



# Assessment of an incentivised scheme to provide annual health checks in primary care for adults with intellectual disability: a longitudinal cohort study



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## Summary

**Background** People with intellectual disabilities (ID) have many comorbidities but experience inequities in access to health care. National Health Service England uses an opt-in incentive scheme to encourage annual health checks of patients with ID in primary care. We investigated whether the first 3 years of the programme had improved health care of people with ID.

**Methods** We did a longitudinal cohort study that used data from The Health Improvement Network primary care database. We did multivariate logistic regression to assess associations between various characteristics and whether or not practices had opted in to the incentivised scheme.

**Findings** We assessed data for 8692 patients from 222 incentivised practices and those for 918 patients in 48 non-incentivised practices. More blood tests (eg, total cholesterol, odds ratio [OR] 1.88, 95% CI 1.47–2.41,  $p < 0.0001$ ) general health measurements (eg, smoking status, 6.0, 4.10–8.79,  $p < 0.0001$ ), specific health assessments (eg, hearing, 24.0, 11.5–49.9,  $p < 0.0001$ ), and medication reviews (2.23, 1.68–2.97,  $p < 0.0001$ ) were done in incentivised than in non-incentivised practices, and more health action plans (6.15, 1.41–26.9,  $p = 0.0156$ ) and secondary care referrals (1.47, 1.05–2.05,  $p = 0.0256$ ) were made. Identification rates were higher in incentivised practices for thyroid disorder (OR 2.72, 95% CI 1.09–6.81,  $p = 0.0323$ ), gastrointestinal disorders (1.94, 1.03–3.65,  $p = 0.0390$ ), and obesity (2.49, 1.76–3.53,  $p < 0.0001$ ).

**Interpretation** Targeted annual health checks for people with ID in primary care could reduce health inequities.

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## Introduction

Intellectual disability (ID), also known as learning disability in the UK, is defined as substantial impairments of intellectual function and social or adaptive functioning present from childhood.<sup>1</sup> People with ID have a different pattern of health needs from the general population, with increased rates of comorbidities, including physical disabilities, sensory impairments, mental health problems, epilepsy, and disorders of the respiratory, gastrointestinal, and endocrine systems.<sup>2,3</sup> Accordingly, patients with ID are at increased risk of death from preventable or treatable illnesses,<sup>4,6</sup> and among those with moderate or profound ID, all-cause mortality is almost three times higher than in the general population.<sup>7</sup> Despite increased health needs, these patients face notable health inequities, including barriers to primary care.<sup>6,8</sup> Identified concerns include lower than expected rates for primary care consultations and uptake of screening activities and poor access to health-promotion activities.<sup>9</sup>

Whether any routine general health checks for middle-aged patients in primary care are effective is debated.<sup>10</sup> However, identification and management of health

issues in other populations with complex needs, such as the frail elderly, gives some support for the effectiveness of comprehensive health assessments (anticipatory care).<sup>11</sup> The ID population is particularly disadvantaged, with many inequalities in terms of provision of physical and mental health care and limited access to health professionals. Small-scale studies of primary care health checks have reported increases in health-promotion activities and management of long-term disorders that have led to improved identification of health needs.<sup>12–14</sup> These steps are crucial to improving health outcomes.

National Health Service (NHS) Wales introduced the first national primary care ID health check in 2006, followed by NHS England in 2008–09. The English scheme is an incentivised directed enhanced service called the LD-DES,<sup>15</sup> and is optional at practice level. Primary care teams are remunerated for undergoing appropriate training and completing health checks on eligible patients. A framework with local guidance for the delivery of primary care health checks is provided by NHS England. Although training requirements for the delivery of checks are not fully standardised, the Royal College of General Practitioners have produced

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guidelines for primary care physicians and their staff.<sup>16</sup> No assessment of clinical outcomes after the rollout of this national scheme has yet been reported.

We aimed to objectively assess the effects of the first 3 years of the NHS England LD-DES scheme for ID. We compared the number of health checks attended, health assessments and investigations done, and diagnoses of common health conditions recorded between general practices that had (incentivised) and had not (non-incentivised) opted in to the scheme. We hypothesised that these activities would be more frequent in practices opting into the LD-DES.

## Methods

### Data source

We did a longitudinal cohort study that used data from The Health Improvement Network database (THIN), which is a large, longitudinal, clinical, primary-care database widely used in epidemiological research. Data for THIN are collected by Cegedim Strategic Data, London, UK, from general practices that have opted in to the data recording scheme,<sup>17</sup> by use of Vision practice management software. Medical events are coded according to the hierarchical Read coding system<sup>18</sup> and prescriptions are classified according to chapters in the *British National Formulary* and coded with encrypted identification codes from the UK Prescription Pricing Authority.<sup>19</sup>

THIN data are representative of the entire UK population.<sup>20</sup> All data collected are anonymised at source, exported from general practice systems, and are continually updated. The dataset contains data from over 10 million patients registered with 578 practices since 1988,<sup>21</sup> and provides details of consultations with physicians and nurses, including symptoms, diagnoses, interventions, laboratory test results, and secondary care referrals, electronically recorded as Read codes.<sup>17</sup> All patients' prescriptions, characteristics, lifestyle factors (height, weight, and smoking status), and Townsend neighbourhood deprivation scores (based on patients' electoral wards from the 2001 Population Census)<sup>22</sup> are recorded. Recording of consultation and prescription details is similar to that for national consultation and prescription statistics.<sup>23</sup>

Cegedim Strategic Data obtained overall ethical approval from the South-East Multicentre Research Ethics Committee for provision of the data and we obtained local ethics approval for the study protocol.

