the DES, but also by encouraging wider practice uptake of the health check DES towards a suggested and necessary target of 90%.[148]

We have identified the following implications from our analysis of health checks and process measures.

- Although there is published guidance on what the GP should cover during a health check,[10] our study has shown that there is substantial variation in what is recorded. This suggests that the experience of a health check may differ across practices, and our discussions with patient and user groups consistently reinforced this view (see page 39). So while the patient view of health checks has been shown to be mainly positive,[158] better standardisation by reinforcing guidance and practice, may lead to improvements to overall patient experience of the health check, and possibly health outcomes.

- The low levels of recording with regards to mental health during health checks, contrasts with its importance in terms of burden of disease for adults with ID from our cross-sectional analyses and from our patient and carer group discussions (see page 39). Improved access from primary care to specialist mental health services for ID patients would encourage greater detection and recording of mental health problems as part of health checks.

- Despite aspiration being a frequent cause of emergency admission to hospital, and a cause of death, among adults with ID, it was not clear that annual health checks were specifically recording any issues around eating, drinking and swallowing. We estimated that 1-in-20 adults with ID had dysphagia recorded, lower than some estimates,[159] so the recent call for dysphagia related questions to be included in the annual health check has merit.[103]

Overall Study Limitations

We have described in detail the limitations of the study in relation to its two original aims: health, healthcare quality, mortality and NHS costs (page 162) and health checks and effectiveness of health checks (page 179). We summarise the key limitations again here

- Our study population of adults with ID, is based on patients known to their GP with ID, and may be missing patients with milder forms of ID who are not in regular contact

with primary care. Additionally, our description of primary care does not include other non GP led services such as optometry and dentistry, which will be important for adults with ID.

- Our description of many outcomes such as disease prevalence or content of health check, is based entirely on recorded information from the GP electronic patient record. While this may not capture everything that is occurring for these patients, the lower recording of some outcomes is still of importance itself (e.g. delayed cancer diagnosis).

- The recording of key characteristics for this group, such as severity of their ID and their living arrangements, was incomplete and we had to rely on proxies (severe health needs, communal accommodation) to try and describe these. For ethnicity, 1-in-4 adults with ID had no recording, and we chose not to investigate by ethnic group any further.

- For patients not recorded as living in shared or communal accommodation we were unable to further determine the level of independence of their living arrangements, such as living with a family carer for example.

- Our estimates of NHS costs must be viewed as conservative and an underestimate of the true cost.

- Our headline finding of reduced emergency admissions for ACSCs associated with the introduction of health checks is derived from observational data, and while we have tried to adjust for confounding and temporal factors, we cannot replicate the conditions of a randomised trial to test their effectiveness.

Research Recommendations

Overall, we wanted to emphasise the following recommendations for research that this study identified:

- We think that further research regarding health checks should focus on two important observations from our study. The first would be in relation to practices which are participating in the DES, but are unable to get the majority of their patients with ID to attend an annual health check. Ensuring all eligible patients are being appropriately

invited, and determining reasons for non-attendance could be investigated. Secondly, it is necessary to understand the recording variations in the patients' medical records around the time of health checks. This could confirm our findings of low recordings of key areas such as mental health and medication reviews. If confirmed, further research could also identify barriers to carrying out standardised health checks, and suggest recommendations for improvement.

- We would also suggest that the lower prevalence of cancer and IHD in adults with ID compared to the general population requires further investigation. It would be important to determine whether patients are being diagnosed later, as well as assessing whether survival time from diagnosis differs for patients with and without ID.

- The potential factors contributing to the observed lower continuity of care and shorter appointment times with their GP for adults with ID could be explored by further surveys of all key parties involved. What are the common barriers for patients and carers, and what steps can practices make as reasonable adjustments?

- The high levels of psychotropic prescribing among adults with ID, particularly among patients where their medical records have no recent indication, or a medication review, is a concern. Health checks may have been expected to address this, but further understanding is needed, particularly in relation to a reliance on some first generation antipsychotics.

- The high rate of emergency hospital admissions that are potentially preventable for adults with ID suggests that a continued targeted approach, such as annual health checks, on this group of patients may be effective in reducing admissions. Further research could helpfully focus on conditions with high admission rates such as epilepsy and urinary tract infection, identifying possible interventions.

- The significant contribution of respiratory causes such as pneumonia and aspiration to emergency admissions and mortality, make improved access to staff with dysphagia training desirable.

- Further detailed research relating to NHS costs for adults with ID could be carried out. The inverse association with deprivation among patients living in communal living needs explanation. As this study suggested that preventable emergency

hospitalisations may reduce as a result of health checks, a formal cost benefit analysis would be appropriate.

Conclusions

In summary, our study has addressed the paucity of information on the quality of healthcare for adults with ID, and has also evaluated the effectiveness of annual health checks in improving outcomes as well as processes of care. Compared to the general population, adults with ID have more chronic diseases, greater utilisation of both primary and secondary care and associated costs, and higher rates of mortality. However, the lower recorded rates of cancer and coronary heart disease in primary care are of potential concern as they may represent missed early diagnoses, and this finding requires further investigation. With more than a third of deaths potentially amenable to health care interventions, continued improvements in access to, and quality of, healthcare are urgently required. In primary care, better continuity of care and longer appointment times are important examples that we identified.

We found evidence that the introduction of health checks for adults with ID may been influential in reducing preventable emergency admissions to hospital during the study. However, we failed to find any evidence of a wider reduction across all emergency admissions. While health checks were introduced to reduce health inequalities, the current incentivised scheme means that not every eligible adult with ID receives one. Further, the recording of health measures associated with the health check varies considerably by practice, with low recording of medication reviews and mental health, and may reflect differences in patient experience. Future research is needed to confirm this finding. Improvements in the standardisation of health checks, and encouraging wider practice uptake of the health check scheme, will continue to address health inequalities and possibly improve health outcomes.

Dissemination

The analyses and results from this study have already been actively disseminated in multiple ways including:

- January 2016. The Society for Academic Primary Care, London Annual Scientific Meeting. Oral presentation of "Do health checks for adults with intellectual disability reduce emergency hospital admissions? Evaluation of a natural experiment" given by Iain Carey.

- January 2016. The Society for Academic Primary Care, London Annual Scientific Meeting. Oral presentation of "Disparities in Mortality and Deaths Amenable to Healthcare Intervention in Adults with Intellectual Disability" given by Fay Hosking.

- April 2016. "Health characteristics and consultation patterns of people with intellectual disability: a cross-sectional database study in English general practice"[63] published by the *British Journal of General Practice*.

- June 2016. "Do health checks for adults with intellectual disability reduce emergency hospital admissions? Evaluation of a natural experiment"[76] published on-line by the *Journal of Epidemiology and Community Health*.

- June 2016. Mencap local adults first, Merton. Oral presentation of "St George's Learning Disability Study" given by Iain Carey.

- July 2016. Skills for life conference, St George's Hospital. Oral presentation of "St George's Learning Disability Study" given by Carole Beighton with assistance from ResearchNet.

- August 2016. "Mortality Among Adults With Intellectual Disability in England: Comparisons With the General Population"[70] published by the *American Journal of Public Health*.

- September 2016. Society for Social Medicine 60th Annual Scientific Meeting, University of York, UK. Oral presentation of "Do health checks for adults with intellectual disability reduce emergency hospital admissions? Evaluation of a natural experiment" given by Iain Carey.

- September 2016. Society for Social Medicine 60th Annual Scientific Meeting, University of York, UK. Oral presentation of "Disparities in Mortality and Deaths

Amenable to Healthcare Intervention in Adults with Intellectual Disability" given by

Fay Hosking.

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Contribution of authors

Dr Iain Carey (Lecturer, Epidemiology & Medical Statistics) contributed to the original conception and design of the study, oversaw the initial data extraction, helped design the analyses, carried out the statistical analyses in Chapter 3, 6 and 7, and wrote the majority of the report.

Dr Fay Hosking (Research Fellow in Statistics) performed the statistical analyses in Chapters 4,5 and 7 and helped draft the report.

Dr Tess Harris (GP and Reader in Primary Care) contributed to the original conception and design of the study, co-led the PPI component of the study and helped draft the report.

Ms Carole Beighton (Senior Research Fellow) co-led the PPI component of the study and helped draft the report.

Dr Stephen DeWilde (GP and Senior Lecturer in Primary Care Epidemiology) contributed to the original conception and design of the study and helped draft the report.

Professor Derek Cook (Professor of Epidemiology) contributed to the original conception and design of the study and helped draft the report.

Data sharing statement

Due to the CPRD license of use, there is no data that can be directly shared from the project. Anyone wishing to access CPRD data can do so at cost though. See www.cprd.com for more details.

