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Characterizing adults with Type 2 diabetes mellitus and intellectual disability: outcomes of a case-finding study

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Abstract

Aims To report the results of a case-finding study conducted during a feasibility trial of a supported self-management intervention for adults with mild to moderate intellectual disability and Type 2 diabetes mellitus, and to characterize the study sample in terms of diabetes control, health, and access to diabetes management services and support.

Methods We conducted a cross-sectional case-finding study in the UK (March 2013 to June 2015), which recruited participants mainly through primary care settings. Data were obtained from medical records and during home visits.

Results Of the 325 referrals, 147 eligible individuals participated. The participants' mean (SD) HbA_{1c} concentration was 55 (15) mmol/mol [7.1 (1.4)%] and the mean (SD) BMI was 32.9 (7.9) kg/m^2, with 20% of participants having a BMI >40 kg/m^2. Self-reported frequency of physical activity was low and 79% of participants reported comorbidity, for example, cardiovascular disease, in addition to Type 2 diabetes. The majority of participants (88%) had a formal or informal supporter involved in their diabetes care, but level and consistency of support varied greatly. *Post hoc* exploratory analyses showed a significant association between BMI and self-reported mood, satisfaction with diet and weight.

Conclusions We found high obesity and low physical activity levels in people with intellectual disability and Type 2 diabetes. Glycaemic control was no worse than in the general Type 2 diabetes population. Increased risk of morbidity in this population is less likely to be attributable to poor glycaemic control and is probably related, at least in part, to greater prevalence of obesity and inactivity. More research, focused on weight management and increasing activity in this population, is warranted.

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Introduction

People with intellectual disability constitute ~2% of the adult population [1]. Although the prevalence of Type 2 diabetes mellitus in this population is uncertain, it is probably more common than in the general population [2–4]. Risk factors for Type 2 diabetes in people with intellectual disability include high levels of obesity associated with a high-fat diet and low levels of activity, but it is also partly associated with greater use of anti-psychotic medication [5,6]. People with intellectual disability are less likely to receive appropriate care for diabetes and other chronic health conditions [4,7–9] and tend to have reduced self-management abilities [9]. There is some evidence that they have poorer outcomes, including more hospital admissions [2].

In the UK, Type 2 diabetes is usually managed in primary healthcare. Each general practice (average 7500 patients) would be expected to have fewer than 10 patients with intellectual disability and Type 2 diabetes [10,11], meaning that relevant clinical experience is often limited. Service planning is facilitated by a requirement for general practitioners (GPs) to maintain registers of patients with diabetes and for patients with intellectual disability [12]; however, only around a quarter of affected adults are on these registers, mainly those with more significant intellectual disability [1]. The majority of individuals with intellectual disability and Type 2 diabetes are therefore difficult to identify and their specific healthcare needs are not well understood.

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What's new?

- This study provides the most comprehensive profile to date of adults in the UK with a mild to moderate intellectual disability and Type 2 diabetes mellitus.
- While diabetes control in this population was similar to that of other adults with Type 2 diabetes, levels of obesity and inactivity were higher.
- Desire to change diet and reduce weight, and desire for help with diabetes management were common and associated with high BMI.
- Goal-setting with regard to weight reduction with increased physical activity may be an effective motivator in a diabetes management strategy for people with intellectual disability.

As the first step in the delivery of a feasibility randomized controlled trial of a supported self-management intervention, we developed and tested a method for identifying and recruiting participants with a mild to moderate intellectual disability and Type 2 diabetes, who were not using insulin, who might be suitable for the intervention [13]. In this paper we present data characterizing the study population in terms of diabetes control, health, and access to diabetes management services and support. Details of the case-finding method, recruitment and self-management intervention are published elsewhere [14].

Methods

Design and setting

We conducted a cross-sectional study in three districts of West Yorkshire, UK. At the time the study began (2013), the combined population of the centres was ~1.8 million; we assumed that: (1) 80% of the total population were adults; (2) of these, ~1.5% would have a mild or moderate intellectual disability and (3) based on local primary care data, 4% would have Type 2 diabetes and would not be using insulin (~800 people; see eligibility criteria).

