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THE PREVALENCE OF PHYSICAL CONDITIONS AND MULTI-MORBIDITY IN A COHORT OF ADULTS WITH INTELLECTUAL DISABILITIES, WITH AND WITHOUT DOWN SYNDROME. CROSS-SECTIONAL STUDY

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Abstract

Objectives: To investigate the prevalence of multi-morbidity in adults with intellectual disabilities with and without Down syndrome.
Design: Large, population-based cross-sectional study.
Setting: The geographical area of one Health Board, Scotland.
Participants: All adults (aged 16+ years) known to general practitioners to have intellectual disabilities, and adults receiving services provided by intellectual disabilities health or social work services. 1,023/1,562 potential participants took part (65.5%); 562 (54.9%) men and 461 (45.1%) women, aged 43.9 years (16-83 years). 186 had Down syndrome and 837 did not.
Main outcome measures: The prevalence of ICD-10 physical health conditions and multi-morbidity detected at a comprehensive health assessment.
Results: The mean number of physical health conditions/participant was 11.04, and 98.7% had multi-morbidity. The most prevalent conditions are not only painful and/or disabling but in some cases life threatening. The five most prevalent were visual impairment, epilepsy, constipation, ataxic/gait disorders, and hearing impairment. The pattern of multi-morbidity differs to that seen in the general population and is spread across the entire adult lifecourse. The extent of multi-morbidity in the adults with Down syndrome was similar to that of the adults without Down syndrome, whilst the prevalence of individual conditions differed.
Conclusions: This robustly-designed study with a large population found an extremely high prevalence of multi-morbidity in adults with intellectual disabilities across the entire adult lifecourse. This increases complexity of medical management that secondary health care services and medical education are not yet geared towards, as these tend to focus on single conditions. This is in addition to complexity due to limitations in communication and understanding. As the physical conditions within their multi-morbidity also differ from that

seen in the older general population, urgent attention is needed to develop the care pathways and guidelines that are required to inform and so improve their health care.

Key words: intellectual disabilities, Down syndrome, multi-morbidity, comorbidity, physical health, health inequalities

Strengths and limitations of this study

- This is the first study to have reported on multi-morbidity in people with intellectual disabilities across the adult lifecourse, where each individual had their health assessed by trained professionals.
- The health assessments were systematic and detailed.
- The study is population-based, large, and the participation rate was high.
- A limitation is that the study was only conducted in one area of Scotland.

Introduction

People with intellectual disabilities have different health needs, shorter life expectancy, and other health inequalities compared to the general population[1-4]. Despite this, there is surprisingly little reported on their prevalence of physical ill-health and multi-morbidity (two or more conditions in addition to intellectual disabilities), and few studies have been population-based and conducted on a large scale. Multi-morbidity is important as its management is more complex than that of single conditions, with risks of drug-drug interactions, drug-disease interactions, and disease-disease interactions. However, health care systems, and care pathways, are focused on management of single conditions. In the general population, awareness has recently been raised on the importance of multi-morbidity, which becomes increasingly prevalent over the age of 50 years[5]. Only three studies were identified that investigated multi-morbidity amongst adults with intellectual disabilities. All three reported high rates of multi-morbidity; 71% in 695 older persons with intellectual disabilities[6] 80 % in 1,047 older persons receiving paid support[7] and 68.2% in 8,014 adults with intellectual disabilities[8]. However, these studies are limited as two included only older adults[6,7]; one relied on self/proxy-reporting of health conditions[6] and the only study of multi-morbidity across the adult lifecourse reported data extracted electronically from primary care case records, therefore only conditions that had previously been presented to the doctor[8]. None conducted individual health assessments, and all three reported on only pre-selected conditions, not on any type of physical health problem.

There is also a lack of consistency in reports on the prevalence of single physical health conditions in people with intellectual disabilities, due to the differences in methods used and populations studied. Reported prevalence rates for vision problems, for example, range from 18% to 99%[9-11]; gastro-oesophageal reflux disease ranges from 33% to 50%[2,13-15]; untreated dental caries range from 18% to 84% [16-18] and obesity ranges from 21 to 35% [19-22]. Thus, findings are conflicting. Conceivably, prevalence of physical health conditions may vary by country, due to differences in lifestyle, and availability, affordability, and organisation of health care. There is a lack of studies carried out in the United Kingdom (UK) on the physical health of people with intellectual disabilities[23]. No UK based data were found on the prevalence of musculoskeletal impairments, constipation, or gastro-oesophageal reflux disease among people with intellectual disabilities. A recent systematic review of systematic reviews of the health or health care of people with intellectual disabilities, also found significant gaps in research on physical health conditions[24].