Publications

Carey IM, Shah SM, Hosking FJ, DeWilde S, Harris T, Beighton C, Cook DG. Health characteristics and consultation patterns of people with intellectual disability: a cross-sectional database study in English general practice. *British Journal of General Practice* 2016;66(645):E264-E70. DOI:10.3399/bjgp16X684301.

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Appendix 1: Adult prevalence of ID estimated using Quality and Outcomes Framework learning disability register data

PREVALENCE OF ID ESTIMATED USING THE QUALITY AND OUTCOMES FRAMEWORK (QOF) IN ENGLAND 2006-7 TO 2014-5

Year	No. of Practices	Total List Size	Number of Adults*	Register Count	Prevalence of ID	QOF indicator
2014-15	7,779	56,817,654	n/a	252,446	0.44%†	LD003 - The contractor establishes and maintains a register of patients with learning disabilities
2013-14	7,921	56,324,887	44,667,478	214,352	0.48%	LD001 - The contractor establishes and maintains a register of patients aged 18 or over with learning disabilities
2012-13	8,020	56,012,096	44,238,483	206,132	0.47%	LD1 - The practice can produce a register of patient with learning disabilities
2011-12	8,123	55,525,732	43,855,136	198,877	0.45%	LD1 - The practice can produce a register of patient with learning disabilities
2010-11	8,245	55,169,643	43,578,391	188,819	0.43%	LD1 - The practice can produce a register of patient with learning disabilities
2009-10	8,305	54,836,561	42,613,280	179,064	0.42%	LD1 - The practice can produce a register of patient with learning disabilities
2008-09	8,229	54,310,660	40,041,250	160,165	0.40%	LD1 - The practice can produce a register of patient with learning disabilities
2007-08	8,294	54,009,831	n/a	144,909	0.36%‡	LD1 - The practice can produce a register of patient with learning disabilities
2006-07	8,372	53,681,098	n/a	139,321	0.35%‡	LD1 - The practice can produce a register of patient with learning disabilities

* - Patients aged 18 years and over

† - In 2014/5 the published prevalence was for all patients and not restricted to adults only

‡ - These have been estimated using the 2008/9 proportion of adults of all patients, as the published estimates are seemingly based on a denominator of all patients and not restricted to adults only

Appendix 2: Read codes used in the definition of ID

LISTING OF ALL READ CODES USED IN THE DEFINITION OF ID

Read Code	Description	QoF LD*
13Z3.00	Low I.Q.	
6664.00	Mental handicap problem	
69DB.00	Learning disability health exam	
918e.00	On learning disability register	y
9HB..00	Learning disabilities administration status	
9HB0.00	Learning disabilities health action plan declined	
9HB1.00	Learning disabilities health action plan offered	
9HB2.00	Learning disabilities health action plan reviewed	
9HB3.00	Learning disabilities health assessment	
9HB4.00	Learning disabilities health action plan completed	
9HB5.00	Learning disabilities annual health assessment	
9HB6.00	Learning disabilities annual health assessment declined	
9HB6.11	Learning disabilities annual health check declined	
9HB7.00	Did not attend learning disabilities annual health assessmnt	
9HB7.11	Did not attend learning disabilities annual health check	
9hL..00	Exception reporting: learning disability quality indicators	
9hL0.00	Exc learn disability quality indicators: informed dissent	
9hL1.00	Exc learn disability quality indicators: patient unsuitable	
9mA..00	Learning disability annual health check invitation	
9mA0.00	Learning disability annual health check verbal invitation	
9mA1.00	Learning disability annual health check telephone invitation	
9mA2.00	Learning disability annual health check letter invitation	
9mA2000	Learning disability annual health check invtation 1st letter	
9mA2100	Learning disability annual health check invtation 2nd letter	
9mA2200	Learning disability annual health check invtation 3rd letter	
C03..11	Cretinism	
C031.00	Goitrous cretin	
C03z.12	Cretinism	
C372.11	Lesch - Nyhan syndrome	
C372000	Hypoxanthine-guanine-phosphoribosyltransferase deficiency	
C372011	Lesch - Nyhan syndrome	
C372300	Lesch-Nyhan syndrome	
C372z00	Other disorder of purine or pyrimidine metabolism NOS	
E141.00	Disintegrative psychosis	
E141.11	Heller's syndrome	
E141000	Active disintegrative psychoses	
E141100	Residual disintegrative psychoses	
E141z00	Disintegrative psychosis NOS	
E3...00	Mental retardation	y
E30..00	Mild mental retardation, IQ in range 50-70	y
E30..11	Educationally subnormal	y
E30..12	Feeble-minded	y
E30..13	Moron	y
E31..00	Other specified mental retardation	y
E310.00	Moderate mental retardation, IQ in range 35-49	y
E310.11	Imbecile	y
E311.00	Severe mental retardation, IQ in range 20-34	y
E312.00	Profound mental retardation with IQ less than 20	y

Read Code	Description	QoF LD*
E312.11	Idiocy	y
E31z.00	Other specified mental retardation NOS	y
E3y..00	Other specified mental retardation	y
E3z..00	Mental retardation NOS	y
Eu7..00	[X]Mental retardation	y
Eu70.00	[X]Mild mental retardation	y
Eu70.11	[X]Feeble-mindedness	y
Eu70.12	[X]Mild mental subnormality	y
Eu70000	[X]Mld mental retard with statement no or min impairm behav	y
Eu70100	[X]Mld mental retard sig impairment behav req attent/treatmt	y
Eu70y00	[X]Mild mental retardation, other impairments of behaviour	y
Eu70z00	[X]Mild mental retardation without mention impairment behav	y
Eu71.00	[X]Moderate mental retardation	y
Eu71.11	[X]Moderate mental subnormality	y
Eu71000	[X]Mod mental retard with statement no or min impairm behav	y
Eu71100	[X]Mod mental retard sig impairment behav req attent/treatmt	y
Eu71y00	[X]Mod retard oth behav impair	y
Eu71z00	[X]Mod mental retardation without mention impairment behav	y
Eu72.00	[X]Severe mental retardation	y
Eu72.11	[X]Severe mental subnormality	y
Eu72000	[X]Sev mental retard with statement no or min impairm behav	y
Eu72100	[X]Sev mental retard sig impairment behav req attent/treatmt	y
Eu72y00	[X]Severe mental retardation, other impairments of behaviour	y
Eu72z00	[X]Sev mental retardation without mention impairment behav	y
Eu73.00	[X]Profound mental retardation	y
Eu73.11	[X]Profound mental subnormality	y
Eu73000	[X]Profound ment retrd wth statement no or min impairm behav	y
Eu73100	[X]Profound ment retard sig impairmnt behav req attent/treat	y
Eu73y00	[X]Profound mental retardation, other impairments of behavr	y
Eu73z00	[X]Prfnd mental retardation without mention impairment behav	y
Eu7y.00	[X]Other mental retardation	y
Eu7y000	[X]Oth mental retard with statement no or min impairm behav	y
Eu7y100	[X]Oth mental retard sig impairment behav req attent/treatmt	y
Eu7yy00	[X]Other mental retardation, other impairments of behaviour	y
Eu7yz00	[X]Other mental retardation without mention impairment behav	y
Eu7z.00	[X]Unspecified mental retardation	y
Eu7z.11	[X]Mental deficiency NOS	y
Eu7z.12	[X]Mental subnormality NOS	y
Eu7z000	[X]Unsp mental retard with statement no or min impairm behav	y
Eu7z100	[X]Unsp mentl retard sig impairment behav req attent/treatmt	y
Eu7zy00	[X]Unspecified mental retardatn, other impairments of behav	y
Eu7zz00	[X]Unsp mental retardation without mention impairment behav	y
Eu81400	[X]Moderate learning disability	y
Eu81500	[X]Severe learning disability	y
Eu81600	[X]Mild learning disability	y
Eu81700	[X]Profound learning disability	y
Eu81z00	[X]Developmental disorder of scholastic skills, unspecified	y
Eu81z11	[X]Learning disability NOS	y
Eu81z12	[X]Learning disorder NOS	y
Eu81z13	[X]Learn acquisition disab NOS	y
Eu84112	[X]Mental retardation with autistic features	
Eu84200	[X]Rett's syndrome	
Eu84300	[X]Other childhood disintegrative disorder	