Participants and eligibility criteria

Eligibility criteria were predetermined by the funders [National Institute for Health Research (NIHR) Health Technology Assessment Programme, HTA call no 10/102]. People were eligible if they: were aged ≥18 years; had been diagnosed with Type 2 diabetes that was controlled with diet alone or hypoglycaemic agents other than insulin; had a mild to moderate learning disability; and were living in the community (not in a hospital setting).

People were excluded from the study if they had any of the following: intellectual impairment acquired from disease in adult life, such as that attributable to adult-onset dementia or traumatic brain injury; Type 1 diabetes, secondary diabetes (such as steroid-induced diabetes and endocrine disorders) or rare causes of monogenic diabetes; and insufficient mental capacity to consent to participate.

To help referrers make a judgement about intellectual disability, they were asked to consider problems with reading, writing, managing money, looking after personal care, telling the time, or communicating. The participant did not need a formal recorded diagnosis. Mild to moderate intellectual disability was further established by an assessment of functional deficits in daily activities, educational and social attainment and support needs, and day-to-day cognitive function. Ability to give informed consent to participation was assessed by the researchers, who received training in how to support informed choice according to the Mental Capacity Act (2005) code of practice [15]. Informed consent could be verbal or written and facilitated by supporters, especially in the case of individuals with communication difficulties. For more detail see the full monograph of the study [14].

Case finding and recruitment

We asked GPs to cross-reference their diabetes and intellectual disability registers. To help identify individuals who were potentially eligible we devised searches using standard descriptive and diagnostic codes that had been entered on clinical computer systems as part of consultation and diagnosis [16]. Further sources of recruitment were intellectual disability services, secondary diabetes care, local authority day centres and third-sector support organizations.

The referrer obtained written consent for contact details to be sent to the research team, from the individual and/or a supporter, defined as the main adult (a family member, close friend, paid carer or partner) providing support in day-to-day living and diabetes management. An easy-to-read letter and participant information sheet were sent out. This was followed by a telephone call. Verbal consent for a research visit was obtained. Researchers contacted GPs to collect medical information to confirm eligibility after capacity was established and consent obtained.

Measures

Researcher interviews were conducted mostly in the home of the participant with a supporter. The interview used a proforma to: establish diabetes management (diet, physical activity, medication, self-care awareness and engagement with health services); identify the role of supporters in diabetes management; elicit feelings about weight, diet and having diabetes, and identify preferences for further assistance with diabetes management. The interview included mainly closed questions, phrased in an exploratory conversational form supported by visual aids (see Supporting

Information online). We found no appropriate standardized self-report measures for mood, self-care or diet in this population. Although there are standardized depression measures for adults with intellectual disability [17], these typically take 10–15 min with a supporter, which we considered represented an unreasonable burden when combined with multiple other measures. Because of its importance to the core aims we attempted to capture diet using the shortened version of the Rapid Eating Assessment for Participants (REAPS) [18]. This measure is not designed for people with intellectual disability; therefore, we piloted it with our service user groups. As a result we supplemented the questions with visual aids; for example, pictures of common foods and a retrospective food diary for the previous week. We also added some examples to include South-Asian food types (for example, ghee and chapatti) and substituted British terms for some of the original North American ones, for example 'fizzy drinks' for soda. The interviews and measures were completed using a conversational approach, taking the person's abilities into account.

Collecting clinical data

We wrote to each participant's GP to confirm eligibility and requesting details of diabetes medication and vascular and diabetes control measures.

Analysis

Statistical analyses were carried out in accordance with a prespecified analysis plan [13]. All percentages were calculated using the total number of participants, with available data as the denominator. We conducted simple *post hoc* exploratory subgroup summaries and analyses to generate hypotheses for relationships between HbA_{1c} and BMI and other variables we anticipated might be associated with diabetes management (presence or absences of supporter, mood, views on diet, weight, having diabetes).