### Study population

English practices were included if, before Jan 1, 2009, the average annual recording rates were at least one medical record, one additional health data record, and two prescription records per patient per year across the whole practice population,<sup>23,24</sup> and practice mortality recording rates were similar to general UK population mortality after accounting for the distributions of age and sex.<sup>23,25</sup> We used this date as the cutoff because the LD-DES was introduced in England in 2008–09.

The Townsend deprivation scores were based on the 2001 census and linked to patients' records via postcodes, which meant that patients living in accommodation built after 2001 did not have Townsend scores. We excluded practices with Townsend score quintiles recorded for less than 80% of patients to ensure that available scores were representative of the whole practice.

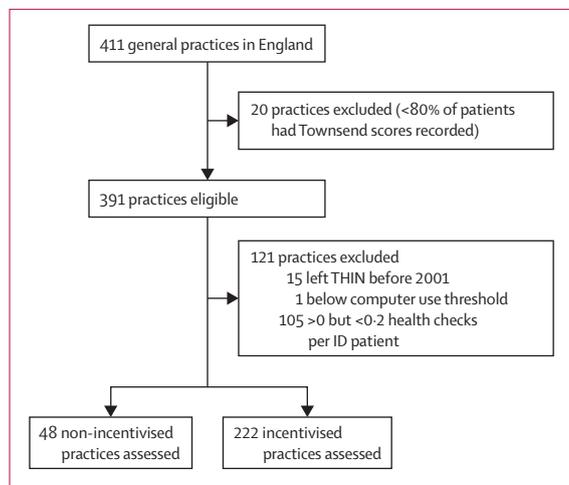


Figure: Trial profile

THIN=The Health Improvement Network.

	Incentivised practice	Non-incentivised practice
Number of practices	222	48
Number of active patients	1 685 430	334 250
Number of patients with QOF-ID code	8692	918
Mean (95% CI) follow-up time for patients with QOF-ID code (years)	2.6 (2.6–2.7)	2.5 (2.5–2.6)
Strategic health authority*		
London	911 (10.5%)	29 (3.2%)
East Midlands	420 (4.8%)	108 (11.8%)
East of England	784 (9.0%)	59 (6.4%)
West Midlands	662 (7.6%)	134 (14.6%)
North East	460 (5.3%)	50 (5.5%)
North West	1314 (15.1%)	98 (10.7%)
Yorkshire and Humberside	298 (3.4%)	75 (8.2%)
South Central	1265 (14.6%)	167 (18.2%)
South East Coast	592 (6.8%)	178 (19.4%)
South West	1986 (22.9%)	20 (2.2%)
Sex		
Male	4943 (56.9%)	522 (56.9%)
Female	3749 (43.1%)	396 (43.1%)
Age group (years)		
18–29	2433 (28.0%)	229 (25.0%)
30–39	1677 (19.3%)	180 (19.6%)
40–49	2008 (23.1%)	216 (23.5%)
50–59	1340 (15.4%)	150 (16.3%)
60–69	797 (9.2%)	94 (10.2%)
70–100	437 (5.0%)	49 (5.3%)

(Table 1 continues on next page)

