





# Onset and Care of Type 2 Diabetes Mellitus in People with a Learning Disability

A LeDeR Deep Dive

[www.kcl.ac.uk/research/leder](http://www.kcl.ac.uk/research/leder)   
leder@kcl.ac.uk 

**Baksh, R. A., Gulliford, M., Chauhan, U., Sheehan, R., Strydom, A. (2023)**

**A 2022 Deep Dive report.**

**Learning from Lives and Deaths -  
People with a Learning Disability and Autistic People (LeDeR) Report for 2022  
(LeDeR 2022).**

**Autism and Learning Disability Partnership.**

**King's College, London.**

The Institute of Psychiatry,  
Psychology and Neuroscience  
(IoPPN)

King's College, London

16 De Crespigny Park  
London  
SE5 8AF  
United Kingdom

[www.kcl.ac.uk/research/leder](http://www.kcl.ac.uk/research/leder)

**We would like to acknowledge and thank the feedback and support from those whose advice and guidance were invaluable in helping guide the creation of this report.**

Baksh, R, A., was supported by a Jérôme Lejeune Foundation postdoctoral research fellowship, special thanks to Adam White for the design of this report, and to Roz Stanley and Rachel Snow-Miller from NHS England.

# CONTENTS

- 1 Key Messages
- 2 Introduction
- 3 Study Design, Setting, and Participants
- 4 Results
- 8 Summary and Areas for Service Improvement
- 9 References
  
- 11 **Appendix**
- 12 Table A1: Quality Indicators Used in this Analysis and Their Sources
- 13 Details of Statistical Analysis
- 14 Table A2: Demographic Characteristics of People with a Learning Disability and General Population Controls
- 15 Table A3: Characteristics of Type 2 Diabetes Cases in People with a Learning Disability and the General Population
- 16 Table A4: Incidence of Type 2 Diabetes by Sex, Ethnicity, and Age Group for people with a Learning Disability and the General Population
- 17 Table A5: Results of a Poisson Regression Model
- 18 Figure A1: Predicted Incidence of Type 2 Diabetes by Age Group from the Initial Regression Model for People with a Learning Disability and General Population Controls
- 18 Table A6: Results of a Poisson Regression Model
- 19 Figure A2: Predicted Incidence of Type 2 Diabetes by Age-Group from the Regression Model that Included Age Interaction for People with a Learning Disability and from the General Population
- 20 Table A7: People with a Learning Disability with Type 2 Diabetes Mellitus
- 21 Table A8: General Population Controls with Type 2 Diabetes Mellitus
- 22 Table A9: Factors Associated with a Type 2 Diabetes Diagnosis in People with a Learning Disability
- 23 Table A:10 Factors Associated with a Type 2 Diabetes Diagnosis in Matches General Population Patients

# KEY MESSAGES

- People with a learning disability in England have higher rates of new onset of type 2 diabetes compared to the general population. The increase in rates of type two diabetes in people with a learning disability is shifted 10-15 years earlier than in people from the general population
- Consideration should be given to offering screening for the presence of type 2 diabetes as part of an annual health check (AHC) to people with a learning disability.
- People with a learning disability and type 2 diabetes were less likely to have eye and foot checks, an area where improvements should be made.
- With regards to the management of conditions associated with diabetes, our analyses support the application of existing NHS guidance for the management of obesity, hypertension, and cardiovascular health, and for reducing or monitoring the long-term impact of antipsychotic medication in people with a learning disability.
- There is a need for improved diabetes care and education for individuals with a learning disability to help prevent and manage the condition effectively. Healthcare providers and caregivers should also be aware of the increased risk of type 2 diabetes mellitus in this population and take steps to ensure that appropriate screening and management strategies are in place.

## Introduction

It has been estimated that approximately 4.9 million people now live with diabetes in the UK, and of these, around 90% have type 2 diabetes (Diabetes UK, 2022). In addition, up to one million people have undiagnosed type 2 diabetes. One in six hospital inpatients has diabetes (Diabetes UK, 2022), and a third of people with type 2 diabetes already have a microvascular (small blood vessel) complication (such as retinal issues) at the time of diagnosis, suggesting that earlier diagnosis may be beneficial. Consequently, the National Health Service spends at least £10 billion a year on diabetes, equivalent to 10% of its budget; 80% of this is spent on the treatment of complications (Whicher et al., 2022), such as kidney, eye and foot problems and heart attacks.

Research suggests that individuals with a learning disability are at a higher risk of developing diabetes than the general population. A recent review of existing research showed that diabetes rates amongst individuals with learning disabilities (33 studies) was approximately 8.5%, with a 95% Confidence interval range between 7.2% – 10.0% (Vancampfort et al., 2022). The odds of having a diagnosis of diabetes were shown to be 2.46 times higher in people with a learning disability (95% CI = 1.89–3.21) compared to the general population.

People with a learning disability may experience a delay in diagnosis which can lead to more severe health complications (Taggart et al., 2013). National diabetes audit data suggests that individuals with a learning disability and type 2 diabetes may be less likely to receive appropriate diabetes care, including regular check-ups, blood glucose monitoring, and medication management (NHS Digital, 2017). This can lead to poor blood sugar control and an increased risk of diabetes-related complications, and poorer health outcomes. Other research has suggested that factors such as having certain kinds of genetic syndromes such as Prader-Willi syndrome (Crinò & Grugni, 2020) or Down syndrome (Aslam et al., 2022), low levels of physical activity and poor diets (Tyrer et al., 2020), and antipsychotic medication may also contribute to the higher risk of developing type 2 diabetes in individuals with a learning disability.

This report summarises work that aimed to 1) determine the new onset (incidence) rate of type 2 diabetes mellitus; 2) examine the quality of care related to the management of type 2 diabetes mellitus and 3) investigate the health issues and demographic factors associated with a type 2 diabetes mellitus diagnosis in people with a learning disability compared to the general population using primary care data from England.

## Study Design, Setting and Participants

We used data extracted from the UK Clinical Practice Research Datalink (CPRD) Aurum database, which is a database of the anonymised electronic health records for 1,345 general practices (GP) in the UK (primarily in England and which are currently contributing data) .

All patients ever diagnosed with a learning disability and currently registered with a GP were identified from the May 2022 release of CPRD Aurum using SNOMED codes for learning disabilities (ref – Lancet paper). People with Autism were included within the sample, but only if they also had a recorded learning disability. We used a matched cohort study design (Cummings et al., 2003); this means that patients with a learning disability were matched to patients from the general population for year of birth, sex and general practice and if their start of record was no more than 365 days after that of the matched learning disability participant.

We planned three analyses:

1. To determine the incidence rate (i.e. new cases) of type 2 diabetes mellitus,
2. To examine the quality of care related to the management of type 2 diabetes mellitus
3. To investigate the morbidities and demographic factors associated with a type 2 diabetes mellitus diagnosis in people with a learning disability compared to general population controls.

### Medical Conditions and Quality of Care Outcomes

As this report is focused on type 2 diabetes, we excluded individuals likely to have type 1 diabetes (see appendix for details). The management of type 2 diabetes mellitus was examined using a combination of quality-of-care outcomes from the Quality and Outcomes Framework (QOF), the Organisation for Economic Co-operation and Development (OECD) quality of care indicators and NICE guideline for type 2 diabetes mellitus (see table A1 in the appendix for a list of care outcomes and how they were defined). We also extracted information from patients' clinical and prescription records using SNOMED codes for known risk factors associated with type 2 diabetes mellitus, such as hypertension, obesity, ischaemic heart disease, and medication such as anti-psychotic medication to explore factors associated with a new diagnosis.