Ethical approval

Ethical approval was granted for the study by the Yorkshire and Humber Research Ethics Committee (Reference: 12/YH/0304).

Results

Case finding

Sixty-percent of general practices in the study catchment areas consented to be involved in recruitment. A total of 365 referrals (325 individuals) were made to the study between June 2013 and March 2015. We were able to contact, consent and interview 172 participants, but after medical information checks, only 147 were eligible (Fig. 1). Table 1 provides demographic data on individuals who were originally referred and those who were eligible for the study. Based on original estimates that ~800 people would meet eligibility within the study area, our final sample represented ~30% of the estimated eligible population of the participating general practices.

Characterizing the study population

Clinical data

We were unable to gain any medical data from the participant's GP in 45/147 (31%) of cases. Where information was returned, there were lower rates of completion, especially for triglyceride levels (66%) and the QRISK2 vascular risk assessment (49%).

Tables 2 and 3 provide data on metabolic variables and vascular risk factors in participants for whom we had clinical data. Mean HbA_{1c} and BMI values were similar to the values originally identified in our study area (Table 4). Suboptimal diabetes control was characterized as HbA_{1c} 48 mmol/mol (6.5%) for those on diet or single-agent therapy or HbA_{1c} > 59 mmol/mol (7.5%) for those on multiple agents [19]. Approximately 65% of participants for whom we had clinical data had HbA_{1c} levels ≥ 48 mmol/mol (6.5%) and 27% had HbA_{1c} levels > 59 mmol/mol (7.5%). In terms of BMI, 87% of participants had a BMI > 25 kg/m^2, with ~20% having a BMI >40 kg/m^2. There was a positive correlation between HbA_{1c} and BMI (Pearson's r = 0.27, P< 0.01, N=102). Fourteen (14%) participants' systolic blood pressure was ≥140 mmHg and 34 (34%) had diastolic blood pressure ≥80 mmHg. Over half of participants for whom data were available had total cholesterol ≥4 mmol/l. Over 75% of participants for whom this figure was reported (n = 67) had a QRISK2 estimated 10-year risk of cardiovascular disease >10% (range 0.3–47%), the recommended target for intervention by the National Institute for Health and Care Excellence (NICE) [20]. The albumin:creatinine ratio was available for 93 participants: median (range) 1.4 (0.1–59.3) mg/mmol. Around a third of participants had levels higher than >2.5 mg/mmol (men) or >3.5 mg/mmol (women), which indicates some reduction in kidney function [21].

In baseline interviews, 118 participants (80%) said they took oral diabetes medication. Table 5 shows the medications reported in GP forms that were returned. Both HbA_{1c} and BMI were higher in those receiving polytherapy [63 mmol/mol (7.9%); 34 kg/m^2] than those receiving monotherapy [52 mmol/mol (6.9%) 32.1 kg/m^2]. Thirty-five participants (30%) reported non-adherence to a diabetes medication regime, 10 (8.5%) said they missed once a week or more and four (3%) said they missed most days. The most common reasons given for missing medication were 'forgetting' or 'being too busy' (n =23, 67%), followed by 'don't like swallowing it' (n =5, 15%). Most participants reported they were prompted to take their medication by their supporters.