	Incentivised practice	Non-incentivised practice
(Continued from previous page)		
Townsend deprivation score quintile		
1 (least)	1595 (18.4%)	189 (20.6%)
2	1618 (18.6%)	184 (20.0%)
3	1866 (21.5%)	153 (16.7%)
4	1994 (22.9%)	192 (20.9%)
5 (most)	1619 (18.6%)	200 (21.8%)
Carer type before 2009		
No carer specified	8085 (93.0%)	854 (93.0%)
Carer (type unspecified)	607 (7.0%)	64 (7.0%)
Carer (informal)	0	0
BMI (kg/m <sup>2</sup> )†		
Mean (95% CI)	29.0 (28.7–29.2)	29.3 (28.6–30.0)
Median (IQR)	28.2 (23.5–33.4)	28.7 (24.1–33.5)
Missing data	4870 (56.0%)	517 (56.3%)
Systolic blood pressure (mm Hg)†		
Mean (95% CI)	125.2 (124.7–125.6)	126.1 (124.8–127.4)
Median (IQR)	124.0 (114.0–135.5)	125.0 (115.0–136.0)
Missing data	4062 (46.7%)	411 (44.8%)
Total cholesterol (mmol/L)†		
Mean (95% CI)	4.99 (4.94–5.04)	5.17 (5.02–5.32)
Median (IQR)	4.9 (4.2–5.7)	5.1 (4.3–5.8)
Missing data	6731 (77.4%)	708 (77.1%)
HbA <sub>1c</sub> (%)†		
Mean (95% CI)	7.14 (7.00–7.28)	7.01 (6.58–7.43)
Median (IQR)	6.7 (5.8–8.3)	6.5 (5.8–8.0)
Missing data	8084 (93.0%)	854 (93.0%)
Comorbidity before 2009		
Epilepsy	2784 (32.0%)	303 (33.0%)
Diabetes	537 (6.2%)	63 (6.9%)
Thyroid disorder	733 (8.4%)	75 (8.2%)
Gastrointestinal disorders	1060 (12.2%)	147 (16.0%)
Constipation	1158 (13.3%)	112 (12.2%)
Underweight (BMI <18.5 kg/m <sup>2</sup> )	726 (8.4%)	80 (8.7%)
Obese (BMI >30.0 kg/m <sup>2</sup> )	2384 (27.4%)	254 (27.7%)
Asthma or COPD	2011 (23.1%)	190 (20.7%)
Hypertension	1524 (17.5%)	162 (17.7%)
Depression	2974 (34.2%)	303 (33.0%)

QOF=practice quality and outcomes framework. ID=intellectual disability. BMI=body-mass index. HbA<sub>1c</sub>=glycated haemoglobin. COPD=chronic obstructive pulmonary disease. \*Previously implemented directives and fiscal policy for regions set by the national Department of Health. †Summary of all measurements in 2007 and 2008.

**Table 1: Baseline characteristics of patients with ID in directed enhanced service incentivised and non-incentivised practices**

Eligible patients had known ID identified with specific Read codes used to include them in the practice quality and outcomes framework (QOF) register, which is an electronic system used to record the care provided for selected groups of patients.<sup>26</sup> Eligible patients were also aged at least 18 years and had been permanently registered with the practice by Jan 1, 2009 with their date of birth, sex, and Townsend deprivation quintile recorded. Follow-up started from Jan 1, 2009, until the earliest of death, transfer of the patient out of the practice, the

See Online for appendix

practice ceasing to contribute THIN data, or Dec 31, 2011 (the latest complete year of available THIN data at the time of analysis).

### Definition of practices

Incentivised practices were identified through specific Read codes used by the practices to claim payment for ID health checks, termed QOF-ID codes in this Article. Because THIN data are anonymised at the patient and practice levels, we needed to find a way of distinguishing between practices that had opted in to the incentivised scheme and those that had not. The distribution of health checks per patient for each practice indicated that practices with rates higher than 0.2 checks per patient with ID were likely to have opted in to the LD-DES scheme and, therefore, we used this cutoff to identify practices offering annual ID checks. We compared these practices with those that had no health checks recorded and which were assumed to have not opted in to the incentivisation scheme. Practices with more than 0 but fewer than 0.2 health checks per patient with ID were excluded from the analysis to reduce potential bias by mistakenly including practices that had not opted in to the scheme in the incentivised group (figure).

### Identification of patients excluded from the ID health check scheme

When English general practices opt in to the incentivised scheme, they are provided with a list of adults known by local authorities to have a diagnosis of an ID to align with the practice ID register.<sup>26</sup> Social-care providers (UK local authorities) apply specific criteria for provision of services, and if ID patients do not meet local thresholds they might not be included in the local authority register and the likelihood of being considered eligible for health checks might be lessened.

Additionally, general practices might under-register patients with ID, because the QOF-ID codes do not include specific conditions. For example, a person with Down's syndrome assigned a Read code for the genetic condition might not necessarily also be assigned one for ID. To address a concern that potentially eligible patients might be excluded from the incentivised health checks, we used code lists developed for another project<sup>27</sup> to identify those with genetic and other conditions known to be associated with ID (eg Down's syndrome) or with disorders where the majority of patients (more than 60%) have ID. For this reason, the International Classification of Diseases 10th edition diagnosis of childhood autism was included, but Asperger's syndrome and cerebral palsy were excluded (a full list of disorders is provided in the appendix). We investigated how many people on these lists had been given QOF-ID codes in the practices being studied and compared them with those not given QOF-ID codes in terms of their recorded health needs and the likelihood of them receiving ID health checks.