### Statistical Analysis

In order to analyze changes in diabetes mellitus rates over time, incidence (i.e. new diagnoses) per 1,000 person-years was used, in age bands 0 to 4 years, 5 to 14 years and then by 10-year age groups up to 85+ years. We calculated confidence intervals, and then compared rates in people with a learning disability with those from the general population using adjusted incidence rate ratios (crudely speaking, the rate in people with a learning disability as a proportion of the rate in people from the general population). We then checked for an age effect, and because a significant effect was present, we conducted adjusted analyses by age band. Finally, quality of care indicators was examined using prevalence data of patients with type 2 diabetes mellitus who contributed data between the financial years of 2011-12 and 2021-22. Other details of statistical analysis are provided in the appendix.

1. CPRD Aurum was made available for research purposes in 2018 and as of May 2022 consists of data from more than 41 million patients with more than 13 million currently registered. The database is from GPs using the EMIS clinical systems and includes data on diagnoses, symptoms, prescriptions, referrals and tests (CPRD, 2021; Wolf et al., 2019). Previous studies have confirmed the quality of data from CPRD Aurum (Gulliford et al., 2020; Jick et al., 2020; Persson et al., 2020). This study protocol was approved by the CPRD Independent Scientific Advisory Committee (ISAC protocol 20-048R).

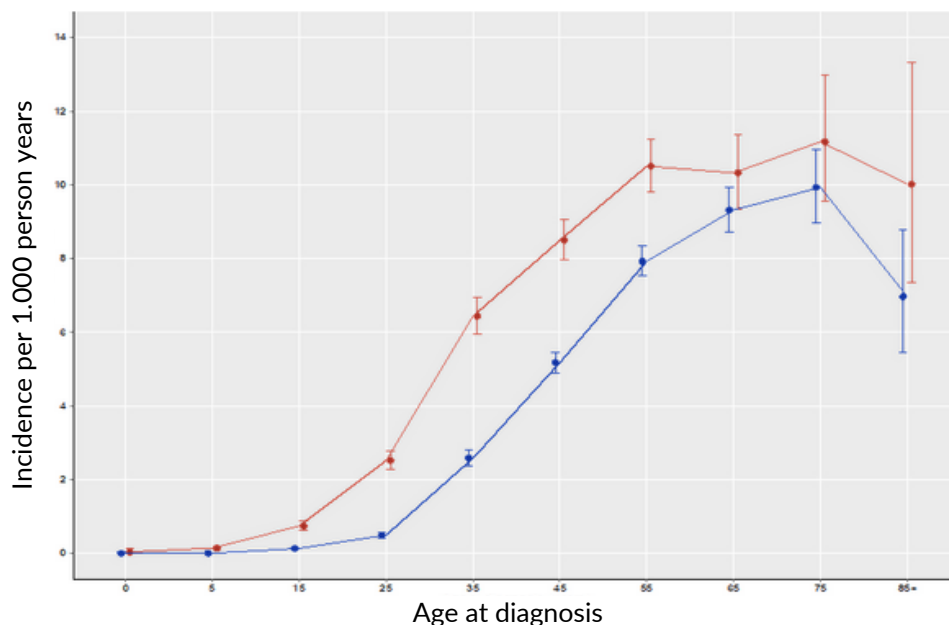
## Results

Demographic details of primary care patients with a learning disability and general population comparison patients included in this analysis are given in table A2 in the appendix. There were 198,263 patients with a learning disability (79,323 females) and 328,139 (129,689 females) general population patients as comparators who were registered with a GP contributing to CPRD Aurum between the financial years of 2011-12 and 2021-22 (calendar years 2011 to 2022).

### Incidence of Type 2 Diabetes Mellitus

The median age at diagnosis for people with a learning disability and type 2 diabetes was 51 (range 40-61), compared to 57 (49-66) for people from the general population. The crude incidence rate for type 2 diabetes in patients with a learning disability was 3.74 (3.62-3.86) per 1,000 person-years (i.e. the rate in 1,000 people each being followed for one year), and for general population patients, it was 2.26 (2.20-2.32) per 1,000 person-years. In both groups, there was an increase in rates with increasing age (figure 1). However, incidence rates for type 2 diabetes in people with a learning disability diverged from those in the general population during adolescence, with higher rates in most subsequent age groups before converging in older age, so that incidence rates in the age 15 – 24 age group was 0.75 (0.63-0.87) per 1,000 person-years for young people with a learning disability, compared to 0.14 (0.11-0.17) for their peers in the general population, peaking at 11.17 (9.56-12.98) for those aged 75- 84 with a learning disability compared to 9.93 (8.97-10.96) for their matched peers in the general population (table A3 in the appendix).

**Figure 1: Incidence of type 2 diabetes by age-group for people with a learning disability (red) and the general population (blue)**



Note: The above graph contains data from 2011-2022 and includes people with Down syndrome who have been shown to differ in their rates of type 2 diabetes compared to the general population.



Adjusted analyses show that if factors such as age, sex, ethnic background, and financial year are taken account of, then people with a learning disability have an incidence rate for type 2 diabetes that is 1.65 times (approximately 65%) higher than the rate in the general population (appendix table A4). However, if the interaction with age is taken into account (in other words, if we fully adjust for the younger age of onset in people with a learning disability), then the rate for young people with a learning disability may be much higher than in the general population (appendix table A5; figure A2 shows the predicted incidence rates by age if the interaction is taken account of). We, therefore, conducted additional adjusted analyses for each age band from age 15 (table 1), which showed that in young people with a learning disability, the rate of new onset of type 2 diabetes is approximately 16 times higher than for their peers without a learning disability, but by age 65 – 74 the rates are similar.

Table 1 - Incidence rate ratio comparing new onset rates of diabetes of people with a learning disability compared to the general population for each age band from age 15-24 years (adjusted analyses)

Age group (years)	Incidence rate ratio (95% confidence interval)	P value
<b>Young people</b>		
15 - 24	16.89 (7.92-36.02)	p <0.0001
25 - 34	15.41 (8.87-26.78)	p <0.0001
<b>Older people</b>		
55 - 64	2.18 (1.82-2.61)	p <0.0001
65 - 74	1.10 (0.90-1.36)	p = 0.354
75 – 84	1.15 (0.85-1.57)	p = 0.356

### Quality of Care Indicators (Table 2, overleaf)

The management of type 2 diabetes mellitus was examined using a combination of quality-of-care outcomes from the QOF Indicators, the OECD quality of care indicators and NICE guideline for type 2 diabetes. We used prevalence data of patients with type 2 diabetes who contributed data between the financial years of 2011-12 and 2021-22.

This showed similar trends across time for these indicators and targets, with a decline in the proportion of patients being offered monitoring and interventions during the pandemic years (2020/21, and 2021/22). The proportions of patients with a learning disability and type 2 Diabetes being offered basic monitoring such as blood pressure, BMI and having smoking status recorded were comparable to those in the general population but improved over time such that these targets are now better met in people with a learning disability than in the general population, presumably due to these measures being recorded as part of the learning disability annual health checks. The proportion of patients with a learning disability with type 2 diabetes being offered weight management and lifestyle advice also improved over time relative to those in the general population, but overall, in typical years less than half of patients are recorded to have been offered such advice. Only a minority of patients with type 2 diabetes (less than 10%) are being offered weight management, which is similar for both those with and without a learning disability.