Read Code	Description	QoF LD*
Eu84311	[X]Dementia infantalis	
Eu84312	[X]Disintegrative psychosis	
Eu84313	[X]Heller's syndrome	
Eu84400	[X]Overactive disorder assoc mental retard/stereotype movts	
PJ0..00	Down's syndrome - trisomy 21	
PJ0..11	Mongolism	
PJ0..12	Trisomy 21	
PJ0..13	Trisomy 22	
PJ00.00	Trisomy 21, meiotic nondisjunction	
PJ01.11	Trisomy 21, mitotic nondisjunction	
PJ02.00	Trisomy 21, translocation	
PJ02.11	Partial trisomy 21 in Down's syndrome	
PJ0z.00	Down's syndrome NOS	
PJ0z.11	Trisomy 21 NOS	
PJ1..00	Patau's syndrome - trisomy 13	
PJ10.00	Trisomy 13, meiotic nondisjunction	
PJ11.00	Trisomy 13, mosaicism	
PJ11.11	Trisomy 13, mitotic nondisjunction	
PJ12.00	Trisomy 13, translocation	
PJ12.11	Partial trisomy 13 in Patau's syndrome	
PJ1z.00	Patau's syndrome NOS	
PJ1z.11	Trisomy 13 NOS	
PJ2..00	Edward's syndrome - trisomy 18	
PJ20.00	Trisomy 18, meiotic nondisjunction	
PJ21.00	Trisomy 18, mosaicism	
PJ21.11	Trisomy 18, mitotic nondisjunction	
PJ22.00	Trisomy 18, translocation	
PJ22.11	Partial trisomy 18 in Edward's syndrome	
PJ2z.00	Edward's syndrome NOS	
PJ2z.11	TRISOMY 18 NOS	
PJ30.00	Antimongolism syndrome	
PJ30.11	Deletion of long arm of chromosome 21	
PJ31.00	Cri-du-chat syndrome	
PJ31.11	Deletion of short arm of chromosome 5	
PJ32.00	Deletion of short arm of chromosome 4	
PJ32.11	Wolff - Hirschorn syndrome	
PJ33100	Deletion of long arm of chromosome 18	
PJ33111	18p- syndrome	
PJ33200	Deletion of short arm of chromosome 18	
PJ33211	18q- syndrome	
PJ33300	Smith-Magenis syndrome	
PJ33400	Jacobsen syndrome	
PJ33500	Greig cephalopolysyndactyly syndrome	
PJ33700	3p deletion syndrome	
PJ33800	Chromosome 4q deletion syndrome	
PJ33900	Langer-Giedion syndrome	
PJ33A00	Kleefstra syndrome	
PJ3z.00	Monosomies and deletions from the autosomes NOS	
PJ50.00	Whole chromosome trisomy syndromes	
PJ50000	Trisomy 6	
PJ50100	Trisomy 7	
PJ50200	Trisomy 8	
PJ50300	Trisomy 9	

Read Code	Description	QoF LD*
PJ50400	Trisomy 10	
PJ50500	Trisomy 11	
PJ50600	Trisomy 12	
PJ50700	Other trisomy C syndromes	
PJ50800	Trisomy 22	
PJ50w00	Whole chromosome trisomy, meitotic nondisjunction	
PJ50x00	Whole chromosome trisomy, mosaicism	
PJ50x11	Whole chromosome trisomy, mitotic nondisjunction	
PJ50y00	Other specified whole chromosome trisomy syndrome	
PJ50z00	Whole chromosome trisomy syndrome NOS	
PJ51.00	Partial trisomy syndromes	
PJ51000	Major partial trisomy	
PJ51100	Minor partial trisomy	
PJ51200	10q partial trisomy syndrome	
PJ51300	Trisomy 4p syndrome	
PJ51400	Trisomy 9p syndrome	
PJ51500	15q partial trisomy syndrome	
PJ51z00	Partial trisomy syndrome NOS	
PJ52.00	Trisomies of autosomes NEC	
PJ52z00	Trisomy of autosomes NEC NOS	
PJ9..00	Mowat-Wilson syndrome	
PJyy200	Fragile X chromosome	
PJyy400	Fragile X syndrome	
PKy0.11	Prader-Willi Syndrome	
PKy0.12	Prader-Willi syndrome	
PKy4.00	William syndrome	
PKy9300	Prader - Willi syndrome	
Pyu0200	[X]Other reduction deformities of brain	
PyuA000	[X]Oth specif trisomies & partial trisomies of autosomes	
R034y11	[D]Global retardation	
ZS34.00	Developmental disorder of scholastic skill	
ZS34.11	Learning disability	

* - Indicates if the code was used by the Quality and Outcomes Framework on their Learning Disability register. Note that the Read code Eu818 ([X]Specific learning disability) was subsequently introduced into QOF in 2014-5 and therefore not counted in our study

TOP TWENTY OCCURRING NON-ADMINISTRATION READ CODES THAT WERE USED TO DEFINE ID THAT DID NOT APPEAR IN QOF DEFINITION OF LEARNING DISABILITY

Read Code	Read Rubric	Total Patients in Initial Extraction	% who appear on QOF Learning Disability register
PJ0..00	Down's syndrome - trisomy 21	1824*	81%
ZS34.11	Learning disability	1527	66%
6664.00	Mental handicap problem	837	73%
PJ0z.00	Down's syndrome NOS	329*	81%
13Z3.00	Low I.Q.	204	32%
ZS34.00	Developmental disorder of scholastic skill	156	68%
PJyy200	Fragile X chromosome	87	34%
PJyy400	Fragile X syndrome	69	49%
PKy4.00	William syndrome	57	59%
PJ0..11	Mongolism	50	78%
Eu84200	[X]Rett's syndrome	47	68%
PKy9300	Prader - Willi syndrome	40	53%
Eu84112	[X]Mental retardation with autistic features	38	81%
PJ0..12	Trisomy 21	33	79%
R034y11	[D]Global retardation	26	49%
PJ33300	Smith-Magenis syndrome	16	70%
PKy0.11	Prader-Willi Syndrome	11	61%
PJ31.00	Cri-du-chat syndrome	10	71%
Eu84400	[X]Overactive disorder assoc mental retard/stereotype movts	6	60%
C03z.12	Cretinism	6	17%

* - Not all these patients were subsequently determined to have Down's syndrome (see page 23)

Appendix 3: Read codes used to define ID sub-groups

READ CODES USED FOR SUB-GROUPS WHICH IDENTIFY A RANGE OF SEVERE HEALTH NEEDS FOR PATIENTS WITH ID

Read Code	Description	Sub-Group
13C5.00	Confined to chair	Severe Mobility
13C5.11	Chairbound	Severe Mobility
13C6.00	Bed-ridden	Severe Mobility
13C6.11	Bedbound	Severe Mobility
13CC.00	Immobile	Severe Mobility
13CD.00	Mobility very poor	Severe Mobility
13CE.00	Mobility poor	Severe Mobility
14U5.00	H/O: gastrostomy	PEG Feeding
1593.00	H/O: stress incontinence	Continence
16F..00	Double incontinence	Continence
19E2.00	Soiling - encopresis	Continence
19E2.11	Encopresis symptom	Continence
19E2.12	Soiling symptom	Continence
19E3.00	Incontinent of faeces	Continence
19E3.11	Incontinent of faeces symptom	Continence
1A22.00	Enuresis	Continence
1A22000	Nocturnal enuresis	Continence
1A22011	Bedwetting	Continence
1A22100	Daytime enuresis	Continence
1A23.00	Incontinence of urine	Continence
1A24.00	Stress incontinence	Continence
1A24.11	Stress incontinence - symptom	Continence
1A26.00	Urge incontinence of urine	Continence
1B75.00	Loss of vision	Severe Visual Loss
1B77.00	Deteriorating vision	Severe Visual Loss
1C13.00	Deafness	Severe Hearing impairment
1C13300	Bilateral deafness	Severe Hearing impairment
1C17.00	Hearing aid problem	Severe Hearing impairment
2836.00	O/E - quadriplegia	Severe Mobility
2BL..11	O/E - deaf	Severe Hearing impairment
2BL3.00	O/E - significantly deaf	Severe Hearing impairment
2BL4.00	O/E - very deaf	Severe Hearing impairment
2BL5.00	O/E - completely deaf	Severe Hearing impairment
2DG..00	Hearing aid worn	Severe Hearing impairment
2DH0.00	Uses hearing loop	Severe Hearing impairment
3930.00	Bowels: incontinent	Continence
3931.00	Bowels: occasional accident	Continence
3940.00	Bladder: incontinent	Continence
3941.00	Bladder: occasional accident	Continence
3960.00	Dependent: chair/bed transfer	Severe Mobility
3980.00	Immobile	Severe Mobility
3981.00	Independent in wheelchair	Severe Mobility
3982.00	Minimal help in wheelchair	Severe Mobility
398A.00	Dependent on helper pushing wheelchair	Severe Mobility
6688.00	Registered partially sighted	Severe Visual Loss
6688.11	Registered partially blind	Severe Visual Loss
6689.00	Registered blind	Severe Visual Loss