In summary, little is known about the extent of multi-morbidity, and prevalence of physical health problems in adults with intellectual disabilities. This paper reports findings from a

large-scale population-based study which was conducted to address this. The aims of this study were to identify in adults with intellectual disabilities with, and without, Down syndrome:

1. the extent of multi-morbidity
2. the prevalence of physical ill-health
3. the top 20 most prevalent physical health conditions, and their associations with age, gender, level of intellectual disabilities and Down syndrome.

Methods

The study was given ethical approval by the NHS Greater Glasgow Primary Care Trust – Community & Mental Health Research Ethics Committee (project number 0144). Individual consent to participate was taken from each person with intellectual disabilities, as far as that person had decision making capacity to consent, with consent given by the nearest relative/welfare guardian when the participant lacked such capacity, in keeping with Scottish law.

Participants

The adult population (aged 16 years and over) of people with intellectual disabilities living within the geographical area of Greater Glasgow Health Board, Scotland, were identified and recruited to a cohort study between 2002-2004. All persons known to general practitioners / family physicians to have intellectual disabilities, persons receiving health, social care, residential, occupational and support services provided by intellectual disabilities health or social work services, or any other support hours or services funded through social work or disability allowances were approached to take part in the study. The general practitioners were financially incentivised to identify their population, and 100% in the area did so. Only participants within the strict study boundary were included. Of the 1,562 potential participants identified, consent was gained for 1,023 adults to take part (65.5%).

Measures and procedure

Six nurses reviewed primary care case records, using a structured format and data collection form. They then completed a comprehensive semi-structured health interview and targeted physical examination, and followed a phlebotomy protocol, with the person with intellectual disabilities and their carer, using the *C21st Health Check* (http://www.gla.ac.uk/media/media_306409_en.pdf). Findings were discussed with one of three general practitioners who specialised in intellectual disabilities, and who coded the physical health conditions using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision[25].The health assessment included measurement of visual acuity and hearing. Blindness or low vision was only recorded if it was not corrected by spectacles/best possible correction; and hearing loss was only recorded if it was not corrected by hearing aids.

The level of intellectual disabilities of each participant, in keeping with the ICD-10 Classification of Mental and Behavioural Disorders - Clinical descriptions and diagnostic guidelines[26], was derived from recorded assessments, or on the basis of the score gained on the health check. A record was made of whether or not each person had Down syndrome.

Analysis

Relevant data from the health check were entered into the Statistical Package for Social Services Version 22[27].The number of individuals, age, gender, level of intellectual

disabilities, and accommodation type were analysed using descriptive statistics. Frequency data were derived to identify the prevalence of multi-morbidity, and physical health conditions across all ICD-10 chapters. Binary logistic regressions were conducted to determine if there were any associations between the dependent variables (each of the twenty most prevalent physical health conditions) and the independent variables of age group, gender, level of ability, and Down syndrome.

Results

Demographics

The sample comprised 562 men (54.9%) and 461 women (45.1%) with a mean age of 43.9 years (range 16–83). 186 (18.2%) had Down syndrome. Table 1 describes the demographics and characteristics of the study sample.

Insert table 1 about here –

The extent of multi-morbidity experienced by adults with intellectual disabilities

The highest number of physical health conditions experienced by an individual was 28. There was a mean number of 11.04 coexisting conditions per participant (*SD* = 4.7) (figure 1). 99.2% of participants (n = 1,015) had at least one condition and 98.7% (n = 1, 010) had two or more conditions (figure 1). Only 8 participants (4 males, 4 females) had no physical health conditions. Multi-morbidity was highly prevalent across the whole of the adult lifecourse (figure 2). Figure 2 displays the mean number of physical health conditions by gender, age and level of intellectual disabilities. For women, the mean number of physical health conditions was higher for individuals with severe (*M* = 12.02, *SD* = 3.91) and profound intellectual disabilities (*M* = 12.55, *SD* = 4.35) than for individuals with mild (*M* = 11.64, *SD* = 5.27) and moderate intellectual disabilities (*M* = 11.46, *SD* = 4.97). For men, the mean number of physical health conditions were higher for individuals with mild (*M* = 10.45, *SD* = 4.52) and profound intellectual disabilities (*M* = 11.69, *SD* = 4.64) than for individuals with moderate (*M* = 9.97, *SD* = 4.54) and severe intellectual disabilities (*M* = 9.65, *SD* = 4.07).