	Incentivised practices (n=4645)*	Non-incentivised practices (n=611)*	Absolute risk difference (95% CI)	Odds ratio (95% CI)†	p value
<b>Blood tests</b>					
Blood glucose					
Prevalence	2305 (49.6%)	272 (44.5%)	5.1% (0.9 to 9.3)	1.24 (0.94 to 1.64)‡	0.1238
Records per patient	0 (0-2)	0 (0-1)	..	..	
HbA <sub>1c</sub>					
Prevalence	576 (12.4%)	74 (12.1%)	0.3% (-2.7 to 2.8)	1.00 (0.75 to 1.35)‡	0.9782
Records per patient	0 (0-0)	0 (0-0)	..	..	
Haemoglobin					
Prevalence	3096 (66.7%)	343 (56.1%)	10.6% (6.4 to 14.7)	1.50 (1.14 to 1.96)‡	0.0034
Records per patient	1 (0-3)	1 (0-2)	..	..	
Thyroid function					
Prevalence	492 (10.6%)	50 (8.2%)	2.4% (-0.2 to 4.5)	1.62 (0.69 to 3.81)‡	0.2655
Records per patient	0 (0-0)	0 (0-0)	..	..	
Total cholesterol					
Prevalence	2412 (51.9%)	234 (38.3%)	13.6% (9.5 to 17.7)	1.88 (1.47 to 2.41)‡	<0.0001
Records per patient	0 (0-2)	0 (0-1)	..	..	
<b>General health status</b>					
Height					
Prevalence	3183 (68.5%)	209 (34.2%)	34.3% (30.2 to 38.2)	4.06 (2.88 to 5.71)‡	<0.0001
Records per patient	1 (0-2)	0 (0-1)	..	..	
Weight					
Prevalence	4365 (94.0%)	383 (62.7%)	31.3% (27.5 to 35.2)	8.75 (5.63 to 13.59)‡	<0.0001
Records per patient	2 (1-4)	1 (0-3)	..	..	
Blood pressure					
Prevalence	4428 (95.3%)	436 (71.4%)	23.9% (20.5 to 27.7)	8.67 (6.14 to 12.23)§	<0.0001
Records per patient	3 (2-5)	2 (0-4)	..	..	
Smoking status					
Prevalence	4355 (93.8%)	450 (73.7%)	20.1% (16.7 to 23.8)	6.00 (4.10 to 8.79)¶	<0.0001
Records per patient	2 (1-3)	1 (0-2)	..	..	
Alcohol consumption					
Prevalence	4227 (91.0%)	283 (46.3%)	44.7% (40.6 to 48.7)	14.12 (9.00 to 22.15)‡	<0.0001
Records per patient	2 (1-3)	0 (0-1)	..	..	
<b>Assessments</b>					
Hearing					
Prevalence	3265 (70.3%)	63 (10.3%)	60.0% (57.0 to 62.5)	23.98 (11.53 to 49.87)‡	<0.0001
Records per patient	1 (0-2)	0 (0-0)	..	..	
Sight					
Prevalence	2049 (44.1%)	40 (6.6%)	37.5% (34.9% to 39.8)	12.89 (4.48 to 37.1)‡	<0.0001
Records per patient	0 (0-1)	0 (0-0)	..	..	
Behaviour					
Prevalence	2584 (55.6%)	67 (11.0%)	44.6% (41.6 to 47.3)	11.45 (5.33 to 24.57)‡	<0.0001
Records per patient	1 (0-2)	0 (0-0)	..	..	
Oral health					
Prevalence	2516 (54.2%)	43 (7.0%)	47.2% (44.4 to 49.4)	15.66 (5.43 to 45.19)§	<0.0001
Records per patient	1 (0-2)	0 (0-0)	..	..	
Mobility					
Prevalence	2180 (46.9%)	45 (7.4%)	39.5% (36.8 to 41.9)	12.96 (4.49 to 37.37)‡	<0.0001
Records per patient	0 (0-1)	0 (0-0)	..	..	
Medication review					
Prevalence	3887 (83.7%)	423 (69.2%)	14.5% (10.8 to 18.4)	2.23 (1.68 to 2.97)‡	<0.0001
Records per patient	4 (2-6)	3 (0-5)	..	..	

(Table 2 continues on next page)

	Incentivised practices (n=4645)*	Non-incentivised practices (n=611)*	Absolute risk difference (95% CI)	Odds ratio (95% CI)†	p value
(Continued from previous page)					
Health action plan offered					
Prevalence	1072 (23.1%)	29 (4.8%)	18.3% (16.0–20.2%)	6.15 (1.41–26.85)	0.0156
Records per patient	0 (0–0)	0 (0–0)	..	..	
Secondary referral					
Prevalence	3531 (76.0%)	421 (68.9%)	7.1% (3.4 to 11.1%)	1.47 (1.05–2.05)‡	0.0256
Records per patient	2 (1–5)	1 (0–3)	..	..	

All patients assessed had complete data for 2009–11 and had received at least one health check in this period. HbA<sub>1c</sub>=glycated haemoglobin. \*Data are n (%) or median (IQR). †Backwards elimination used in multivariate logistic regression analysis to find significant (p<0.1) covariates. ‡Adjusted for age, sex, and strategic health authority. §Adjusted for age and sex. ¶Adjusted for age, sex, Townsend deprivation quintile, and strategic health authority. ||Adjusted for age, sex, and Townsend deprivation quintile.