Read Code	Description	Sub-Group
6689.11	Registered severely sight impaired	Severe Visual Loss
668C.00	Certificate of vision impairment	Severe Visual Loss
668D.00	Registered sight impaired	Severe Visual Loss
7007300	Insertion of auditory implant to brainstem	Severe Hearing impairment
7308400	Placement of hearing implant in external ear	Severe Hearing impairment
7308500	Attention to hearing implant in external ear	Severe Hearing impairment
7308600	Removal of hearing implant from external ear	Severe Hearing impairment
7311A00	Insertn bone anchors subcutaneous bone anchored hearing aid	Severe Hearing impairment
7317C00	Placement of hearing implant in middle ear	Severe Hearing impairment
7317D00	Attention to hearing implant in middle ear	Severe Hearing impairment
7317E00	Removal of hearing implant from middle ear	Severe Hearing impairment
7319.00	Attachment of bone anchored hearing prosthesis	Severe Hearing impairment
7319000	Insertion fixtures bone anchored hearing prosthesis Stage 1	Severe Hearing impairment
7319100	Insertion fixtures bone anchored hearing prosthesis Stage 2	Severe Hearing impairment
7319200	Reduction soft tissue for bone anchored hearing prosthesis	Severe Hearing impairment
7319300	Attention to fixtures for bone anchored hearing prosthesis	Severe Hearing impairment
7319400	One stage insert fixtures bone anchored hearing prosthesis	Severe Hearing impairment
7319500	Fitting external hearing prosthesis bone anchored fixtures	Severe Hearing impairment
7319y00	Other specified attachment bone anchored hearing prosthesis	Severe Hearing impairment
7319z00	Attachment of bone anchored hearing prosthesis NOS	Severe Hearing impairment
7617.00	Gastrostomy operations	PEG Feeding
7617.12	Creation of gastrostomy	PEG Feeding
7617000	Creation of permanent gastrostomy	PEG Feeding
7617100	Creation of temporary gastrostomy	PEG Feeding
7617400	Attention to gastrostomy tube	PEG Feeding
7617500	Removal of gastrostomy tube	PEG Feeding
7617600	Change of gastrostomy tube	PEG Feeding
7617700	Maintenance of percutaneous endoscopic gastrostomy tube	PEG Feeding
7617z00	Gastrostomy operation NOS	PEG Feeding
7619.11	Gastrotomy NEC	PEG Feeding
761E300	Temporary percutaneous endoscopic gastrostomy	PEG Feeding
761E400	Permanent percutaneous endoscopic gastrostomy	PEG Feeding
761E600	Fibreoptic endoscopic percutaneous insert gastrostomy (PEG)	PEG Feeding
761E900	Fibreoptic endoscopic removal of gastrostomy tube	PEG Feeding
761EA00	Fibreoptic endoscopic percutaneous insertion of gastrostomy	PEG Feeding
8CJ2.00	Percutaneous endoscopic gastrostomy feeding	PEG Feeding
8D2..00	Auditory aid	Severe Hearing impairment
8D2..11	Auditory aid provision	Severe Hearing impairment
8D2..12	Hearing aid provision	Severe Hearing impairment
8D21.00	Provide head worn hearing aid	Severe Hearing impairment
8D22.00	Provide body worn hearing aid	Severe Hearing impairment
8D23.00	Ear fitting hearing aid	Severe Hearing impairment
8D24.00	Replace hearing aid battery	Severe Hearing impairment
8D25.00	Physiolog. hearing assistance	Severe Hearing impairment
8D2Z.00	Auditory aid NOS	Severe Hearing impairment
8D3..00	Visual aid	Severe Visual Loss
8D3..13	Visual aid provision	Severe Visual Loss
8D31.00	Physiolog. visual assistance	Severe Visual Loss
8D3Z.00	Visual aid NOS	Severe Visual Loss

Read Code	Description	Sub-Group
8D73.00	Nocturnal bladder warning syst	Continence
8D73.11	Enuretic alarm	Continence
8D73.12	Enuresis alarm	Continence
8D9..13	Wheel chair	Severe Mobility
8D92.00	Self propelled wheel chair	Severe Mobility
8D93.00	Pedal powered wheel chair	Severe Mobility
8D94.00	Powered wheel chair	Severe Mobility
8D95.00	Wheel chair unspecified	Severe Mobility
8D9A.00	Attendant powered wheel chair	Severe Mobility
8D9B.00	Wheel chair seating	Severe Mobility
8E3..00	Deafness remedial therapy	Severe Hearing impairment
8E3Z.00	Deafness remedial therapy NOS	Severe Hearing impairment
8F6..11	Blind rehabilitation	Severe Visual Loss
8F61.00	Blind rehabilitation	Severe Visual Loss
8F62.00	Blind lead dog rehabilitation	Severe Visual Loss
8HHC.00	Referred for wheelchair assessment	Severe Mobility
8HlE.00	Referral to visual impairment multidisciplinary team	Severe Visual Loss
8M41.00	Hearing aid requested	Severe Hearing impairment
9m08.00	Excluded from diabetic retinopathy screening as blind	Severe Visual Loss
9N0b.00	Seen in hearing aid clinic	Severe Hearing impairment
9NfB.00	Requires deafblind communicator guide	Severe Hearing impairment
9NfB.00	Requires deafblind communicator guide	Severe Visual Loss
9NlD.00	Seen by visual impairment teacher	Severe Visual Loss
9R43.00	Wheelchair in need of repair	Severe Mobility
9R44.00	Wheelchair in good repair	Severe Mobility
9RA..00	Wheelchair applied for	Severe Mobility
A560200	Rubella deafness	Severe Hearing impairment
E276.00	Non-organic enuresis	Continence
E276000	Non-organic primary enuresis	Continence
E276100	Non-organic secondary enuresis	Continence
E276z00	Non-organic enuresis NOS	Continence
E277.00	Non-organic encopresis	Continence
E277000	Non-organic continuous encopresis	Continence
E277100	Non-organic discontinuous encopresis	Continence
E277z00	Non-organic encopresis NOS	Continence
E311.00	Severe mental retardation, IQ in range 20-34	Severe/Profound
E312.00	Profound mental retardation with IQ less than 20	Severe/Profound
E312.11	Idiocy	Severe/Profound
Eu72.00	[X]Severe mental retardation	Severe/Profound
Eu72.11	[X]Severe mental subnormality	Severe/Profound
Eu72000	[X]Sev mental retard with statement no or min impairm behav	Severe/Profound
Eu72100	[X]Sev mental retard sig impairment behav req attent/treatmt	Severe/Profound
Eu72y00	[X]Severe mental retardation, other impairments of behaviour	Severe/Profound
Eu72z00	[X]Sev mental retardation without mention impairment behav	Severe/Profound
Eu73.00	[X]Profound mental retardation	Severe/Profound
Eu73.11	[X]Profound mental subnormality	Severe/Profound
Eu73000	[X]Profound ment retrd wth statement no or min impairm behav	Severe/Profound
Eu73100	[X]Profound ment retard sig impairmnt behav req attent/treat	Severe/Profound

Read Code	Description	Sub-Group
Eu73y00	[X]Profound mental retardation, other impairments of behavr	Severe/Profound
Eu73z00	[X]Prfnd mental retardation without mention impairment behav	Severe/Profound
Eu81500	[X]Severe learning disability	Severe/Profound
Eu81700	[X]Profound learning disability	Severe/Profound
Eu9y000	[X]Nonorganic enuresis	Continence
Eu9y100	[X]Nonorganic encopresis	Continence
F132100	Progressive myoclonic epilepsy	Epilepsy
F132111	Unverricht - Lundborg disease	Epilepsy
F137.00	Symptomatic torsion dystonia	Cerebral Palsy
F137.11	Athetoid cerebral palsy	Cerebral Palsy
F137.12	Athetosis - congenital	Cerebral Palsy
F137.13	Vogt's disease	Cerebral Palsy
F137000	Athetoid cerebral palsy	Cerebral Palsy
F137011	Vogt's disease	Cerebral Palsy
F137100	Double athetosis	Cerebral Palsy
F137111	Congenital athetosis	Cerebral Palsy
F137y00	Other specified symptomatic torsion dystonia	Cerebral Palsy
F137z00	Symptomatic torsion dystonia NOS	Cerebral Palsy
F23..00	Congenital cerebral palsy	Cerebral Palsy
F23..11	Congenital spastic cerebral palsy	Cerebral Palsy
F23..12	Infantile cerebral palsy	Cerebral Palsy
F23..13	Littles disease	Cerebral Palsy
F23..14	Cerebral atonia	Cerebral Palsy
F230.00	Congenital diplegia	Cerebral Palsy
F230.11	Paraplegia - congenital	Cerebral Palsy
F230000	Congenital paraplegia	Cerebral Palsy
F230100	Cerebral palsy with spastic diplegia	Cerebral Palsy
F230z00	Congenital diplegia NOS	Cerebral Palsy
F231.00	Congenital hemiplegia	Cerebral Palsy
F232.00	Congenital quadriplegia	Cerebral Palsy
F232.11	Tetraplegia - congenital	Cerebral Palsy
F233.00	Congenital monoplegia	Cerebral Palsy
F233.11	Congenital spastic foot	Cerebral Palsy
F234.00	Infantile hemiplegia NOS	Cerebral Palsy
F23y.00	Other congenital cerebral palsy	Cerebral Palsy
F23y000	Ataxic infantile cerebral palsy	Cerebral Palsy
F23y100	Flaccid infantile cerebral palsy	Cerebral Palsy
F23y200	Spastic cerebral palsy	Cerebral Palsy
F23y300	Dyskinetic cerebral palsy	Cerebral Palsy
F23y400	Ataxic diplegic cerebral palsy	Cerebral Palsy
F23y500	Worster-Drought syndrome	Cerebral Palsy
F23y511	Congenital suprabulbar paresis	Cerebral Palsy
F23yz00	Other infantile cerebral palsy NOS	Cerebral Palsy
F23z.00	Congenital cerebral palsy NOS	Cerebral Palsy
F240.00	Quadriplegia	Severe Mobility
F240.11	Tetraplegia	Severe Mobility
F240100	Spastic tetraplegia	Severe Mobility
F241.00	Paraplegia	Severe Mobility
F241100	Spastic paraplegia	Severe Mobility
F242.00	Diplegia of upper limbs	Severe Mobility
F243.00	Monoplegia of lower limb	Severe Mobility