However, patients with a learning disability with type 2 diabetes were slightly less likely to be offered blood tests for HbA1c and cholesterol, and retinal screening and foot examination are consistently less often recorded to have been offered to patients with a learning disability – for example, during 2021/2022, only 36.2% of people with a learning disability and type 2 diabetes had retinal screening compared to 47.9% in the general population.



Table 2: Percentage of quality-of-care metrics recorded for type 2 diabetes patients with a learning disability (ID) and General Population Controls (GPC)

Quality of care metric	2011-12		2012-13		2013-14		2014-15		2015-16		2016-17		2017-18		2018-19		2019-20		2020-21		2021-22	
	GPC	ID	GPC	ID	GPC	ID	GPC	ID	GPC	ID	GPC	ID	GPC	ID	GPC	ID	GPC	ID	GPC	ID	GPC	ID
Yearly n	6439	3711	6695	3889	7017	4267	7237	4602	7485	4968	7676	5401	7917	5768	8144	6110	8168	6427	8047	6484	8104	6606
Systolic blood pressure measurement	90.90	90.27	90.19	89.84	91.75	92.20	91.10	90.98	90.34	90.36	91.49	91.19	91.64	90.90	92.10	91.31	89.68	89.03	69.22	73.58	81.34	82.38
Diastolic blood pressure measurement	90.88	90.30	90.20	89.87	91.76	92.27	91.10	90.98	90.34	90.36	91.49	91.22	91.64	90.93	92.10	91.28	89.65	89.03	69.21	73.58	81.33	82.36
HbA1c measurement	86.52	83.62	85.91	84.65	89.58	87.81	88.75	87.40	88.83	87.24	89.93	87.22	90.02	87.22	89.70	87.61	88.48	85.25	76.28	76.30	83.37	81.08
Cholesterol measurement	83.07	79.79	82.54	80.28	87.26	84.81	85.78	83.49	85.68	82.89	86.01	82.73	86.19	82.23	85.82	82.77	82.47	78.56	67.81	66.27	75.35	72.09
Retinal screening	64.84	55.86	63.35	57.55	67.49	58.92	60.55	52.65	56.82	49.09	56.66	48.66	54.31	46.29	53.98	45.27	51.97	44.33	26.56	21.33	47.88	36.22
BMI recording	81.07	90.38	80.70	89.97	77.84	92.34	73.83	91.03	72.88	90.40	74.40	91.24	74.79	90.93	77.27	91.29	75.78	89.03	58.30	73.60	71.96	82.39
Foot exam	74.33	69.79	70.77	67.55	78.62	72.86	76.26	71.56	75.94	71.16	77.14	71.89	75.82	70.27	76.65	70.87	71.67	66.45	48.01	44.86	61.99	54.53
Weight management/intervention	6.97	8.95	6.86	8.46	7.87	10.55	6.41	9.21	6.85	8.57	6.67	9.22	6.20	7.89	5.33	7.94	4.74	7.22	3.08	4.64	7.66	9.10
Lifestyle advice	54.74	49.29	52.96	50.55	53.95	50.93	45.14	44.89	46.80	46.12	48.61	47.71	48.06	48.68	46.82	48.79	46.01	49.43	34.96	43.54	42.76	46.70
Smoking status recorded	77.71	77.93	75.85	77.60	80.02	80.83	77.64	78.97	77.37	78.50	78.93	79.99	80.04	80.43	81.39	82.34	79.11	80.71	63.45	74.66	73.47	77.08
COVID-19 vaccination																			84.09	79.44	89.93	89.46

Financial year

## Health conditions and demographic factors associated with a type 2 diabetes diagnosis

We compared predictors of a diagnosis for type 2 diabetes in people with a learning disability and those from the general population – details in the appendix, table A9 and A10. This analysis showed similar patterns in people with a learning disability compared to the general population, though with some differences in strength of association. In particular, in people with a learning disability, sex was less strongly associated with type 2 diabetes with women being slightly less likely than men to have new onset (OR 0.94; 95% CI 0.90 – 0.98), compared to women in the general population who are considerably less likely to receive a new diagnosis compared to men (OR 0.65; 95% CI 0.63 - 0.68). Similarly, the effect of ethnicity in people with a learning disability was also less pronounced, with for example South Asian people (Bangladeshi, Indian, and Pakistani) with a learning disability being approximately 45 % more likely to develop type 2 diabetes compared to those with white ethnicity (OR 1.45; 95% CI 1.33-1.58), while in the general population, South Asian people are several times (more than 200%) more likely to be diagnosed with type 2 diabetes than their peers with a recorded white ethnicity (OR 2.81; 95% CI 2.63-3.01) (see appendix table A6).

With regards to most other health conditions, the association with the onset of type 2 diabetes was similar, with the exception of alcohol use (as indicated by advice on consumption), which was more strongly associated with a diagnosis in the general population compared to those with a learning disability.

## Summary and Areas for Service Improvement

People with a learning disability in England have higher rates of new onset of type 2 diabetes compared to the general population. This is in keeping with similar research in other parts of the world (Flygare Wallen, 2018). The incidence rate increases in people with a learning disability from adolescence and is particularly high in those aged 25 – 54; we estimated this to be approximately 16 times higher in people with a learning disability compared to peers in the general population. Put another way, the increase in rates of type two diabetes in people with a learning disability is shifted 10-15 years earlier than in people from the general population. This suggests that consideration should be given to offering screening for the presence of type 2 diabetes as part of an annual health check (AHC) for people with a learning disability (AHC is currently offered to people from age 14).

In terms of quality-of-care indicators that may require improvement, the annual health checks for people with a learning disability may have helped to improve basic checks in primary care, such as blood pressure and BMI. However, people with a learning disability and type 2 diabetes were less likely to have eye and foot checks, an area where improvements should be made. The pathways for these checks involve input from clinics or specialists outside of primary care and suggest that work may be required to improve these, for example, with higher referral rates, provision of accessible information, and reasonable adjustments to improve uptake and completion of checks.

Another area for improvement is weight management and lifestyle advice. Barriers previously identified include a poor understanding of diabetes in people with a learning disability (Holden and Lee, 2022). Structured education for people with a learning disability and training for caregivers to support self-efficiency may be required to address this (Maine et al., 2018). There have been efforts to adapt health promotion programs for people with a learning disability (Taggart et al., 2018), including specific education programs (Dunkley et al., 2018); further work may be required to ensure such programs are successfully implemented within the NHS. In the USA, specialist input (defined as a visit to an endocrinologist, diabetes care educationalist or other relevant specialists) was associated with better diabetes care for people with a learning disability (Lu et al., 2019).

With regards to the management of conditions associated with diabetes, our analyses support the application of existing NHS guidance for the management of obesity, hypertension, and cardiovascular health, and for reducing or monitoring the long-term impact of antipsychotic medication in people with a learning disability.

Overall, there is a need for improved diabetes care and education for individuals with a learning disability to help prevent and manage the condition effectively. Healthcare providers and caregivers should also be aware of the increased risk of type 2 diabetes mellitus in this population and take steps to ensure that appropriate screening and management strategies are in place.