**Table 2: Association between health assessments and information and practices opting into the incentivised health check scheme**

	Incentivised practices	Non-incentivised practices	Absolute risk difference (95% CI)	Odds ratio (95% CI)*	p value
Epilepsy	144 of 3030 (4.8%)	22 of 419 (5.3%)	-0.5% (-3.2 to 1.4)	0.90 (0.54 to 1.50)†	0.6865
Diabetes	140 of 4356 (3.2%)	23 of 568 (4.1%)	-0.9% (-2.9 to 0.6)	0.91 (0.57 to 1.47)‡	0.7119
Thyroid disorder	101 of 4214 (2.4%)	5 of 561 (0.9%)	1.5% (0.3 to 2.2)	2.72 (1.09 to 6.81)†	0.0323
Gastrointestinal disorders	294 of 4080 (7.2%)	22 of 520 (4.2%)	3.0% (0.8 to 4.6)	1.94 (1.03 to 3.65)§	0.0390
Constipation	198 of 3962 (5.0%)	11 of 547 (2.0%)	3.0% (1.3 to 4.1)	2.59 (1.29 to 5.22)†	0.0080
Underweight (BMI <18.5 kg/m <sup>2</sup> )	118 of 4263 (2.8%)	8 of 558 (1.4%)	1.4% (-0.1 to 2.2)	1.96 (0.94 to 4.07)†	0.0721
Obese (BMI >30.0 kg/m <sup>2</sup> )	565 of 3248 (17.4%)	34 of 444 (7.7%)	9.7% (6.6 to 12.3)	2.49 (1.76 to 3.53)‡	<0.0001
Asthma or COPD	185 of 3632 (5.1%)	24 of 489 (4.9%)	0.2% (-2.2 to 2.0)	1.03 (0.69 to 1.53)†	0.8798
Hypertension	256 of 3854 (6.6%)	30 of 510 (5.9%)	0.7% (-1.7 to 2.7)	1.16 (0.78 to 1.73)‡	0.4521
Depression	343 of 3104 (11.1%)	42 of 409 (10.3%)	0.8% (-2.7 to 3.6)	1.07 (0.73 to 1.55)¶	0.7375

BMI=body-mass index. COPD=chronic obstructive pulmonary disease. \*Backwards elimination used to find significant (p<0.1) covariates. †Adjusted for age and sex. ‡Adjusted for age, sex, and strategic health authority. §Adjusted for age, sex, Townsend deprivation quintile, and strategic health authority. ¶Adjusted for age, sex, and Townsend deprivation quintile.

**Table 3: Common comorbidities newly diagnosed after Jan 1, 2009**

**Statistical analysis**

First, we did a logistic regression analysis to investigate the association between practice-level characteristics (number of patients in each practice, proportion of men, patients older than 60 years, patients within the most deprived Townsend deprivation score quintile, patients with ID, and former strategic health authority) and opting into the incentivised scheme for all active patients, mutually adjusted for confounding to reduce potential bias. Next, we did an assessment limited to patients with 3 complete years of data, from 2009 to 2011. From the incentivised practices, we included patients with at least one health check recorded during these 3 years, and compared the recording of health assessments completed, interventions offered, and newly identified common health conditions with those in non-incentivised practices. We did a logistic regression analysis with each of these features as a predictor to investigate their association with practices opting into LD-DES, with use of robust SEs to allow for clustering within practices and adjustment for confounding to reduce potential bias. We initially fitted logistic regression models adjusted for age

(years) in 2009, sex, strategic health authority, and Townsend deprivation score quintile, and used backwards elimination to eliminate strategic health authority, Townsend deprivation score quintile, or both, if these proved to be non-significant (p<0.050), because associations might also differ by these two features.

In eligible incentivised practices, we identified ID patients where a Read code indicated they had been invited to attend a health check, and separated them into groups of attendees (health check Read code recorded) or non-attendees (no health check Read codes recorded or Read codes indicated they did not attend a check). We did a multivariate logistic regression analysis, mutually adjusted to reduce potential bias, to test the association between attending a health check and strategic health authority, sex, age, Townsend deprivation quintile, carer type, and comorbidity. We excluded health indicators from the regression analysis because of missing data.

We compared patients who had identified disorders that are associated with ID but without a recorded QOF-ID code and patients with relevant QOF-ID codes, in

terms of the proportions offered health checks and baseline characteristics, including age, sex, and comorbidities. We hypothesised that all ID-related activities would be more frequent in practices opting into the LD-DES. All analyses were done with Stata SE (version 12.1).

### Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

### Results

222 incentivised practices with 8692 registered patients with ID, and 48 non-incentivised practices with 918 registered patients with ID were identified (figure, table 1). The proportions of incentivised practices differed between former strategic health authorities. For example, 10% of patients from incentivised practices were located in the London strategic health authority, compared with only 3% from non-incentivised practices. The total number of patients with ID in individual practices was the only variable significantly associated with opting into the LD-DES scheme after controlling for other practice-level covariates (odds ratio [OR] 1.09, 95% CI 1.05–1.13,  $p < 0.0001$ ).