Read Code	Description	Sub-Group
F244.00	Monoplegia of upper limb	Severe Mobility
F25..00	Epilepsy	Epilepsy
F250.00	Generalised nonconvulsive epilepsy	Epilepsy
F250200	Epileptic seizures - atonic	Epilepsy
F250300	Epileptic seizures - akinetic	Epilepsy
F250500	Lennox-Gastaut syndrome	Epilepsy
F250y00	Other specified generalised nonconvulsive epilepsy	Epilepsy
F250z00	Generalised nonconvulsive epilepsy NOS	Epilepsy
F251.00	Generalised convulsive epilepsy	Epilepsy
F251000	Grand mal (major) epilepsy	Epilepsy
F251011	Tonic-clonic epilepsy	Epilepsy
F251200	Epileptic seizures - clonic	Epilepsy
F251300	Epileptic seizures - myoclonic	Epilepsy
F251400	Epileptic seizures - tonic	Epilepsy
F251500	Tonic-clonic epilepsy	Epilepsy
F251y00	Other specified generalised convulsive epilepsy	Epilepsy
F251z00	Generalised convulsive epilepsy NOS	Epilepsy
F253.00	Grand mal status	Epilepsy
F253.11	Status epilepticus	Epilepsy
F254.00	Partial epilepsy with impairment of consciousness	Epilepsy
F254000	Temporal lobe epilepsy	Epilepsy
F254100	Psychomotor epilepsy	Epilepsy
F254200	Psychosensory epilepsy	Epilepsy
F254300	Limbic system epilepsy	Epilepsy
F254400	Epileptic automatism	Epilepsy
F254500	Complex partial epileptic seizure	Epilepsy
F254z00	Partial epilepsy with impairment of consciousness NOS	Epilepsy
F255.00	Partial epilepsy without impairment of consciousness	Epilepsy
F255000	Jacksonian, focal or motor epilepsy	Epilepsy
F255011	Focal epilepsy	Epilepsy
F255012	Motor epilepsy	Epilepsy
F255100	Sensory induced epilepsy	Epilepsy
F255200	Somatosensory epilepsy	Epilepsy
F255300	Visceral reflex epilepsy	Epilepsy
F255311	Partial epilepsy with autonomic symptoms	Epilepsy
F255400	Visual reflex epilepsy	Epilepsy
F255500	Unilateral epilepsy	Epilepsy
F255600	Simple partial epileptic seizure	Epilepsy
F255y00	Partial epilepsy without impairment of consciousness OS	Epilepsy
F255z00	Partial epilepsy without impairment of consciousness NOS	Epilepsy
F257.00	Kojevnikov's epilepsy	Epilepsy
F25B.00	Alcohol-induced epilepsy	Epilepsy
F25C.00	Drug-induced epilepsy	Epilepsy
F25D.00	Menstrual epilepsy	Epilepsy
F25E.00	Stress-induced epilepsy	Epilepsy
F25F.00	Photosensitive epilepsy	Epilepsy
F25X.00	Status epilepticus, unspecified	Epilepsy
F25y.00	Other forms of epilepsy	Epilepsy
F25y000	Cursive (running) epilepsy	Epilepsy
F25y100	Gelastic epilepsy	Epilepsy
F25y200	Locl-rlt(foc)(part)idiop epilep&epilptic syn seiz locl onset	Epilepsy
F25y300	Complex partial status epilepticus	Epilepsy
F25y500	Panayiotopoulos syndrome	Epilepsy

Read Code	Description	Sub-Group
F25yz00	Other forms of epilepsy NOS	Epilepsy
F25z.00	Epilepsy NOS	Epilepsy
F25z.11	Fit (in known epileptic) NOS	Epilepsy
F2B..00	Cerebral palsy	Cerebral Palsy
F2B0.00	Spastic quadriplegic cerebral palsy	Cerebral Palsy
F2B1.00	Spastic hemiplegic cerebral palsy	Cerebral Palsy
F2By.00	Other cerebral palsy	Cerebral Palsy
F2Bz.00	Cerebral palsy NOS	Cerebral Palsy
F49..00	Blindness and low vision	Severe Visual Loss
F49..11	Impaired vision	Severe Visual Loss
F49..12	Low vision	Severe Visual Loss
F49..13	Partial sight	Severe Visual Loss
F49..14	Sight impaired	Severe Visual Loss
F490.00	Blindness, both eyes	Severe Visual Loss
F490000	Unspecified blindness both eyes	Severe Visual Loss
F490100	Both eyes total visual impairment	Severe Visual Loss
F490400	Better eye: near total VI, Lesser eye: near total VI	Severe Visual Loss
F490600	Better eye: profound VI, Lesser eye: total VI	Severe Visual Loss
F490900	Acquired blindness, both eyes	Severe Visual Loss
F490z00	Blindness both eyes NOS	Severe Visual Loss
F491.00	Better eye: low vision, Lesser eye: profound VI	Severe Visual Loss
F491000	One eye blind, one eye low vision	Severe Visual Loss
F491100	Better eye: severe VI, Lesser eye: blind, unspecified	Severe Visual Loss
F491300	Better eye: severe VI, Lesser eye: near total VI	Severe Visual Loss
F491400	Better eye: severe VI, Lesser eye: profound VI	Severe Visual Loss
F491500	Better eye: moderate VI, Lesser eye: blind, unspecified	Severe Visual Loss
F491700	Better eye: moderate VI, Lesser eye: near total VI	Severe Visual Loss
F491z00	One eye blind, one eye low vision NOS	Severe Visual Loss
F492.00	Low vision, both eyes	Severe Visual Loss
F492000	Low vision, both eyes unspecified	Severe Visual Loss
F492200	Better eye: severe VI, Lesser eye: severe VI	Severe Visual Loss
F492300	Better eye: moderate VI, Lesser eye: low vision unspecified	Severe Visual Loss
F492400	Better eye: moderate VI, Lesser eye: severe VI	Severe Visual Loss
F492500	Better eye: moderate VI, Lesser eye: moderate VI	Severe Visual Loss
F492z00	Low vision, both eyes NOS	Severe Visual Loss
F493.00	Visual loss, both eyes unqualified	Severe Visual Loss
F494.00	Legal blindness USA	Severe Visual Loss
F497.00	Severe visual impairment, binocular	Severe Visual Loss
F498.00	Moderate visual impairment, binocular	Severe Visual Loss
F49z.00	Visual loss NOS	Severe Visual Loss
F49z.11	Acquired blindness	Severe Visual Loss
F4H7300	Cortical blindness	Severe Visual Loss
F581211	Noise induced deafness	Severe Hearing impairment
F59..11	Deafness	Severe Hearing impairment
F590.11	Conductive deafness	Severe Hearing impairment
F591.13	Perceptive deafness	Severe Hearing impairment
F591211	Nerve deafness	Severe Hearing impairment
F591400	Congenital sensorineural deafness	Severe Hearing impairment
F591500	Ototoxicity - deafness	Severe Hearing impairment
F591511	Drug ototoxicity - deafness	Severe Hearing impairment
F591800	Congenital prelingual deafness	Severe Hearing impairment
F592.00	Mixed conductive and sensorineural deafness	Severe Hearing impairment
F593.00	Deaf mutism, NEC	Severe Hearing impairment