## References

- Aslam, A. A., Baksh, R. A., Pape, S. E., Strydom, A., Gulliford, M. C., Chan, L. F., & GO-DS21 Consortium (2022). Diabetes and Obesity in Down Syndrome Across the Lifespan: A Retrospective Cohort Study Using U.K. Electronic Health Records. *Diabetes care*, 45(12), 2892–2899. Advance online publication. <https://doi.org/10.2337/dc22-0482>
- Crinò, A., & Grugni, G. (2020). Update on Diabetes Mellitus and Glucose Metabolism Alterations in Prader-Willi Syndrome. *Current diabetes reports*, 20(2), 7. <https://doi.org/10.1007/s11892-020-1284-5>
- CPRD. (2021). Data highlights. Retrieved 14 April 2021 from <https://www.cprd.com/data-highlights>
- Cummings, P., McKnight, B., & Greenland, S. (2003). Matched cohort methods for injury research. *Epidemiologic reviews*, 25(1), 43-50.
- Diabetes UK. (2022). Diabetes is Serious. Recovering Diabetes Care: Preventing the Mounting Crisis. <https://diabetes-resources-production.s3.eu-west-1.amazonaws.com/resources-s3/public/2022-04/Diabetes%20is%20Serious%20Report%20Digital.pdf>
- Dunkley, A. J., Tyrer, F., Doherty, Y., Martin-Stacey, L., Patel, N., Spong, R., Makepeace, C., Bhaumik, S., Gangadharan, S. K., Yates, T., Davies, M. J., Khunti, K., & STOP Diabetes Team (2018). Development of a multi-component lifestyle intervention for preventing type 2 diabetes and cardiovascular risk factors in adults with intellectual disabilities. *Journal of public health (Oxford, England)*, 40(2), e141–e150. <https://doi.org/10.1093/pubmed/fox067>
- Flygare Wallén, E., Ljunggren, G., Carlsson, A. C., Pettersson, D., & Wändell, P. (2018). High prevalence of diabetes mellitus, hypertension and obesity among persons with a recorded diagnosis of intellectual disability or autism spectrum disorder. *Journal of intellectual disability research : JIDR*, 62(4), 269–280. <https://doi.org/10.1111/jir.12462>
- Gulliford, M. C., Sun, X., Anjuman, T., Yelland, E., & Murray-Thomas, T. (2020). Comparison of antibiotic prescribing records in two UK primary care electronic health record systems: cohort study using CPRD GOLD and CPRD Aurum databases. *BMJ Open*, 10(6), e038767.
- Holden, B. and Lee, A. (2022), Barriers and enablers to optimal diabetes care for adults with learning disabilities: A systematic review. *Br J Learn Disabil*, 50: 76-87. <https://doi.org/10.1111/bld.12393>
- Imkampe, A. K., & Gulliford, M. C. (2011, Jul). Trends in Type 1 diabetes incidence in the UK in 0- to 14-year-olds and in 15- to 34-year-olds, 1991-2008. *Diabet Med*, 28(7), 811-814. <https://doi.org/10.1111/j.1464-5491.2011.03288.x>
- Jick, S. S., Hagberg, K. W., Persson, R., Vasilakis-Scaramozza, C., Williams, T., Crellin, E., & Myles, P. (2020). Quality and completeness of diagnoses recorded in the new CPRD Aurum Database: evaluation of pulmonary embolism. *Pharmacoepidemiology and Drug Safety*, 29(9), 1134-1140.

- Lu, Z., Cogan, L., McDermott, S., Lauer, E., Lindner, S., Tracy, K., & Momany, E. T. (2020). Disparities in diabetes management among medicaid recipients with intellectual and developmental disabilities (IDD): Evidence from five U.S. states. *Disability and health journal*, 13(2), 100880. <https://doi.org/10.1016/j.dhjo.2019.100880>
- Maine, A., Brown, M., Dickson, A., & Truesdale, M. (2020). The experience of type 2 diabetes self-management in adults with intellectual disabilities and their caregivers: A review of the literature using meta-aggregative synthesis and an appraisal of rigor. *Journal of intellectual disabilities : JOID*, 24(2), 253–267. <https://doi.org/10.1177/1744629518774172>
- NHS Digital. (2017 January 31). National Diabetes Audit, 2015-2016. Report 1: Care Processes and Treatment Targets Learning Disability - Supplementary Information [Slide show]. <https://files.digital.nhs.uk/publicationimport/pub23xxx/pub23241/nati-diab-rep1-audi-ld-suppl-2015-16.pdf>
- Persson, R., Vasilakis-Scaramozza, C., Hagberg, K. W., Sponholtz, T., Williams, T., Myles, P., & Jick, S. S. (2020). CPRD Aurum database: Assessment of data quality and completeness of three important comorbidities. *Pharmacoepidemiology and Drug Safety*, 29(11), 1456-1464.
- Taggart, L., Coates, V. and Truesdale-Kennedy, M. (2013), Management and quality indicators of diabetes mellitus. *J Intellect Disabil Res*, 57: 1152-1163. <https://doi.org/10.1111/j.1365-2788.2012.01633.x>
- Taggart, L., Truesdale, M., Dunkley, A., House, A., & Russell, A. M. (2018). Health Promotion and Wellness Initiatives Targeting Chronic Disease Prevention and Management for Adults with Intellectual and Developmental Disabilities: Recent Advancements in Type 2 Diabetes. *Current developmental disorders reports*, 5(3), 132–142. <https://doi.org/10.1007/s40474-018-0142-5>
- Tyrer, F., Ling, S., Bhaumik, S., Gangadharan, S. K., Khunti, K., Gray, L. J., & Dunkley, A. J. (2020). Diabetes in adults with intellectual disability: prevalence and associated demographic, lifestyle, independence and health factors. *Journal of intellectual disability research : JIDR*, 64(4), 287–295. <https://doi.org/10.1111/jir.12718>
- Vancampfort, D., Schuch, F., Van Damme, T., Firth, J., Suetani, S., Stubbs, B., & Van Biesen, D. (2022). Prevalence of diabetes in people with intellectual disabilities and age- and gender-matched controls: A meta-analysis. *Journal of Applied Research in Intellectual Disabilities*, 35( 2), 301– 311. <https://doi.org/10.1111/jar.12949>
- Whicher, C. A., O'Neill, S., & Holt, R. I. G. (2020). Diabetes in the UK: 2019. *Diabetic medicine: a journal of the British Diabetic Association*, 37(2), 242–247. <https://doi.org/10.1111/dme.14225>
- Wolf, A., Dedman, D., Campbell, J., Booth, H., Lunn, D., Chapman, J., & Myles, P. (2019). Data resource profile: clinical practice research Datalink (CPRD) aurum. *International journal of epidemiology*, 48(6), 1740-1740g.






# Onset and Care of Type 2 Diabetes Mellitus in People with a Learning Disability

A LeDeR Deep Dive

## APPENDIX

[www.kcl.ac.uk/research/leder](http://www.kcl.ac.uk/research/leder)   
[leder@kcl.ac.uk](mailto:leder@kcl.ac.uk) 



## APPENDIX

### Identification of Type 2 Diabetes Mellitus

Participants were classified as having diabetes mellitus if a diabetes diagnosis was recorded in CPRD Aurum observation file. As diabetes types cannot be definitively classified from clinical records alone, participants were classified as having probable type 1 diabetes mellitus if they were first prescribed insulin within 91 days of the diabetes mellitus diagnosis and were less than 35 years old at diagnosis (Imkampe & Gulliford, 2011); these individuals were excluded from further analysis in order to focus on individuals likely to have type 2 diabetes mellitus.