5256 patients with ID had complete data for 2009–11, of whom 4645 (88.4%) were registered with LD-DES incentivised practices and had received at least one health check during the 3-year study period (table 2). Incentivised practices were more likely than non-incentivised practices to do blood tests to measure haemoglobin and total cholesterol concentrations in patients with ID. Being a patient in an incentivised practice was also strongly associated with being offered general health status checks, specific health assessments for hearing or vision, medication reviews, recorded health action plans, and secondary referrals (table 2).

Among newly identified common health conditions, rates of gastrointestinal and thyroid disorders, constipation, and being underweight or obese were higher for patients with ID in incentivised practices than in non-incentivised practices after adjustment (table 3). The rates of identification of new cases of epilepsy and diabetes seemed to be slightly higher in the non-incentivised practices, but the differences were not significant.

Read codes identifying that patients with ID had been invited to attend a health check were infrequently used; most practices only recorded completion of incentivised health checks. We identified 771 patients with codes indicating they had been invited to attend a health check (table 4), of whom 659 (85%) attended. Patients who did not attend health checks were more likely to be younger and to live in more deprived neighbourhoods than those

who did attend, after adjustment for other covariates and clustering within practices (table 4).

We identified 2034 patients registered at incentivised practices who had disorders usually associated with ID according to our Read code list. Most of these had either Down's syndrome ( $n=1119$  [55%]) or autism ( $n=325$  [16%]). 1223 (60%) of the 2034 had QOF-ID codes recorded and

	Attendees (n=659)	Non-attendees (n=112)	Odds ratio (95% CI)	p value
<b>Strategic health authority</b>				
London	78 (11.8%)	21 (18.8%)	1.00	0.2888
East Midlands	29 (4.4%)	4 (3.6%)	1.64 (0.27–10.09)	
East of England	67 (10.2%)	27 (4.1%)	0.80 (0.44–1.54)	
West Midlands	27 (4.1%)	5 (4.5%)	1.30 (0.65–2.61)	
North East	55 (8.4%)	7 (6.3%)	2.30 (0.83–6.36)	
North West	145 (22.0%)	15 (13.4%)	2.71 (0.74–9.88)	
Yorkshire and Humber	0	0	..	
South Central	40 (6.1%)	9 (8.0%)	1.06 (0.22–5.22)	
South East Coast	4 (0.6%)	0	N/A*	
South West	214 (32.5%)	25 (22.3%)	2.52 (1.00–6.39)	
<b>Sex</b>				
Male	387 (58.7%)	68 (60.7%)	1.00	0.6501
Female	272 (41.3%)	44 (39.3%)	0.91 (0.62–1.35)	
<b>Age group (years)</b>				
18–29	143 (21.7%)	47 (42.0%)	1.00	<0.0001
30–39	118 (17.9%)	24 (21.4%)	1.43 (0.74–2.76)	
40–49	158 (24.0%)	22 (19.6%)	2.06 (1.18–3.60)	
50–59	145 (22.0%)	13 (11.6%)	3.46 (1.57–7.62)	
60–69	70 (10.6%)	6 (5.4%)	4.88 (1.81–13.20)†	
70–100	25 (3.8%)	0	..	
<b>Townsend deprivation score quintile</b>				
1 (least)	104 (15.8%)	13 (11.6%)	1.00	0.0062
2	80 (12.4%)	16 (14.3%)	0.69 (0.31–1.50)	
3	158 (24.0%)	19 (17.0%)	1.19 (0.71–1.98)	
4	170 (25.8%)	40 (35.7%)	0.48 (0.25–0.92)	
5 (most)	147 (22.3%)	24 (21.4%)	0.70 (0.32–1.57)	
<b>Carer type before 2009</b>				
No carer specified	624 (94.7%)	109 (97.3%)	1.00	0.5613
Carer (type unspecified)	35 (5.3%)	3 (2.7%)	1.42 (0.44–4.62)	
Carer (informal)	0	0	..	
<b>BMI (kg/m<sup>2</sup>)‡</b>				
Mean (95% CI)	28.8 (28.0–29.6)	28.2 (25.4–31.0)	..	..
Missing data	344 (52.2%)	80 (71.4%)	..	
<b>Systolic blood pressure (mm Hg)‡</b>				
Mean (95% CI)	127.0 (126–129)	127 (124–132)	..	..
Missing data	267 (40.5%)	71 (63.4%)	..	
<b>Total cholesterol (mmol/L)‡</b>				
Mean (95% CI)	5.0 (4.8–5.1)	5.0 (4.5–5.4)	..	..
Missing data	479 (72.7%)	100 (89.3%)	..	
<b>HbA<sub>1c</sub> (%)‡</b>				
Mean (95% CI)	7.2 (6.6–7.8)	7.7 (2.3–13.1)	..	..
Missing data	610 (92.6%)	109 (97.3%)	..	

