

# An evaluation of the effectiveness of annual health checks and quality of health care for adults with intellectual disability: an observational study using a primary care database

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## Scientific summary

**Intellectual disability: health check and health-care effectiveness**

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# 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 at a younger age. 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 health care, 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 for a health check are thought to have received one. It is unclear what exactly happens during these health checks, and what impact they have on important health outcomes, such as emergency hospitalisation.

## Objectives

The study had two overall aims.

1. To describe the health, health-care quality, equity of health care, mortality rates and NHS costs for adults with ID in a national sample.
2. 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 (Clinical Practice Research Datalink) linked to national hospital admissions (Hospital Episode Statistics) and mortality data sets (Office for National Statistics). Overall, from 451 English general 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, gender and practice to a maximum of seven controls without ID or associated conditions ( $n = 152,846$ ). Specific analyses were based on smaller subgroups of adults with ID: a cross-sectional analysis of health and health-care quality on 1 January 2012 ( $n = 14,751$ ), a longitudinal analysis of mortality and hospital admissions during 2009–13 ( $n = 16,666$ ) and individual health checks ( $n = 7510$ ). A practice-based analysis of health checks compared a subset of predominantly participating practices ( $n = 126$ ) with non-participating ones ( $n = 68$ ). Analyses of health checks further considered adults with ID without health checks ( $n = 6922$ ), assigning a random index date based on the distribution of the dates recorded in the 7510 adults with health checks during the study.

The 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, with published costings assigned to primary and secondary care events when these were clearly identifiable. The outcomes for longitudinal analyses were mortality and emergency hospital admissions using the linked Office for National Statistics and Hospital Episode Statistics 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 subgroup 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 (Carers Support Merton). These meetings initially helped us to identify and modify important outcomes for our study, and later provided assistance with interpreting and disseminating findings.

Statistical analyses comparing adults with ID with matched controls included conditional Poisson models to derive prevalence ratios (PRs) and rate ratios (RRs), conditional models for odds ratios (ORs) and Cox models stratified on the matched sets to obtain hazard ratios (HRs). Further adjustment was made for selected comorbidities, smoking and area deprivation, when appropriate.

## Results

### *Cross-sectional comparison with the general population*

Adults with ID had high levels of recorded comorbidity compared with the general population, in particular epilepsy [18.5%; PR 25.33, 95% confidence interval (CI) 23.29 to 27.57] and severe mental illness (8.6%; PR 9.10, 95% CI 8.34 to 9.92). Large relative differences were also seen for dementia (PR 7.52, 95% CI 5.95 to 9.49), dysphagia (PR 3.30, 95% CI 3.01 to 3.61) and hypothyroidism (PR 2.69, 95% CI 2.52 to 2.87). However, adults with ID were less likely to have recordings of coronary heart disease (PR 0.65, 95% CI 0.57 to 0.74) and cancer (PR 0.70, 95% CI 0.61 to 0.80) in their primary care record. Nearly one in four adults (23.9%) with ID was 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 among the general population, as was the recording of other key health indicators (smoking, body mass index, alcohol consumption and 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 to 0.66) or a mammogram during the last 3 years (PR 0.75, 95% CI 0.72 to 0.78). Adults with ID were nearly twice as likely as controls to have received repeat medication during 2011 (PR 1.82, 95% CI 1.79 to 1.84). They were almost three times as likely to be prescribed a psychotropic drug (PR 2.73, 95% CI 2.66 to 2.81), with almost 4 in 10 (38.2%) receiving at least one psychotropic prescription during the year. Adults with ID had a higher primary care consultation rate during 2011 (RR 1.70, 95% CI 1.66 to 1.74) but, once this was accounted for, they were less likely to have had a doctor consultation of > 10 minutes (OR 0.73, 95% CI 0.69 to 0.77), and had lower continuity of care with the same doctor (OR 0.77, 95% CI 0.73 to 0.82). Overall, their estimated NHS costs during 2011 were estimated to be twice those of patients of the same age and gender without ID (RR 2.05, 95% CI 2.01 to 2.10). Only 46.8% of adults with ID had received a health check by 1 January 2012.

### *Longitudinal analysis of hospital admissions and mortality*

Adults with ID had higher mortality rates (HR 3.62, 95% CI 3.33 to 3.93) during 2009–13 than matched controls, and these remained high after adjustment for differences in comorbidity (HR 3.05, 95% CI 2.73 to 3.41). The higher risk was seen across all causes of death, except some cancers and transport accidents. Adults with Down syndrome were at a much higher risk (HR 9.21, 95% CI 7.22 to 11.76) than their controls, with one in four who died (25.4%) having Down 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 with 22.5% in the matched controls. However, as 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 six times higher among adults with ID than among adults of the same age and gender in the general population without ID (HR 5.86, 95% CI 5.06 to 6.80). For almost 7 in 10 deaths (69.1%) among adults with ID there was no recording of ID in the death certification data.

Adults with ID were more likely to have had an emergency hospital admission during 2009–13 [incidence rate ratio (IRR) 2.82, 95% CI 2.66 to 2.98], with 33.7% being admitted for ACSCs compared with 17.3% of controls (IRR 5.62, 95% CI 5.14 to 6.13). The most common ACSCs resulting in admission for adults with ID were epilepsy (35.6%), lower respiratory tract infections (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**

No difference was seen in the change in overall emergency admissions between adults with ID with a first health check recorded during 2009–13 and controls (IRR 0.96, 95% CI 0.87 to 1.07). However, there was evidence for a relative reduction among those with severe health needs (IRR 0.80, 95% CI 0.67 to 0.95). When emergency admissions for ACSCs were solely considered, there was evidence of a reduced change in admission rate post health check compared with controls (IRR 0.82, 95% CI 0.69 to 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 to 1.19), but emergency admissions for ACSCs did fall (IRR 0.74, 95% CI 0.58 to 0.95), consistent with the individual-level analysis.

### **Health checks and process measures**

Among practices carrying out health checks, adults with ID who had 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, than patients who did not receive health checks by 2011. Although we failed to detect any evidence that health checks had a significant impact on the overall level of consultations or diagnoses between adults with ID with health checks and adult with ID 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 health care.

- Adults with ID are at high risk of emergency hospitalisation, particularly potentially preventable admissions, which represent one-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 one-third of deaths potentially amenable to health-care interventions, this suggests that improvements of access to, and quality of, health care among adults with ID are possible and desirable. In primary care, better continuity of care and longer appointment times are important examples that we have identified.

- The high prescribing levels of psychotropic drugs to adults with ID, combined with low levels of recorded medication reviews, suggest that improvements in monitoring could be made, assessing the appropriateness of long-term prescribing for these patients.
- The low level of recording of ID on death certification has implications for the surveillance of this population and consideration is needed of ways in which this could be improved. Even when ID is recorded, the questionable coding of it as an underlying cause for many deaths suggests that more consistent guidance would be helpful.

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

- Although adults with ID have greater levels of chronic disease than the general population, recording of cancer and coronary heart disease was found to be lower, and further investigation is warranted as to whether this represents missed diagnoses or lower risk due to a 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 these findings represent how health checks are being administered, 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 or not the cost of health checks is offset by savings from fewer emergency hospitalisations.

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