**Table A1 – Quality indicators used in this analysis, and their sources.**

Outcome	Metric	
Blood pressure	Percentage of patients with most recent blood pressure	OECD
	Last blood pressure reading (measured in the preceding 12 months) is 140/80 mmHg or less	QOF
Cholesterol	Last measured total cholesterol (measured within the preceding 12 months) is 5 mmol/L or less	QOF
	Percentage of patients with at least one LDL cholesterol test annually	OECD
Urinary protein	Percentage of patients with at least one test for microalbuminuria during the measurement year; or who had evidence of medical attention for existing nephropathy	OECD
Blood sugar	Last IFCC-HbA1c is 59 mmol/mol or less in the preceding 12 months	QOF
	Last IFCC-HbA1c is 64 mmol/mol or less in the preceding 12 months	
	Last IFCC-HbA1c is 75 mmol/mol or less in the preceding 12 months	
	Percentage of patients with one or more HbA1c tests annually	OECD
	6 months once the HbA1c level and blood glucose lowering therapy are stable	NICE
	Self-monitoring of capillary blood glucose: Do not routinely offer self-monitoring of capillary blood glucose levels for adults with type 2 diabetes unless: the person is on insulin or there is evidence of hypoglycaemic episodes or the person is on oral medication that may increase their risk of hypoglycaemia while driving or operating machinery or the person is pregnant or is planning to become pregnant (see the NICE guideline on diabetes in pregnancy).	NICE
Eyes	Record of retinal screening in the preceding 12 months	QOF
Feet	Percentage of patients receiving at least one-foot exam annually	OECD
Structured education	Have a record of being referred to a structured education programme within 9 months after entry on to the diabetes register	QOF
Flu vaccination	Had influenza and COVID-19 immunisation in the preceding 1 August to 31 March	QOF
Other conditions	Percentage of patients whose smoking status was ascertained and documented annually	OECD
Dietary advice	Provide individualised and ongoing nutritional advice from a healthcare professional with specific expertise and competencies in nutrition.	NICE

## Details of Statistical Analyses

Person time was analysed between 2011 and 2022. In this analysis, the date of the first event that was more than 365 days after the start of the patients' registration was considered as the diabetes mellitus incidence date. New diagnoses of diabetes were compared for people with a learning disability and controls by aggregating over age group, sex and ethnicity. Age was divided into the categories 0 to 4 years, 5 to 14 years and then by 10-year age groups up to 85+ years. Incidence rates were estimated per 1,000 person-years, and confidence intervals were derived from the Poisson distribution. A Poisson regression model was fitted to calculate an adjusted incidence rate ratio (IRR). Age was fitted as a continuous predictor in the regression model, with a quadratic term to allow for non-linearity; similarly, financial year and financial year-squared were fitted to align with the Quality and Outcomes Framework. Sex, ethnicity, and having a learning disability were fitted as factors. In a separate analysis, an interaction term between learning disability and age was included, this allowed the effect of age to differ between patients with a learning disability and those from the general population. Predicted rates were plotted. Quality of care indicators were examined using prevalence data of patients with type 2 diabetes mellitus who contributed data between the financial years of 2011-12 and 2021-22. These included a record of blood pressure measurements (systolic and diastolic), HbA1c measurement, cholesterol measurement, retinal screening, BMI recording, foot examination, weight management/intervention recording, lifestyle advice, flu vaccination, smoking status, and COVID-19 vaccination (from 2021-22). A count was documented for each indicator as to whether they had a record of the indicator in their clinical record within each financial year. The frequencies for each indicator were then expressed as a percentage of the total number of prevalent cases within the financial year. This was done separately for patients with a learning disability and those from the general population.

Finally, health conditions and demographic factors associated with a type 2 diabetes mellitus diagnosis were examined using logistic regression models in patients with a learning disability and separately in those from the general population while adjusting for sex, ethnicity and the known risk factors associated with type 2 diabetes mellitus diagnosis. Health conditions and demographic factors associated with a type 2 diabetes diagnosis were examined using logistic regressions in people with a learning disability and separately in matched general population patients. This analysis used the whole sample of 197,969 (minus 294 type 1 diabetes cases) people with a learning disability (79,198 females) and 327,980 from the general population (129,612 females; minus 159 type 1 cases). There was a total of 12,492 (%) type 2 diabetes cases and 185,477 without diabetes in patients with a learning disability. In the general population patients, there was a total of 13,128 (%) type 2 diabetes cases and 314,852 without diabetes.

## Additional results

**Table A2: Demographic characteristics of people with learning disability and general population controls**

Demographics	Learning disability	General population controls
n	198,263	328,139
Sex (%)		
Male	118,940 (59.99)	198,450 (60.48)
Female	79,323 (40.01)	129,689 (39.52)
Median age in years at cohort entry (IQR)	26 (14-46)	23 (11-42)
Median age in years at cohort exit (IQR)	30 (19-51)	29 (18-50)

*Note: Cohort exit may have been due to patient death, patient changing family practice or the end of the study period in 2020.*

### **Incidence of type 2 diabetes mellitus**

There were 8,791 cases of pre-existing type 2 diabetes in patients with a learning disability and 7,391 in general population patients at cohort entry. Because the study focused on incidence (new onset) rates from birth, these patients with diagnoses of pre-existing type 2 diabetes at baseline were excluded from both groups. In addition, 13,723 general population patients were removed as they did not have comparator patients with a learning disability once pre-existing type 2 diabetes cases in the learning disability group were removed. There were 294 patients with a learning disability and 159 general population patients who met the criteria for type 1 diabetes (prescribed insulin within 91 days of the diabetes diagnosis and were aged <35 years) and were excluded from further analyses. After these exclusions, there were 189,178 patients with a learning disability and 306,866 general population comparator patients who were eligible for analysis.

There was a total of 3,684 new diagnoses of type 2 diabetes in patients with a learning disability and 4,998 in the matched patients from the general population (table A3), with 985,031.6 person-years of follow-up for patients with a learning disability and 2,210,856.9 person-years for control patients. The median age at diagnosis for people with a learning disability and type 2 diabetes was 51 (range 40-61), compared to 57 (49-66) for people from the general population.

The crude incidence rate for type 2 diabetes in patients with a learning disability was 3.74 (3.62-3.86) per 1,000 person-years (i.e. the rate equivalent to 1,000 people each being followed for one year), and for general population patients, it was 2.26 (2.20-2.32) per 1,000 person-years. In both groups, there was an increase in rates with increasing age (figure 1). However, incidence rates for type 2 diabetes in people with a learning disability diverged from those in the general population during adolescence, with higher rates in most subsequent age groups before converging in older age, so that incidence rates in the age 15 – 24 age group was 0.75 (0.63-0.87) per 1,000 person-years for young people with a learning disability, compared to 0.14 (0.11-0.17) for their peers in the general population, peaking at 11.17 (9.56-12.98) for those aged 75- 84 with a learning disability compared to 9.93 (8.97-10.96) for their matched peers in the general population (table A4).