(Table 4 continues on next page)

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	Attendees (n=659)	Non-attendees (n=112)	Odds ratio (95% CI)	p value
<b>Comorbidity before 2009</b>				
Epilepsy	197 (29.9%)	22 (19.6%)	1.56 (0.75–3.01)	0.2573
Diabetes	42 (6.4%)	4 (3.6%)	1.11 (0.40–3.09)	0.8352
Thyroid disorder	56 (8.5%)	3 (2.7%)	2.64 (0.77–9.05)	0.1229
Gastrointestinal disorders	77 (11.7%)	3 (2.7%)	3.52 (1.44–8.61)	0.0057
Constipation	83 (12.6%)	5 (4.5%)	2.05 (0.77–5.48)	0.1509
Underweight (BMI <18.0 kg/m <sup>2</sup> )	52 (7.9%)	15 (13.4%)	0.82 (0.42–1.60)	0.5589
Obese (BMI >30.0 kg/m <sup>2</sup> )	203 (30.8%)	22 (19.6%)	1.37 (0.79–2.37)	0.2654
Asthma or COPD	154 (23.4%)	22 (19.6%)	1.44 (0.76–2.69)	0.2604
Hypertension	126 (19.1%)	15 (13.4%)	0.80 (0.44–1.48)	0.4771
Depression	206 (31.3%)	35 (31.3%)	1.06 (0.65–1.67)	0.8534

Baseline characteristics are shown. Data were adjusted for other covariates and clustering within practices. BMI=body-mass index. HbA<sub>1c</sub>=glycated haemoglobin. COPD=chronic obstructive pulmonary disease. \*As data were available for only four patients, this strategic health authority was excluded from the analysis. †Ages 60–100 years were combined for this analysis. ‡Mean of all measurements in 2007 and 2008.

**Table 4: Multivariate logistic regression analysis of variables associated with attendance in patients with intellectual disability invited to attend health checks**

### Panel: Research in context

#### Systematic review

We did not do a systematic review before starting this cohort study, as we were aware of several comprehensive reviews in this area to which we referred. Lennox and colleagues<sup>31</sup> did a pooled analysis of relevant studies published between 1980 and 2009 identified on Medline, PsycINFO, Embase, and CINAHL with the search terms “intellectual disability”, “trial OR study OR control”, “adults”, and “short health screening or health assessment”, and identified two randomised trials and one cohort study which reported that participants who had the health screening received more health assessments and health promotion activities than those who did not. We also referred to a systematic review of health checks for people with intellectual disabilities (ID) that was based on searches of Medline, CINAHL, Web of Science, and PsycINFO for peer-reviewed quantitative research or qualitative research published between 1989 and 2010 with terms related to “learning disabilities” and associated database-specific synonyms, combined with search terms relating to the effectiveness of annual health checks for people with ID. The evidence indicated that health checks are effective to identify previously undetected disorders in people with ID and showed some evidence for an association between increased medical activity and positive effects on health outcomes.<sup>32</sup> We updated our literature search by checking the references of a 2013 publication that covered the time period of our study.<sup>33</sup> These reviews highlight the variability of the provision and uptake of primary care health checks for people with ID, despite evidence that such checks can be effective in recognising previously unrecognised important morbidities.

#### Interpretation

Our study contributes substantial evidence in favour of primary care health checks for people with ID in English primary care and provides specific information about what activities are associated with incentivised health checks (increased investigations, general and specific health assessments, identification of common comorbid disorders, medication reviews, and referrals to secondary care) across a large, demographically representative population sample. Development of the methodology for analysis of large datasets in this way will enable further assessment of long-term effects of primary care health checks on health outcomes in the ID population and investigation of other factors contributing to the poor health they experience and the variable delivery and uptake of such checks.

were, therefore, on the practice register to be considered for the LD-DES, but 811 (40%) did not. No patients without QOF-ID codes were offered annual ID health checks, irrespective of whether they were registered with incentivised or non-incentivised practices. Patients who did not have QOF-ID codes across all practices were more likely to be women (63.1% vs 43.1%), in the youngest age group (36.7% vs 28.0%), and have Townsend deprivation scores in quintile 1 (21.6% vs 18.4%).

### Discussion

This study was a large-scale analysis of a national annual health check scheme based in primary care and specifically targeting adults with ID, which used data representative of patients throughout England.<sup>20</sup> Practices that had opted in to the LD-DES scheme generally had increased rates of general and specific health assessments of their patients with ID recorded, and an increased likelihood of identifying new comorbidities, including thyroid and gastrointestinal disorders. Incentivised practices were also more likely than non-incentivised practices to offer health action plans and refer ID patients to secondary care. Among invited patients who did not attend health checks, non-attenders were younger and more socially deprived than attenders.