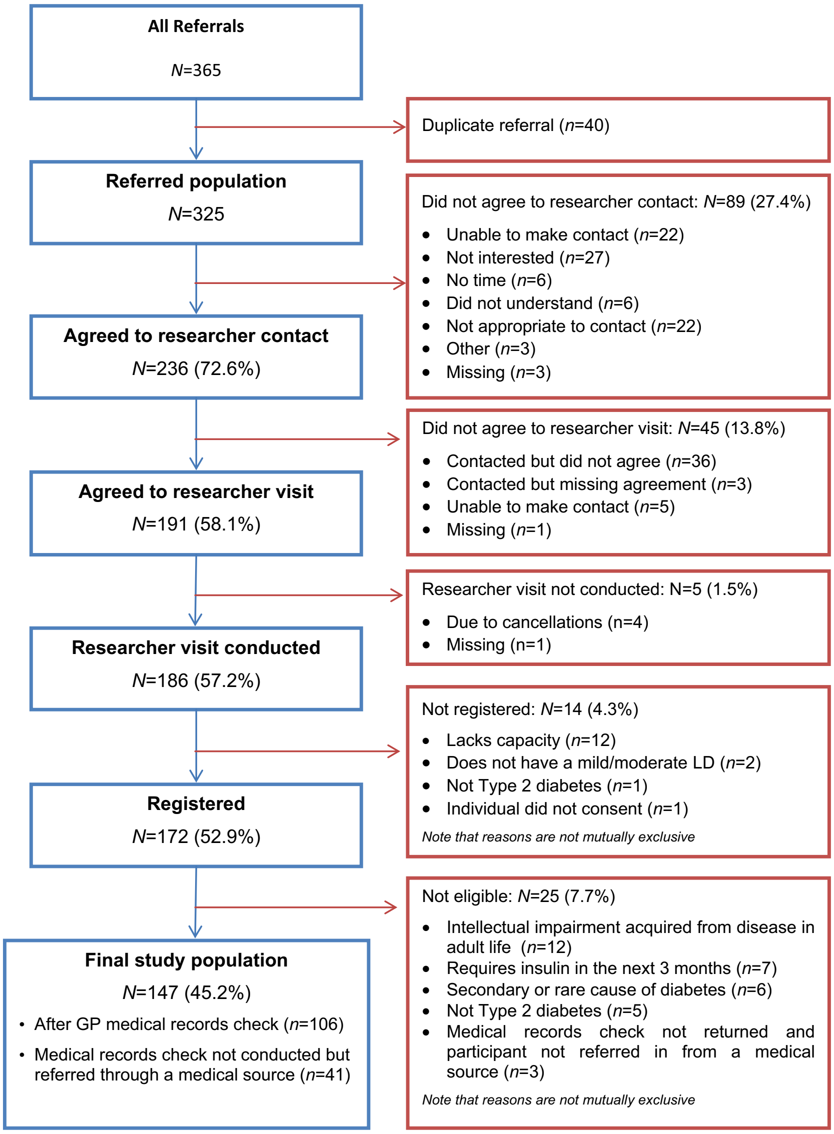

FIGURE 1 Flow chart of recruitment process.

Self-reported use of diabetes healthcare services and self-care practice

Most participants reported that they had seen their general practice nurse (*n* =135, 92%), attended retinal screening (*n* =117, 80%), and seen their GP (*n* =92, 63%) in the past 12 months. Approximately half reported visiting the podiatrist (*n* =72, 49%), and 10 (7%), had received input from a dietician. Most participants (*n* =107, 73%) reported no difficulty attending appointments for their diabetes, usually with a supporter.

When asked about self-care for diabetes, 74 participants (51%) had been told to have their teeth and gums checked regularly, 51 participants (35%) said that they had been told they needed to check their feet and 35 participants (24%) reported being told that they needed to check their blood sugar. Eighty-five percent of participants (*n* =123) said they would like further help looking after their diabetes. At this interview the researcher did not ask for more detail on the type of further help a person might want.

Levels of self-reported comorbidities were high (Table 6), with mental health problems reported by nearly half of participants. Many participants for whom data were available (*n*=101) were on registers in addition to those for diabetes and intellectual disability, most commonly for cardiovascular illness (*n* = 37, 37%), obesity (*n* = 33, 33%) and mental health problems (*n* = 28, 28%). A total of 46 participants (31%) reported they ‘felt poorly’ either sometimes or most of the time.