**Table A3: Characteristics of type 2 diabetes cases in people with learning disability and the general population; percentages in brackets unless otherwise indicated.**

Variable	Category	Learning disability	General population
<b>Total type 2 diabetes incidences</b>		3684	4998
<b>Financial year</b>	2011-12	85	90
	2012-13	278	463
	2013-14	352	497
	2014-15	327	466
	2015-16	346	494
	2016-17	397	460
	2017-18	365	512
	2018-19	384	527
	2019-20	379	464
	2020-21	340	340
	2021-22	431	483
	2022-23	-	202
<b>Sex</b>	Male	2089 (56.70)	2925 (58.52)
	Female	1595 (43.30)	2073 (41.48)
<b>Ethnicity</b>	White	2868 (77.85)	3462 (69.27)
	Black, Black British, Caribbean or African	140 (3.80)	225 (4.50)
	Asian or Asian British	311 (8.44)	579 (11.58)
	Mixed or Multiple Ethnic groups	36 (0.98)	53 (1.06)
	Other ethnic groups	68 (1.85)	182 (3.64)
	Unknown	261 (7.08)	497 (9.94)
<b>Age (years)</b>	Median (IQR)	51 (40-61)	57 (49-66)
<b>Treatment in first 5 years from diagnosis</b>	Oral agents	2746 (74.53)	3558 (71.19)
	Insulin	305 (8.28)	404 (8.08)

Note – ethnicity was classified using 2021 Census Ethnic groups <https://www.ethnicity-facts-figures.service.gov.uk/style-guide/ethnic-groups> with the exception of Chinese, which is included in the “other ethnic groups” category, because of the known risk for diabetes in people with south Asian ethnicity

**Table A4: Incidence of type 2 diabetes by sex, ethnicity and age-group for people with a learning disability and the general population.**

		Learning disability			General population		
		Type 2 diabetes diagnoses	Person years at risk	Incidence per 1,000 person years (95% confidence interval)	Type 2 diabetes diagnoses	Person years at risk	Incidence per 1,000 person years (95% confidence interval)
<b>Total</b>		3684	985,031.59	3.74 (3.62-3.86)	4998	2,210,856.90	2.26 (2.20-2.32)
<b>Sex</b>	Male	2089	608,491.36	3.43 (3.29-3.58)	2925	1,362,235.37	2.15 (2.07-2.23)
	Female	1595	376,540.23	4.24 (4.03-4.45)	2073	848,621.53	2.44 (2.34-2.55)
<b>Ethnicity</b>	White	2868	691,896.84	4.15 (3.99-4.30)	3462	1,343,614.82	2.58 (2.49-2.66)
	Black, black British, Caribbean or African	140	42,926.34	3.26 (2.74-3.85)	225	78,512.73	2.87 (2.50-3.27)
	Asian or Asian British	311	61,916.69	5.02 (4.48-5.61)	579	131,897.52	4.39 (4.04-4.76)
	Mixed or Multiple Ethnic groups	36	20,535.61	1.75 (1.23-2.43)	53	36,986.02	1.43 (1.07-1.87)
	Other	68	22,174.77	3.07 (2.38-3.89)	182	66,060.45	2.76 (2.37-3.19)
	Unknown	261	145,581.35	1.79 (1.58-2.02)	497	553,785.36	0.90 (0.82-0.98)
<b>Age-group</b>	0-4	2	57,512.50	0.03 (0.004-0.13)	1	137,546.14	0.01 (0.0002-0.04)
	5-14	29	197,308.48	0.15 (0.10-0.21)	2	426,713.18	0.005 (0.0006-0.02)
	15-24	159	213,247.16	0.75 (0.63-0.87)	69	502,622.55	0.14 (0.11-0.17)
	25-34	404	160,080.24	2.52 (2.28-2.78)	166	332,664.31	0.50 (0.43-0.58)
	35-44	692	107,479.71	6.44 (5.97-6.94)	574	222,226.18	2.58 (2.38-2.80)
	45-54	945	111,207.89	8.50 (7.96-9.06)	1307	252,319.52	5.18 (4.90-5.47)
	55-64	825	78,492.09	10.51 (9.81-11.25)	1484	187,145.56	7.93 (7.53-8.34)
	65-74	411	39,796.59	10.33 (9.35-11.38)	931	99,855.13	9.32 (8.73-9.94)
	75-84	170	15,217.57	11.17 (9.56-12.98)	393	39,569.96	9.93 (8.97-10.96)
	85+	47	4689.36	10.02 (7.36-13.33)	71	10,194.38	6.96 (5.44-8.78)

**Table A5: Results of a Poisson regression model. Diabetes incidence rate ratios were adjusted for each of the variables shown.**

Variable	Category	Incidence rate ratio	95% confidence interval		p-value
			LL	UL	
Learning disability		1.65	1.59	1.73	<0.0001
Financial year (per year)		1.26	1.23	1.30	<0.0001
Financial year-squared		0.98	0.98	0.99	<0.0001
Age (per year)		1.21	1.20	1.22	<0.0001
Age-squared		0.99	0.99	0.99	<0.0001
Sex	Male	Ref.			
	Female	0.88	0.84	0.92	<0.0001
Ethnicity	White	Ref.			
	Black, Black British, Caribbean, or African	1.51	1.36	1.68	<0.0001
	Asian or Asian British	2.77	2.58	2.97	<0.0001
	Mixed or Multiple Ethnic groups	1.14	0.93	1.41	0.22
	Other	1.62	1.43	1.84	<0.0001
	Unknown	0.65	0.60	0.70	<0.0001



Figure A1: - Predicted incidence of type 2 diabetes (95% CI) by age-group from the initial regression model for people with learning disability (red) and general population controls (blue)