Our study provides important evidence that health checks targeting adults with ID have positive effects on health-service provision that can reduce the health inequities commonly experienced by this population.<sup>4,6</sup> This finding is particularly pertinent in view of a confidential enquiry into premature deaths of people with ID in England, which found far more deaths from causes potentially preventable with good quality health care than in the general population.<sup>5</sup> Our results suggest that annual health checks for people with ID could contribute to a reduction in the excess of avoidable deaths. Similar interventions have been assessed in Scotland<sup>13</sup> and Australia,<sup>12,14</sup> but the studies were small. An English study showed that the LD-DES scheme is associated with increased identification of disorders that are incentivised for the general population under the QOF scheme, such as diabetes.<sup>28</sup> Our data indicated that epilepsy and diabetes, which are incentivised under this general scheme, were likely to be identified by practices in general, whereas targeted health checks for people with ID resulted in increased identification of other disorders, such as thyroid and gastrointestinal disorders, which are common and potentially problematic in the ID population.

Although our results provide support for the LD-DES in England, which is, to our knowledge, the largest such national scheme, longer-term effects of the scheme on morbidity and mortality need to be investigated. The current gross inequalities in provision of and access to health care for the ID population make a strong case for the potential benefit of systematic health checks, but whether these increased health assessments and

detection of comorbidities are associated with improved access to appropriate secondary health care and improved outcomes should be urgently established. Database studies of large populations over longer periods could assist in such analyses.

Factors relating to the variability between practices opting into such incentivisation schemes and patients taking up the offer of health checks need to be clarified as they contribute to the underlying health inequalities in the ID population. Data from the English Public Health Observatory indicate that nationally only 52% of patients eligible for incentivised ID health checks currently receive them, with large variations between and within localities.<sup>29</sup> We found that even when practices opted in to the LD-DES, more than a third of adults with specific disorders known to cause ID were excluded from health checks because no QOF-ID codes were recorded. All primary care physicians participating in the LD-DES should be encouraged to cross-reference individuals with Read codes for such specific syndromes, for instance Down's syndrome or fragile X syndrome, against QOF-ID codes and their LD-DES registers to ensure that all potentially eligible patients are included. We suggest making this approach a national-level criterion for participation in the LD-DES.

In the current climate of budgetary constraint, establishing the cost effectiveness of health checks for people with ID would be useful. A study in Glasgow, UK, found that the mean cost of care for adults with ID who received standard care only was greater than that for those receiving ID health checks.<sup>30</sup>

Finally, health systems differ worldwide, and it remains to be established whether similar health-check schemes for people with ID can be usefully implemented in other countries.

Our research had several limitations. First, we had to infer which practices had opted in to the LD-DES because this information was not available to the THIN recording scheme. We based our assumption on the distribution of health checks. What we defined as the incentivised practices might have included some practices that had not opted in to the scheme, and there might have been some in the non-incentivised group that had opted in but had not implemented the programme successfully. We think, however, that such instances are unlikely because most practice reimbursement is given on evidence of completed health checks indicated by appropriate Read codes.

Second, we assessed all the data together and did not investigate the quality of health checks within individual practices. Our data indicate that the number of patients recorded in the practice register as having ID was a significant practice-level factor associated with opting into the LD-DES. Primary care physicians in practices with high numbers of patients with ID are likely to be more experienced and confident in working with this population. Provision of additional training for practitioners with fewer ID patients on their registers,

or possibly a model of experienced primary care physicians working across several practices might be ways to address this potential inequity.

Third, as this was an observational study, we attempted to reduce bias by adjusting for known confounding. We were unable, however, to adjust for all confounders because we had to exclude those with missing data. The information in medical databases is generally well recorded,<sup>23</sup> although we identified some issues with missing data. Only 5256 (55%) of 9610 patients had complete data for the 3-year period. Data might have been missing for people who did not attend consultations or for those who attended consultations where QOF-ID codes were not accurately recorded.

Our study indicates that primary care health checks for people with ID are associated with an increase in health-related activities as well as the identification of important comorbidities, which might lead to a reduction in avoidable deaths if effectively managed. However we found that 40% (811 of 2034) of patients with specific ID syndromes (eg, Down's syndrome) did not have specific QOF-ID codes recorded and were therefore not offered a health check. The provision and uptake of primary care health checks for people with ID are highly variable (panel) and the contributing factors need to be addressed if access to such checks is not to be another of the inequities experienced by this population. Longitudinal research needs to be done to assess the relation between primary care health checks, identification of serious comorbidities, and longer-term health outcomes in the ID population.

#### Contributors

MB and AS conceived the initial idea for this study and all authors contributed to its planning, including defining the aims, variables of interest, and analysis strategy. CW and LH wrote the study protocol with input from MB, IN, DO, and AS, and all authors approved the final version before submission to the ethics committee. Analyses were done by CW and LH, but all authors had access to the statistical outputs. MB, CW, LH, RH, and AS drafted the Article and all authors contributed to revisions. All authors approved the final manuscript.

#### Declaration of interests

AH has acted as an adviser to Novartis for work related to the diagnostic features, comorbidities, and economic modelling of interventions in fragile X syndrome. AS has participated in clinical trials sponsored by Roche of medication to ameliorate some of the comorbidities associated with genetic intellectual disability syndromes, and has acted as an adviser to the Downs Syndrome Association. All other authors declare no competing interests.

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