Healthy lifestyle, diet and exercise

When questioned about diet using the REAPS, >40% of participants reported that they ‘usually or often’ ate too many fats or high-fat snacks, too few wholegrains and too little fruit, >60% (*n* = 95) reported that ‘usually or

Table 1 Demographics of the referred and eligible populations

	Referred population N=325	Eligible population N=147
Age at referral, years		
Mean (range)	53.5 (18–93)	54.4 (19–83)
Missing, *n* (%)	22 (6.8)	0
Gender, *n* (%)		
Male	174 (53.5)	74 (50.3)
Female	137 (42.2)	73 (49.7)
Missing	14 (4.3)	0
Ethnicity, *n* (%)		
White	249 (76.6)	125 (85.0)
Asian	45 (13.9)	17 (11.6)
Black	2 (0.6)	1 (0.7)
Mixed	6 (1.8)	3 (2.0)
Other ethnic group	1 (0.3)	1 (0.7)
Missing	22 (6.8)	0

Table 2 Metabolic variables and vascular risk factors from general practitioner medical records

	N*	Mean (SD)	Missing data
HbA_{1c} mmol/mol	102	55 (15)	45
HbA_{1c} %	102	7.1 (1.4)	45
BMI, kg/m^2	102	32.9 (7.9)	45
Systolic blood pressure, mmHg	101	124.7 (13.8)	46
Diastolic blood pressure, mmHg	101	74.3 (8.4)	46
Total cholesterol, mmol/l	100	4.2 (1.1)	47
Triglycerides, mmol/l	67	2.2 (1.2)	80

Table 3 Metabolic variables and vascular risk factor categories from general practitioner medical records

Variable	*n* (%)
HbA_{1c} (N* = 102)	
<48 mmol/mol (<6.5%)	36 (35.3)
48 to 59 mmol/mol (6.5% to <7.5%)	38 (35.3)
≥59 mmol/mol (≥7.5%)	28 (27.4)
BMI (N* = 102)	
<18.5 kg/m^2: underweight	2 (2.0)
18.5–24.9 kg/m^2: normal weight	11 (10.8)
25–29.9 kg/m^2: overweight	23 (22.5)
30–34.9 kg/m^2: obese class I	27 (26.5)
35–39.9 kg/m^2: obese class II	18 (17.6)
≥40 kg/m^2: obese class III	21 (20.6)
Systolic blood pressure (N* = 101)	
<140 mmHg	87 (86.1)
≥140 mmHg	14 (13.9)
Diastolic blood pressure (N* = 101)	
<80 mmHg	67 (66.3)
≥80 mmHg	34 (33.7)
Total cholesterol (N* = 100)	
<4 mmol/l	43 (43.0)
≥4 mmol/l	57 (57.0)
Triglycerides (N* = 67)	
<4.5 mmol/l	64 (95.5)
4.5–9.9	3 (4.5)
QRISK2 (N* = 72)	
<10%	17 (23.6)
10 to <20%	25 (34.7)
≥20%	30 (41.7)
Microalbuminuria (N* = 93)	
Yes (>2.5 mg/mmol [Men], >3.5mg/mmol [Women])	30 (32.3)
No (≤ 2.5mg/mmol [Men], ≤3.5 mg/mmol [Women])	63 (67.7)

*minus missing data.

sometimes' they ate 'too many sweets', and 34% consumed 'too much fizzy drink', while 88% (*n* = 123) said they 'rarely or never' consumed too much alcohol (defined by recommended weekly units described in accessible terms). A total of 31 participants (21%) reported that they smoked. Approximately 40% of all participants reported mobility problems. Of the 126 people who said they exercised, 39 participants (31%) reported that they did not do enough exercise and 48 (38%) found doing exercise 'hard'. In terms of exercise frequency, 38 participants (26%) reported engaging in some level of physical activity every day, 64 (44%) every week, and 19 (12%) some weeks, while 21 (14%) reported doing no activity at all. The most common exercise was walking (*n* =117, 93%), 23 participants went to exercise classes or the gym (18%), 10 (8%) went swimming and eight (6%) went cycling. Exercise intensity was not assessed.