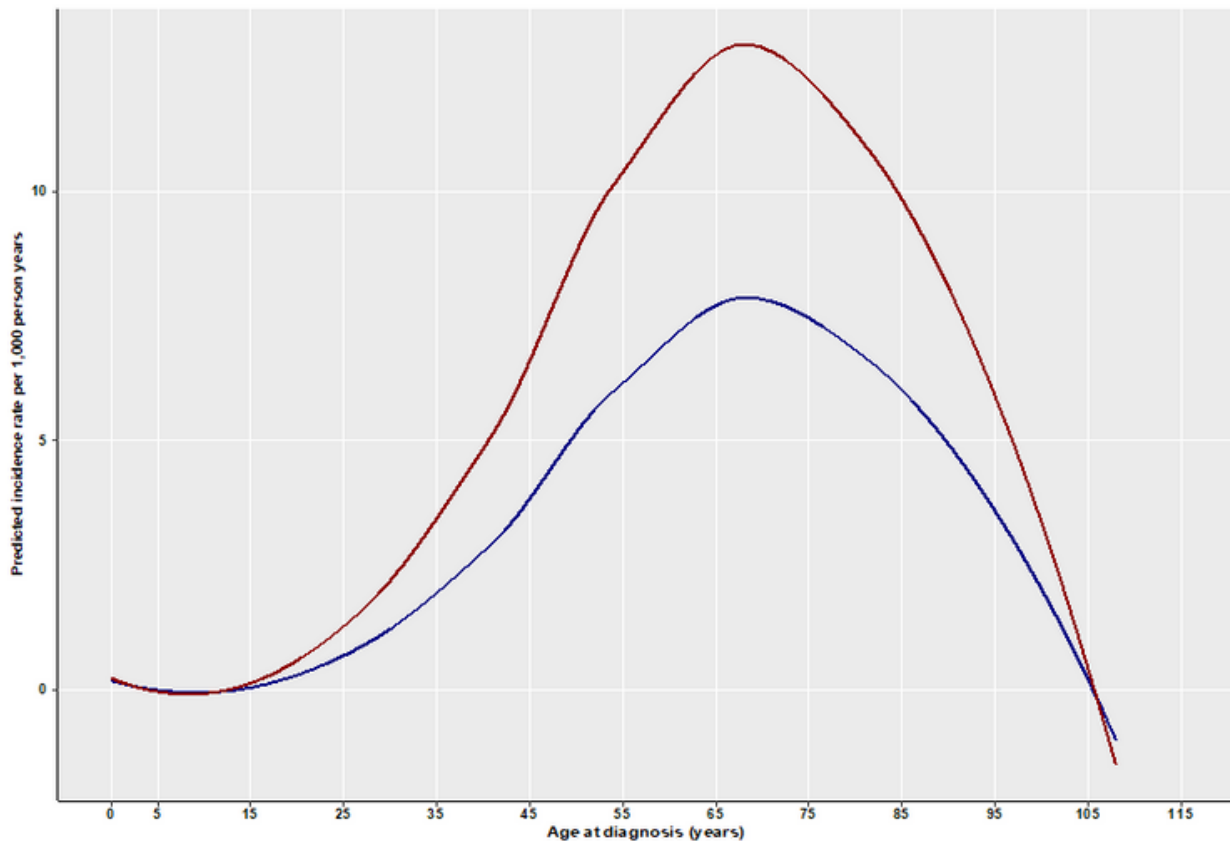
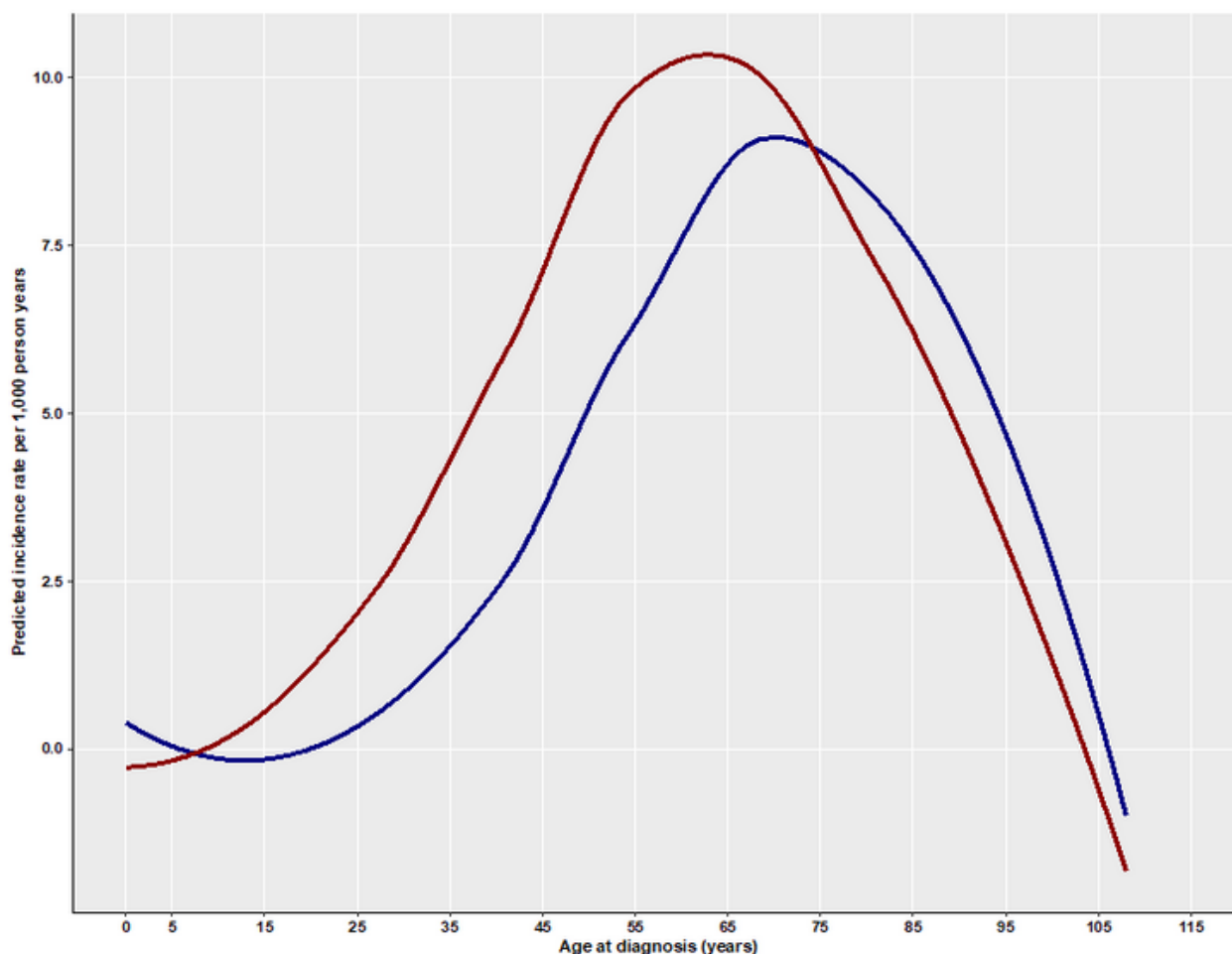


Table A6: Results of a Poisson regression model. Diabetes incidence rate ratios were adjusted for each of the variables shown (with learning disability x age interaction)

Variable	Category	Incidence rate ratio	95% confidence interval		p-value
			LL	UL	
Learning disability		7.18	6.05	8.53	<0.0001
Financial year (per year)		1.26	1.22	1.30	<0.0001
Financial year-squared		0.98	0.98	0.99	<0.0001
Age (per year)		1.24	1.23	1.25	<0.0001
Age-squared		0.99	0.99	0.99	<0.0001
Learning disability x age interaction		0.97	0.97	0.98	<0.0001
Sex	Male	Ref.			
	Female	0.88	0.84	0.91	<0.0001
Ethnicity	White	Ref.			
	Black AAC	1.50	1.35	1.67	<0.0001
	Asian	2.76	2.57	2.96	<0.0001
	Mixed	1.13	0.91	1.39	0.26
	Other	1.64	1.44	1.86	<0.0001
	Unknown	0.67	0.62	0.72	<0.0001

**Figure A2: Predicted incidence of type 2 diabetes (95% CI) by age-group from the regression model that included age interaction for people with a learning disability (red) and from the general population (blue)**



### Quality of care indicators (table A7 and A8 overleaf)

To determine differences in quality of care, we used prevalence data of patients with type 2 diabetes who contributed data between the financial years of 2011-12 and 2021-22. To include as many patients as possible, partial contributions of data to the financial year were included and patients did not have to contribute a full year, this therefore accommodated patients who may have exited the study at any time during the financial year. There were a total of 11,177 people with a learning disability and 12,982 general population controls with varying start and end dates within the study timeframe.

Percentage of quality-of-care indicators recorded by financial year (separately for people with a learning disability, and those from the general population).