Read Code	Description	Sub-Group
F594.00	High frequency deafness	Severe Hearing impairment
F595.00	Low frequency deafness	Severe Hearing impairment
F596.00	Maternally inherited deafness	Severe Hearing impairment
F598.00	Moderate acquired hearing loss	Severe Hearing impairment
F599.00	Severe acquired hearing loss	Severe Hearing impairment
F59A.00	Profound acquired hearing loss	Severe Hearing impairment
F59A.11	Deafened	Severe Hearing impairment
F59z.00	Deafness NOS	Severe Hearing impairment
F59z.11	Chronic deafness	Severe Hearing impairment
Fyu9.00	[X]Cerebral palsy and other paralytic syndromes	Cerebral Palsy
Fyu9000	[X]Other infantile cerebral palsy	Cerebral Palsy
Fyu9100	[X]Other specified paralytic syndromes	Cerebral Palsy
FyuU000	[X]Deaf mutism, not elsewhere classified	Severe Hearing impairment
K198.00	Stress incontinence	Continence
K586.00	Stress incontinence - female	Continence
Kyu5A00	[X]Other specified urinary incontinence	Continence
P40z.11	Deafness due to congenital anomaly NEC	Severe Hearing impairment
R00A.00	[D] Poor mobility	Severe Mobility
R00C.00	[D]Immobility	Severe Mobility
R076.00	[D]Incontinence of faeces	Continence
R076000	[D]Encopresis NOS	Continence
R076100	[D]Sphincter ani incontinence	Continence
R076z00	[D]Incontinence of faeces NOS	Continence
R083.00	[D]Incontinence of urine	Continence
R083000	[D]Enuresis NOS	Continence
R083100	[D]Urethral sphincter incontinence	Continence
R083200	[D] Urge incontinence	Continence
R083z00	[D]Incontinence of urine NOS	Continence
SJ15.12	Deafness - traumatic - NOS	Severe Hearing impairment
Z1J..00	Procedures to aid continence	Continence
Z6R3.00	Wheelchair dancing therapy	Severe Mobility
Z6R8100	Wheelchair sport	Severe Mobility
Z6X1.00	Wheelchair transfer practice	Severe Mobility
Z6Z..00	Wheelchair education	Severe Mobility
Z6Z1.00	Wheelchair use training	Severe Mobility
Z6Z1200	Propelling wheelchair training	Severe Mobility
Z6Z1300	Controlling electric wheelchair training	Severe Mobility
Z8B5.00	Ability to use hearing aid	Severe Hearing impairment
Z8B5100	Able to use hearing aid	Severe Hearing impairment
Z8B5200	Unable to use hearing aid	Severe Hearing impairment
Z8B5300	Does use hearing aid	Severe Hearing impairment
Z8B5311	Uses hearing aid	Severe Hearing impairment
Z8B5400	Does not use hearing aid	Severe Hearing impairment
Z8B5500	Difficulty using hearing aid	Severe Hearing impairment
Z911.00	Hearing aid procedure	Severe Hearing impairment
Z911100	Fit hearing aid	Severe Hearing impairment
Z911300	Adjust hearing aid settings	Severe Hearing impairment
Z911400	Changing hearing aid battery	Severe Hearing impairment
Z911500	Checking hearing aid	Severe Hearing impairment
Z911700	Switching on hearing aid	Severe Hearing impairment
Z911800	Turning off hearing aid	Severe Hearing impairment
Z911900	Putting on hearing aid	Severe Hearing impairment
Z911A00	Listening for feedback whistle of hearing aid	Severe Hearing impairment

Read Code	Description	Sub-Group
Z911B00	Attention to hearing aid	Severe Hearing impairment
Z911E00	Fit ear mould for existing hearing aid	Severe Hearing impairment
Z96..00	Provision for visual and hearing impairment	Severe Visual Loss
Z961.00	Provision of guide help for visual and hearing impairment	Severe Visual Loss
Z9E2.00	Optical low vision aid provision	Severe Visual Loss
Z9E3.00	Provision of optical low vision aid - near	Severe Visual Loss
Z9E3100	Provision of magnifier low vision aid - near	Severe Visual Loss
Z9E3200	Provision of low vision hand magnifier	Severe Visual Loss
Z9E3300	Provision of low vision stand magnifier	Severe Visual Loss
Z9E3500	Provision of spectacle low vision aid - near	Severe Visual Loss
Z9E3600	Provision of telescopic spectacles	Severe Visual Loss
Z9E3700	Provision of spectacle magnifier	Severe Visual Loss
Z9E3900	Near low vision aid - clip-on spectacle magnifier	Severe Visual Loss
Z9E3A00	Provision of spectacle telescope	Severe Visual Loss
Z9E3B00	Near low vision aid - integral spectacle telescope	Severe Visual Loss
Z9E3C00	Near low vision aid - clip-on spectacle telescope	Severe Visual Loss
Z9E3D00	Near low vision aid - extra cap for telescope	Severe Visual Loss
Z9E3E00	Provision of headband telescope	Severe Visual Loss
Z9E4.00	Provision of optical low vision aid - distance	Severe Visual Loss
Z9E5.00	Provision of non-optical low vision aid	Severe Visual Loss
Z9E5200	Provision of closed circuit television	Severe Visual Loss
Z9E5300	Provision of image intensifier	Severe Visual Loss
Z9E5400	Provision of ancillary low vision aid	Severe Visual Loss
Z9E5700	Provision of work board	Severe Visual Loss
Z9E6.00	Provision of visual appliance	Severe Visual Loss
Z9E6500	Provision of audiotaped services	Severe Visual Loss
Z9E6600	Provision of talking book	Severe Visual Loss
Z9E8100	Hearing aid provision	Severe Hearing impairment
Z9E8111	Auditory aid provision	Severe Hearing impairment
Z9EA.00	Provision of incontinence appliance	Continence
Z9EA100	Provision of nocturnal bladder warning system	Continence
Z9EA111	Provision of enuresis alarm	Continence
Z9EA112	Provision of enuretic alarm	Continence
Z9EH400	Provision of wheelchair	Severe Mobility
Z9MO.00	Enuresis support	Continence
ZC65200	Gastrostomy feeding	PEG Feeding
ZC65300	Percutaneous endoscopic gastrostomy feeding	PEG Feeding
ZC65311	PEG - Percutaneous endoscopic gastrostomy feeding	PEG Feeding
ZC65400	Button gastrostomy feeding	PEG Feeding
ZC65500	Jejunostomy feeding	PEG Feeding
ZE83200	Hearing for loud voice impaired	Severe Hearing impairment
ZE84200	Hearing for voice impaired	Severe Hearing impairment
ZE87.00	Hearing loss	Severe Hearing impairment
ZE87.11	Deafness	Severe Hearing impairment
ZE87.13	Hard of hearing	Severe Hearing impairment
ZE87.16	HL - Hearing loss	Severe Hearing impairment
ZE87.17	HOH - Hard of hearing	Severe Hearing impairment
ZL22400	Under care of continence nurse	Continence
ZN56800	Blind telephone user	Severe Visual Loss
ZN56900	Deaf telephone user	Severe Hearing impairment
ZO2..00	Unable to mobilise	Severe Mobility
ZO4..00	Does not mobilise	Severe Mobility
ZO72.00	Unable to mobilise indoors	Severe Mobility

Read Code	Description	Sub-Group
ZO74.00	Does not mobilise indoors	Severe Mobility
ZO75.00	Difficulty mobilising indoors	Severe Mobility
ZO92.00	Unable to mobilise using mobility aids	Severe Mobility
ZO93.00	Does mobilise using aids	Severe Mobility
ZO94.00	Does not mobilise using mobility aids	Severe Mobility
ZO96.00	Ability to mobilise using wheelchair	Severe Mobility
ZO96.11	Wheelchair mobility	Severe Mobility
ZO96100	Able to mobilise using wheelchair	Severe Mobility
ZO96200	Unable to mobilise using wheelchair	Severe Mobility
ZO96300	Does mobilise using wheelchair	Severe Mobility
ZO96311	Mobilises using wheelchair	Severe Mobility
ZO96400	Does not mobilise using wheelchair	Severe Mobility
ZO96500	Difficulty mobilising using wheelchair	Severe Mobility
ZOC6200	Unable to get in and out of a chair	Severe Mobility
ZOC6400	Does not get in and out of a chair	Severe Mobility
ZOC8200	Unable to get out of a chair	Severe Mobility
ZOC8400	Does not get out of a chair	Severe Mobility
ZOC9200	Unable to get on and off a bed	Severe Mobility
ZOC9400	Does not get on and off a bed	Severe Mobility
ZOCA200	Unable to get on a bed	Severe Mobility
ZOCB200	Unable to get off a bed	Severe Mobility
ZOCB400	Does not get off a bed	Severe Mobility
ZOD2.00	Unable to move in bed	Severe Mobility
ZOD4.00	Does not move in bed	Severe Mobility
ZOD6200	Unable to roll over in bed	Severe Mobility
ZOD6211	Unable to turn over in bed	Severe Mobility
ZOD7500	Difficulty turning onto side in bed	Severe Mobility
ZOD8200	Unable to move up and down bed	Severe Mobility
ZT12711	Voice associated with hearing loss	Severe Hearing impairment
ZV44100	[V]Has gastrostomy	PEG Feeding
ZV45G00	[V]Presence of external hearing-aid	Severe Hearing impairment
ZV45N00	[V]Bone anchored hearing aid in situ	Severe Hearing impairment
ZV46200	[V]Dependence on wheelchair	Severe Mobility
ZV4L011	[V] Poor mobility	Severe Mobility
ZV53200	[V]Fitting or adjustment of hearing aid	Severe Hearing impairment
ZV53800	[V]Fitting or adjustment of wheelchair	Severe Mobility
ZV53D00	[V]Adjustment and management of implanted hearing device	Severe Hearing impairment
ZV55100	[V]Attention to gastrostomy	PEG Feeding