Living arrangements and presence of a supporter

Only 42 participants (29%) lived alone. Most (*n* = 103, 71%) lived with others, typically in a shared house with staff present or on call for 24 hours (*n* = 61, 41%) or with immediate family or their partner. Most participants (*n* = 130, 88%) reported having a supporter, although levels and consistency of support were highly variable.

HbA_{1c} and BMI: exploratory subgroup analyses

In the present study, there was a significant difference in BMI, but not HbA_{1c} concentration, according to whether participants reported they 'felt miserable/sad' or not [mean (SD) 34.4 (7.9) vs 30.4 (7.4) kg/m^2, t(99) = 2.53; P <0.05], were happy with their diet or not [mean (SD) 30.4 (7.2) vs 36.6 (7.1) kg/m^2, t(94) = 4.02; P<0.001]; or were happy with their weight or not [mean (SD) 29.5 (6.7) vs 34.8 (7.8) kg/m^2, t(96) = 3.54; P <0.001]. HbA_{1c} was numerically but not statistically lower in those who named a supporter involved with their diabetes management when compared with those who did not, whereas BMI was similar in each group.

Discussion

The aim of the present study was to characterize a sample of adults with mild to moderate intellectual disability and Type 2 diabetes in terms of diabetes control, health, and access to diabetes management services and support.

Table 4 Mean HbA_{1c} and BMI by intellectual disability register membership: NHS Clinical Commissioning Group data for Bradford, Leeds and Wakefield (2015)

	On intellectual disability register (Total *N*=448)		Not on intellectual disability register (Total *N*=74,771)	
Population	Not on insulin (*n*=348, 78%)	On insulin (*n*=100, 22%)	Not on insulin (*n*=53,560, 72%)	On insulin (*n*=20,211, 28%))
Mean HbA_{1c}, mmol/mol (%)	55 (7.2)	60 (7.6)	55 (7.1)	67 (8.3)
Mean BMI, kg/m^2	32.0	32.4	30.7	31.6

Table 5 Diabetes-related medication (general practitioner medical records only)

	n (%)
Participant takes medication for their diabetes (**N = 68***)	
Yes	47 (69.1)
No	21 (30.9)
If yes, which medications (not mutually exclusive; *N*=47)	
Biguanide (metformin)	41 (87.2)
Sulfonylureas	22 (46.8)
Gliptin (DPP-4 inhibitors)	6 (12.8)
Thiazolidinedione (glitazone)	5 (10.6)
SGLT-2 inhibitors	2 (4.3)
Metformin combinations (metformin and sitagliptin)	1 (2.1)
Statins	2 (4.3)
Antihypertensive agent	3 (6.4)
Other	1 (2.1)
Mono- or polytherapy (*N*=47)	
Polytherapy	22 (46.8)
Monotherapy	25 (53.2)

*Difference between levels of self-reported and general practitioner (GP)-reported medication is attributable to a high volume of missing data, because detailed medication questions were added to GP data collection form part-way through the study, because of non-return of GP data collection forms and because of incomplete data on returned forms.

Table 6 Self-reported co-morbidities

"Other than diabetes, is there anything else that makes you poorly?"	**Eligible population N=147**
Yes	114 (79.2%)
No	25 (17.4%)
Don't know	5 (3.5%)
Missing	3
If yes what?	**Not mutually exclusive n=114**
Mental health problems/depression	56 (49.1%)
Cardiovascular illness	46 (40.4%)
High cholesterol	18 (15.8%)
Musculoskeletal problem	17 (14.9%)
Epilepsy	17 (14.9%)
Asthma	17 (14.9%)
Partially sighted	8 (7.0%)
Chronic Obstructive Pulmonary Disease	4 (3.5%)
Stroke	3 (2.6%)
Hypothyroidism	7 (6.1%)
Chronic kidney disease	1 (0.9%)
Other	36 (31.6%)

We found that glycaemic management in this non-insulin-using population with Type 2 diabetes was broadly effective and similar to that of the general population with Type 2 diabetes; however, around one-fifth of respondents for whom we had clinical data had HbA_{1c} levels higher than the recommended levels. Self-reported diabetes medication adherence was problematic for at least a third of participants, suggesting that some may need additional help with taking medication. Most participants reported being able to access diabetes care in general practice and, in this study, HbA_{1c} levels were not related to whether or not a supporter could be named. As the majority of participants were identified through general practice, however, these findings may not reflect the experience of those not on GP-held registers [22]. Control of vascular risk factors in this population was suboptimal, particularly in relation to obesity and blood pressure. While the significant amount of missing GP data has to be taken into consideration here, sub-optimal monitoring of this population has been identified elsewhere [7].