Table A7: People with learning disability with Type 2 Diabetes Mellitus

Quality of care metric	Financial year											
	2011-12	2012-13	2013-14	2014-15	2015-16	2016-17	2017-18	2018-19	2019-20	2020-21	2021-22	
Yearly n	3711	3889	4267	4602	4968	5401	5768	6110	6427	6484	6606	
Systolic blood pressure measurement	n 335 % 90.2 7	n 349 % 89.8 4	n 393 % 92.2 0	n 418 % 90.9 8	n 448 % 90.3 6	n 492 % 91.1 9	n 524 % 90.9 0	n 557 % 91.3 1	n 572 % 89.0 3	n 477 % 73.5 8	n 544 % 82.3 2	
Diastolic blood pressure measurement	n 335 % 90.3 0	n 349 % 89.8 7	n 393 % 92.2 7	n 418 % 90.9 8	n 448 % 90.3 6	n 492 % 91.2 2	n 524 % 90.9 3	n 557 % 91.2 8	n 572 % 89.0 3	n 477 % 73.5 8	n 544 % 82.3 1	
HbA1c measurement	n 310 % 83.6 2	n 329 % 84.6 5	n 374 % 87.8 1	n 402 % 87.4 0	n 433 % 87.2 4	n 471 % 87.2 2	n 503 % 87.2 1	n 535 % 87.6 3	n 547 % 85.2 5	n 494 % 76.3 0	n 535 % 81.0 6	
Cholesterol measurement	n 296 % 79.7 9	n 312 % 80.2 8	n 361 % 84.8 1	n 384 % 83.4 9	n 411 % 82.8 9	n 446 % 82.7 3	n 474 % 82.2 3	n 505 % 82.7 7	n 504 % 78.5 6	n 429 % 66.2 7	n 476 % 72.0 2	
Retinal screening	n 207 % 55.8 6	n 223 % 57.5 5	n 251 % 58.9 2	n 242 % 52.6 5	n 243 % 49.0 9	n 262 % 48.6 6	n 267 % 46.2 0	n 276 % 45.2 7	n 284 % 44.3 9	n 138 % 21.3 3	n 239 % 36.2 3	
BMI recording	n 335 % 90.3 8	n 349 % 89.9 7	n 394 % 92.3 4	n 418 % 91.0 3	n 449 % 90.4 0	n 492 % 91.2 4	n 524 % 90.9 5	n 557 % 91.2 8	n 572 % 89.0 3	n 477 % 73.6 0	n 544 % 82.3 3	
Foot exam	n 259 % 69.7 9	n 262 % 67.5 5	n 310 % 72.8 6	n 329 % 71.5 6	n 353 % 71.1 6	n 388 % 71.8 9	n 405 % 70.2 7	n 433 % 70.8 7	n 427 % 66.4 5	n 290 % 44.8 6	n 360 % 54.5 2	
Weight management/intervention	n 332 % 8.95	n 329 % 8.46	n 450 % 10.5 5	n 424 % 9.21	n 426 % 8.57	n 498 % 9.22	n 455 % 7.89	n 485 % 7.94	n 464 % 7.22	n 301 % 4.64	n 601 % 9.10	
Lifestyle advice	n 182 % 49.2 9	n 196 % 50.5 5	n 217 % 50.9 3	n 206 % 44.8 9	n 229 % 46.1 2	n 257 % 47.7 1	n 280 % 48.6 8	n 298 % 48.7 9	n 317 % 49.4 3	n 282 % 43.5 4	n 308 % 46.7 5	
Smoking status recorded	n 289 % 77.9 3	n 301 % 77.6 0	n 344 % 80.8 3	n 363 % 78.9 7	n 390 % 78.5 0	n 432 % 79.9 9	n 463 % 80.4 3	n 503 % 82.3 4	n 518 % 80.7 1	n 484 % 74.6 6	n 509 % 77.0 8	
COVID-19 vaccination	n 2 % 77.9 3	n 8 % 77.6 0	n 9 % 80.8 3	n 4 % 78.9 7	n 0 % 78.5 0	n 0 % 79.9 9	n 9 % 80.4 3	n 1 % 82.3 4	n 7 % 80.7 1	n 4 % 79.4 4	n 0 % 89.4 6	



Results of logistic regression analyses of predictors of type 2 diagnosis are given in table A9 and A10.

**Table A9: Factors associated with a type 2 diabetes diagnosis in people with a learning disability**

		OR	LL	UL	p-value
<b>Sex</b>	<b>Male</b>	Ref.			
	<b>Female</b>	0.94	0.90	0.98	0.0037
<b>Ethnicity</b>	<b>White</b>	Ref.			
	<b>Asian</b>	1.45	1.33	1.58	0.0000
	<b>Black AAC</b>	1.01	0.90	1.12	0.9214
	<b>Other</b>	0.92	0.79	1.08	0.3204
	<b>Unknown</b>	0.88	0.83	0.94	0.0001
	<b>Mixed</b>	0.79	0.66	0.95	0.0121
	<b>Hypertension</b>	5.54	5.29	5.80	0.0000
	<b>Obesity</b>	2.80	2.67	2.94	0.0000
	<b>Ischemic heart disease</b>	2.28	2.11	2.47	0.0000
	<b>Kidney disease</b>	2.18	2.04	2.33	0.0000
	<b>Family history of diabetes</b>	2.10	2.00	2.21	0.0000
	<b>Advice on alcohol consumption</b>	2.10	2.01	2.19	0.0000
	<b>Antipsychotic medication</b>	1.50	1.44	1.58	0.0000
	<b>Mobility issues</b>	1.50	1.42	1.57	0.0000
	<b>Antidepressant medication</b>	1.39	1.33	1.45	0.0000
	<b>Hypothyroidism</b>	1.38	1.30	1.47	0.0000
	<b>Other endocrine disorders</b>	1.37	1.27	1.48	0.0000
	<b>Steroid medication</b>	1.15	1.05	1.26	0.0022
	<b>Sleep problems (disturbed sleep)</b>	0.94	0.89	0.99	0.0169

**Table A10: Factors associated with a type 2 diabetes diagnosis in matched general population patients**

		OR	LL	UL	p-value
<b>Sex</b>	<b>Male</b>	Ref.			
	<b>Female</b>	0.65	0.63	0.68	0.0000
<b>Ethnicity</b>	<b>White</b>	Ref.			
	<b>Black, Black British, Caribbean or African</b>	2.81	2.63	3.01	0.0000
	<b>Asian or Asian British</b>	1.80	1.62	2.00	0.0000
	<b>Mixed or Multiple Ethnic groups</b>	1.49	1.35	1.64	0.0000
	<b>Other</b>	1.02	0.85	1.22	0.8337
	<b>Unknown</b>	0.78	0.73	0.83	0.0000
	<b>Hypertension</b>	6.53	6.24	6.84	0.0000
	<b>Obesity</b>	3.65	3.47	3.84	0.0000
	<b>Advice on alcohol consumption</b>	2.79	2.67	2.92	0.0000
	<b>Ischemic heart disease</b>	2.32	2.18	2.47	0.0000
	<b>Kidney disease</b>	2.24	2.10	2.38	0.0000
	<b>Family history of diabetes</b>	2.23	2.13	2.34	0.0000
	<b>Mobility issues</b>	1.80	1.65	1.96	0.0000
	<b>Antidepressant medication</b>	1.57	1.50	1.64	0.0000
	<b>Steroid medication</b>	1.42	1.33	1.52	0.0000
	<b>Hypothyroidism</b>	1.42	1.31	1.53	0.0000
	<b>Other endocrine disorders</b>	1.38	1.27	1.50	0.0000
	<b>Antipsychotic medication</b>	1.33	1.26	1.41	0.0000
	<b>Sleep problems (disturbed sleep)</b>	1.07	1.00	1.14	0.0447

**END**