READ CODES USED TO IDENTIFY LIVING ARRANGEMENTS THAT WERE DEEMED TO BE COMMUNAL OR SHARED

Read Code	Description
13F4.00	Warden attended
13F4.11	Lives in warden controlled accommodation
13F4000	Resident in sheltered accommodation
13F5.00	Part III accommodation
13F5.11	Part 3 accommodation
13F5100	Part III accommodation arranged
13F5111	Part 3 accommodation arranged
13F5200	Resident in part III accommodation
13F6.00	Nursing/other home
13F6100	Lives in a nursing home
13F7.00	Residential institution
13F7100	Lives in a welfare home
13F7200	Lives in an old peoples home
13F7300	Lives in a childrens home
13F7400	Admitted to a children's home
13F8100	Long stay hospital inpatient
13F9.00	Living in hostel
13F9.11	Living in sheltered accomodatn
13FK.00	Lives in a residential home
13FS.00	Long stay hospital inpatient
13FT.00	Lives in an old peoples home
13FV.00	Lives in a welfare home
13FX.00	Lives in care home
13FY.00	Lives in a children's unit
Z177100	24 hour care
Z177500	Custodial care
Z177C00	Residential care
Z177D00	Local authority residential care
Z177D11	LA - local authority residential care
ZU37.00	Lives in a community
ZU37100	Lives in a school community
ZU37200	Lives in boarding school
ZV60600	[V]Institution resident
ZV60611	[V]Boarding school resident
ZV60700	[V]Sheltered housing
ZU37100	Lives in a school community

READ CODES USED TO IDENTIFY AUTISM

Read Code	Description
E140.00	Infantile autism
E140.11	Kanner's syndrome
E140.12	Autism
E140.13	Childhood autism
E140000	Active infantile autism
E140100	Residual infantile autism
E140z00	Infantile autism NOS
E2F5.00	Mixed development disorder
Eu83.00	[X]Mixed specific developmental disorders
Eu84.00	[X]Pervasive developmental disorders
Eu84000	[X]Childhood autism
Eu84011	[X]Autistic disorder
Eu84012	[X]Infantile autism
Eu84013	[X]Infantile psychosis
Eu84014	[X]Kanner's syndrome
Eu84100	[X]Atypical autism
Eu84111	[X]Atypical childhood psychosis
Eu84511	[X]Autistic psychopathy
Eu84y00	[X]Other pervasive developmental disorders
Eu84z00	[X]Pervasive developmental disorder, unspecified
Eu84z11	[X]Autistic spectrum disorder

READ CODES USED TO IDENTIFY DOWN'S SYNDROME

Read Code	Description
PJ0..00	Down's syndrome - trisomy 21
PJ0..11	Mongolism
PJ0..12	Trisomy 21
PJ0..13	Trisomy 22
PJ00.00	Trisomy 21, meiotic nondisjunction
PJ01.00	Trisomy 21, mosaicism
PJ01.11	Trisomy 21, mitotic nondisjunction
PJ02.00	Trisomy 21, translocation
PJ02.11	Partial trisomy 21 in Down's syndrome
PJ0z.00	Down's syndrome NOS
PJ0z.11	Trisomy 21 NOS

Appendix 4: Definition of a consultation in CPRD

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┌─────────────────────────────────────────────────────┐
│  The 3 conditions below must all be satisfied for a   │
│           consultation to have taken place            │
└─────────────────────────────────────────────────────┘
        │                    │                    │
        ▼                    ▼                    ▼
┌──────────────────┐  ┌──────────────────┐  ┌──────────────────────┐
│ CONSULTATION FILE │  │ CONSULTATION FILE │  │ CLINICAL, TEST,      │
│                  │  │                  │  │ THERAPY &            │
│                  │  │                  │  │ IMMUNISATION FILES   │
└──────────────────┘  └──────────────────┘  └──────────────────────┘
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CONSTYPE must equal
1=Clinic
3=Follow-up/routine visit
9=Surgery consultation
10=Telephone call from a patient
11=Acute visit
18=Emergency Consultation
21=Telephone call to a patient
27=Home Visit
30=Nursing Home Visit
31=Residential Home Visit
55=Telephone Consultation

STAFF ROLE must equal
0=Senior Partner
1=Partner
2=Assistant
3=Associate
4=Non-commercial local rota
5=Commercial Deputising service
6=Locum
7=GP Registrar
9=Sole Practitioner
10=Practice Nurse (N)
11=Health Visitor
12=Community Nurse (N)
45=Carer
46=Salaried Partner
49=GP Retainer

Must have one of the following

READ CODE
Except any of these
- 69DB (Learning dis. health examination)
- 8B3H.00 (Medication requested)
- 9* Admin Read codes (except 9N11, 9N12, 9N1C, 9N1D, 9N1E, 9N1F, 9N1G, 9N1H, 9N1t, 9N1w, 9N1x, 9N2. , 9N21, 9N22, 9N2D, 9N2L, 9N2N, 9N2O, 9N2l, 9N31, 9N3A, 9N3F, 9N5. , 9N51, 9N52, 9N53, 9N54, 9N55, 9N58, 9N5B, 9N7. , 9N79, 9N7A, 9N7B, 9N7H, 9NF4, 9NF5, 9NF6, 9NF7, 9NF8, 9NF9, 9NFB, 9NV. , 9Na. , 9Na1, 9Na3, 9Nt0, 9Nt3, 9b0m, 9b0n, 9b0o)

OR

NON-REPEAT THERAPY
(ISSUE SEQ=0)

CONSULTATION TYPE

= Nurse
if STAFFROLE = (10 or 12)

= Telephone
If CONSTYPE = (10, 21 or 55)
OR
Read Codes = (8CAK, 8CAN, 8H9*, 9N31*, 9N3A, 9N3F, 9b0m, 9b0n, 9b0o)

SUMMARY OF HOW CONSULTATIONS WERE IDENTIFIED IN CPRD

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Appendix 5: Economic costs

SUMMARY OF CALCULATION ESTIMATES FOR COSTING ANALYSIS

Area	Calculation Details
Primary Care Consultations	GP consultations: £3.70 per min (maximum length 60 mins). If 5 minutes or less or not recorded assume £43.00 per consultation. Nurse consultations: £0.88 per min (maximum length 60 mins). If 5 minutes or less or not recorded assume £10.34 per consultation. GP Home visits £110.00 per visit
Prescribing (primary care)	Use net ingredient cost per quantity where a quantity tablets or capsules are issued. Use net ingredient cost per Item for other drug formulations. Use a default average cost of £9.85 per item where it was not possible to easily merge CPRD and Prescription Cost Analysis (PCA) data.
Other Primary Care Led Activity	Referrals (community services only) costed at £33 each (maximum of 1 per day) Outpatients (evidence of attendance) were costed at £139 each (maximum of 1 per day)
A&E or Casualty attendance	£112 each (maximum of 1 per day)
Hospital Admissions	Use NHS Reference costs for 2011-12 classified by HRG4, calculated from ICD-10 and OPCS codes. Where a hospitalisation has multiple episode, use the episode with the maximum cost. Some exceptions which failed to merge and were coded differently: Cystic Fibrosis (2009-10 costings used), Dialysis (2009-10 costings used), Non-specialist mental health service provider (2012-3 costings used) Admissions which could not be assigned by the above were costed by defaults estimated by PSSRU[54]: Elective impatient stays=£3,191, Non-elective inpatient long stay (2+ days)=£2,461, Non-elective inpatient short stay (0-1 day)=£586, Elective day cases=£680