As in previous research, the majority of participants in the present study were overweight or obese, and many ate a diet relatively high in fat and sugar [7,23]. High levels of sedentary behaviour were also identified, consistent with existing research [24]. Although data on hypoglycaemic therapies were incomplete, around half of participants were on sulfonylurea therapy, which may not be the best treatment, given the potential for weight gain and hypoglycaemia risk [25]. Self-reported levels of comorbidity were high, as described elsewhere [7], with self-reported mental health problems being particularly prevalent. This is of concern because depression has been found to have a negative impact on diabetes management and to be associated with higher levels of diabetes complications, including foot ulceration [26,27]. We found an association between elevated BMI (but not HbA_{1c}) and low mood and dissatisfaction with weight and diet, which has not been identified in this population previously. These findings warrant further investigation given the relationship between low mood and poor self-management of Type 2 diabetes [28].

Around a quarter of our participants had scope for better diabetes control, and further studies are needed to clarify whether a different treatment strategy is needed in this subpopulation. Barriers to better blood pressure control should be explored, but the main need is for help with diet and weight management that takes into account high rates of mental health difficulties [29]. Recent NICE guidelines recommend including a mental health review in the annual health check for people with intellectual disability [30].

Knowledge about the need for foot, eye and dental health is generally low in this population. During every diabetic review, time should be taken to explain self-care, and the reasons why it is important, because recall as well as understanding can be significantly lower in those with intellectual disability. Accessible information for these checks can be found online.

The involvement of adults with intellectual disability in research starts with case ascertainment. The time and associated resources required to make contact with potential participants often via a number of different gatekeepers was substantial, and should not be underestimated in future work. Current approaches do not make it easy to identify those with milder intellectual disability who are not on intellectual disability registers. Research into new ways to record details of intellectual disability on GP registers is needed to evaluate efforts to improve inclusion.

A limitation of the present study is that sampling bias might have arisen because of high non-response rates for clinical data, although the data on local HbA_{1c} levels and BMI suggest our sample is typical. This also meant that further analyses of, for example, HbA_{1c} and BMI with diabetes complications, other comorbidities or medication regimes, were not appropriate. The exclusion of people using insulin was required by the study funders, and is likely to have excluded individuals with poorest health and diabetes control (Table 4). Future research would benefit from obtaining direct researcher access to medical records to minimize missing data. Nevertheless, the study still provides the most comprehensive available profile of adults in the UK with mild to moderate intellectual disability and Type 2 diabetes. One reason for the relative success of our recruitment was the development of a search strategy that was simple to implement in general practice using techniques familiar to practitioners. A second reason was strong engagement with local third-sector organizations.

In conclusion, weight management with a focus on both physical exercise and diet is essential to improving the health of adults with intellectual disability and Type 2 diabetes; only 7% of our sample reported having contact with a dietician, suggesting that support with diet is very limited. Strategies that take into account both social circumstance and intellectual capacity are required; for example, excess weight is more tangible than ‘blood sugar’, an important consideration in a population that works best with concrete concepts. It is encouraging that so many of our participants said that they wanted help with diabetes management; however specialized services are very limited. The urgent clinical need is therefore to provide reasonable adjustments to existing weight management and diabetes services that are more closely linked to routine health checks [3].

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Competing interests

None declared.

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Supporting Information

Additional Supporting Information may be found in the online version of this article:

Figure S1 Overview of interview schedule.
Figure S2 Overview of research project.