Appendix 6: PPI quotations

QUOTATIONS FROM RESEARCHNET AND MERTON CARERS REGARDING PPI

PPI Group	Quotation
Merton Carers Group	"CP3: *I genuinely felt, and I've said this to various people, but this wasn't just a tick box exercise, ooh yes, I've consulted carers, it was a genuine … lets see how you can get involved and I'd like to incorporate your ideas in it, so it did feel like genuine involvement which was great.*" CP1: "*… it was a very positive experience all around and umm / I'm absolutely delighted that both parents and people with a learning disability viewpoints actually were taken in to the study and I'm sure we made it a better study as a result. I think that should be an exemplar for all LD studies as you feel you're being listened to and helping shape what's important rather than having it come from top down what people think is best*" CP2: "*Definitely. I would definitely work with this team from St Georges again as I know that they are serious about what they are doing. You know that they are serious about involving parents and they have listened to us. I just hope the research makes an impact.*" CP4: "*To actually involve the carers and the people themselves. If there was a way of flagging that up and making that best practice, that would be fantastic.*"
ResearchNet	**What did you feel about helping to guide this research project using your expertise?** IDP1: "*Loved every minute.*" IDP3: "*Loved it.*" IDP5: "*Loved everything about it.*" IDP2: "*50/50.*" **What was / what's 50/50 N., what didn't you like?** IDP2: "*Umm / I think / something / something what /* " **Was it because we were asking you to share things, your personal story?** IDP2: "*I don't know, maybe yes.*" **Did you feel it was a waste of time?** IDP2:"*No.*" IDP1: "*No, far from it.*" IDP4: "*Not at all.*" IDP3:"*We / we are actually being listened to and taken note of.*" IDP2: "*It's important to get our views across and we're not just numbers on someone's spreadsheet.*" IDP5: "*Exactly. Well said…*"

Appendix 7: Cause of death groupings

LISTING OF ICD-10 CODES USED TO IDENTIFY AND GROUP CAUSE OF DEATH

ICD-10 Code	Main grouping	ICD-10 Code	Secondary group of interest
A00-B99	Infectious and parasitic disorders		
C00-D48	Neoplasms	C16	Oesophageal cancer
		C17	Stomach cancer
		C18-C21	Colorectal cancer
		C25	Pancreatic cancer
		C33-C34	Lung cancer
		C43-C44	Skin cancers
		C50	Breast cancer
		C53	Cervical cancer
		C61	Prostate cancer
		C64-C68	Urinary tract cancers
		C81-C96	Lymphoma
E00-E90	Endocrine, nutritional and metabolic diseases		
F00-F99	Mental and behavioural disorders	F00-F03	Dementia
G00-G99	Diseases of the nervous system	G40-G41	Epilepsy
I00-I99	Diseases of the circulatory system	I20-I25	Ischaemic heart disease
		I60-I69	Cerebrovascular disease
		I61, I63-I64	Stroke
J00-J99	Diseases of the respiratory system	J09-J11	Influenza
		J40-J47	Chronic lower respiratory disease
		J41-J44, J47	COPD
		J69	Pneumonitis due to solids and liquids
K00-K93	Diseases of the digestive system	K70-K77	Diseases of liver
M00-M99	Diseases of the musculoskeletal system and connective tissue		
N00-N99	Diseases of the genitourinary system		
Q00-Q99	Congenital malformations, deformations and chromosomal abnormalities		
V01-Y98	External causes of morbidity and mortality	V01-V99	Transport accidents
		W00-X59	Other external causes of accidental injury
		X60-X84	Intentional self-harm
All other	Other (skin, blood, residual codes)		

Appendix 8: Ambulatory care sensitive conditions (ACSCs) for emergency hospital admission

LISTING OF ICD-10 CODES USED TO IDENTIFY AND GROUP AMBULATORY CASE SENSITIVE CONDITIONS

Conditions	ICD-10 Code
Angina	I20, I24.0, I24.8-I24.9
Aspiration	J69.0, J69.8
Asthma	J45-J46
Cellulitis	L03-L04, L08, L88, L98.0, L98.3
Congestive heart failure	I11.0, I50, J81
Constipation	K59.0
Convulsions/epilepsy	G40-G41, R56, O15
Chronic obstructive pulmonary disease (COPD)	J41-J44, J47
Dehydration & gastroenteritis	E86, K52.2, K52.8, K52.9
Dental conditions	A69.0, K02-K06, K08, K09.8, K09.9, K12-K13
Diabetes complications	E10.0-E10.8, E11.0-E11.8, E12.0-E12.8, E13.0-E13.8, E14.0-E14.8
Ear, nose and throat infections	H66-H67, J02-J03, J06, J31.2
Gangrene	R02
Gastro-oesophageal reflux disease	K21
Hypertension	I10, I11.9
Iron deficiency anaemia	D50.1, D50.8-D50.9
Influenza	J10-J11
Nutritional deficiencies	E40-E43, E55, E64.3
Pelvic inflammatory disease	N70, N73-N74
Perforated/bleeding ulcers	K25.0-K25.2, K25.4-K25.6, K26.0-K26.2, K26.4-K26.6, K27.0-K27.2, K27.4-K27.6, K28.0-K28.2, K28.4-K28.6
Pneumonia & other acute lower respiratory tract infection (LRTI)	J13-J14, J15.3-J15.4, J15.7, J15.9, J16.8, J18.1, J18.8, J20-J20.2, J20.8, J20.9, J22
Tuberculosis & other vaccine preventable	A15-A16, A19, A35-A37, A80, B05-B06, B16.1, B16.9, B18.0-B18.1, B26, G00.0, M01.4
Urinary tract infection (UTI)/ pyelonephritis	N10-N12, N13.6, N39.0

Note: Only the ICD-10 code entered as primary cause of admission was used to define emergency admissions for ACSCs.

Appendix 9: Read codes used to define categories summarising content of health checks

READ CODE LISTING OF HEALTH CHECK CONTENT CATEGORIES

Category Identified	Read codes (* indicates all codes in hierarchy)
Weight/BMI	162*, 22A*, 66C*, 679P.00, 67I9.00
Blood pressure	246*
Alcohol	136*, 388u.00, 6792.00, 67H0.00, 8CAM.00, 9k1*
Smoking	137*, 6791*, 67H1.00, 67H6.00, 8CAL.00
Mobility	13C*, 398*, 399*, 39A*, 39B*, 68O*, ZO*,
Ears	1C1*, 1C2*, 1C3*, 1C4*, 1CD..00, 1CE..00, 2BL*, 2BM*, 2D...11, 2D13.00, 2D16.00 2D5*, 2D6*, 2D7*, 2D8*, 2D9*, 2DG..00, 2DH*, 2DZ..00, 313*, 7P12*, 9N2T.00, Z174500, ZE*, ZF*, ZV41200, ZV41300
Eyes	1B7*, 1B8*, 22E*, 2B6*, 2B7*, 2B8*, 2B9*, 2BA*, 2BB*, 2BC*, 2BD*, 2BE*, 2BF*, 2BG*, 2BH*, 2BI*, 2BJ*, 2BT*, 312*, 668*, 9N2U.00, 9N2V.00, Z174300, ZL47*, ZV41*
Carer	8O7..00, 9180*, 918F*, 918J*, 918K.00, 918L.00, 918V.00
Pulse	24* except 246*
Height	229*
Health action plan	9HB0.00 - 9HB4.00
Behaviour	1B1X.00, 1P*, 3AB*, Z15*, ZV40.11, ZV40300
Dental	254*, 3165.00, 67IG.00, 9N2C.00, Z174600, Z174700, Z174800, ZL9G500
Communication	13o*, 1B9*, 8E2*, ZT4*
Exercise	138*, 6798.00, 67H2.00, 8CA5*
Diet	13A*, 13B*, 161*, 1F*, 6799.00, 67H7.00, 8CA4*
Blood test	4131.00, 41D0.00, 4142.00 - 4145.00, 42*, 44*, 7L17*
Urine test	41D1.00, 4146.00, 46*, 4JJ*, 68K*
Mental health	1B1*, 1BD*, 1BE*, 1BF*, 1BG*, 1BH*, 1BI..00, 1BJ..00, 1BK..00, 1BL..00, 1BM..00, 1BN*, 1BO..00, 1BP..00, 1BP0.00, 1BQ..00, 1BR*, 1BS*, 1BT*, 1BU..00, 225*, 6891*, 6896.00, 6A6*, 8CM2.00, 8CR7.00, ZQ3E.00
Bowels & bladder	16F..00, 19E*, 19F*, 1A.*, 1A.*, 1A1*, 1A2*, 1A3*, 1A4*, 26...00, 26...12, 393*, 394*, 39H*, 679H*, 8C14*, 8D7*, ZQ3B.00, ZQ3C.00
Respiratory	23*, 339*,
Sexual related	1AB*, 61*, 6777.00, 679K.00, 679S.00, 67IJ*, 8CAw.00
Medication review	66c*, 8B31400, 8B3S*, 8B3V.00, 8B3h.00, 8B3j.00, 8B3k.00, 8B3l.00, 8B3x.00, 8B3y.00, 8BI*, 8BM*, 9N73.00
Breast exam	1A8*, 26...11, 26B*, 6795.00, 6862*, 8CAz.00, 9OH*, Z1P1400
Cervical smear	4149.00, 4JRL.00, 4K2*, 4K3*, 4K4*, 4K55.00, 6793.00, 685*, 8I6K.00, 9O8*, ZG52100, ZV762*
Epilepsy	667*
Flu vaccination	65E*, ZV048*