-Insert figures 1 and 2 about here –

The extent of multi-morbidity was similar for the adults with, and without, Down syndrome (figure 3).

-Insert figure 3 about here -

The prevalence of physical ill-health by ICD-10 Chapter

Figure 4 reports the prevalence rates of physical ill-health by ICD-10 chapter. Participants were only counted once if they had more than one condition within each chapter. The most prevalent conditions reported were from the ICD-10 chapters on symptoms & signs (n = 772), diseases of the skin and subcutaneous tissue (n = 625), diseases of the digestive system (n = 573), endocrine, nutritional and metabolic diseases (n = 526), diseases of the nervous system (n = 494), diseases of the musculoskeletal system and connective tissue (n = 493) and diseases of the eye and adnexa (n = 481). ICD-10 codes within the symptoms and signs chapter include physical health conditions such as ataxic gait and dysphagia.

-Insert figure 4 about here-

Top 20 most prevalent physical health conditions

Physical health conditions in order of prevalence were: visual impairment, epilepsy, constipation, ataxic/gait disorders, hearing impairment, nail disorder, epidermal thickening/xerosis, cerebral palsy and other paralytic syndromes, osteoporosis, fungal infection, hypertension, bone deformity, obesity, musculoskeletal pain/dorsalgia, eczema/dermatitis, gastro-oesophageal reflux disorder, dysphagia, lower respiratory tract infection, dyspnoea/wheezing and dental/oral (table 2). For adults with Down syndrome, these conditions were also common, but the most prevalent conditions were visual impairments, hearing impairments, xerosis, nail disorder, and constipation, with the first four of these conditions being more prevalent than in the adults without Down syndrome. Some conditions were much less common than in the adults without Down syndrome – epilepsy, hypertension, ataxia, cerebral palsy, and osteoporosis (table 2). Whilst constipation was prevalent in the adults with Down syndrome, it was less so than for the adults without Down syndrome.

-Insert table 2 about here-

In Table 3, the top 20 most prevalent physical health conditions are stratified by gender, age and level of intellectual disabilities for all the adults, with and without Down syndrome combined, and odds ratios (95% confidence intervals) presented. Women experienced some conditions more frequently than men, notably: constipation, epidermal thickening/xerosis, osteoporosis, dyspnoea/wheezing, and musculoskeletal pain/dorsalgia. For most conditions, there is not an association with age, however, epilepsy and hearing impairment appear to be less prevalent in older age groups, and osteoporosis and hypertension more prevalent in older age groups. Several of the conditions showed a gradient across level of ability, being more prevalent the more severe the intellectual disabilities, including visual impairment, epilepsy, constipation, ataxia, cerebral palsy, osteoporosis, bone deformity, gastro-oesophageal reflux disorder, and dysphagia; whilst for hypertension and dorsalgia the relationship with ability level was reversed.

- Insert table 3 about here –

Discussion

Principal findings and interpretation

It is believed that this is the first study to have reported on multi-morbidity in people with intellectual disabilities across the adult lifecourse, in a large population-based sample where each individual had their health comprehensively assessed. The full range of physical health problems were included rather than a shorter list of pre-selected conditions. An extremely high prevalence of multi-morbidity was reported, at 98.7%. The extent of multi-morbidity was similar for both the adults with, and without, Down syndrome, though, as expected, there were some differences in the pattern of conditions. Multi-morbidity was prevalent across the entire adult lifecourse, unlike the general population in whom it increases over the age of 50[5], hence health care availability is equally essential at all ages. The pattern of multi-morbidity also differs from the general population, hence findings from the general population are not transferrable; multi-morbidity amongst people with intellectual disabilities requires specific study.

With regards to single conditions, constipation was the third most prevalent physical health condition. This has been reported as common in adults with intellectual disabilities in

institutional settings[28], but has received little research attention in population-based cohorts. Evenhuis[29], reported on the occurrence of constipation in 70 individuals over a 10-year period (mean age 70 years, range 60–92) in a Dutch residential care centre and found that 57% suffered from chronic constipation and 56% were permanently taking laxative treatment. Eight people with chronic constipation had serious side effects (rectal prolapse, diverticula of colon, intestinal obstruction, megacolon and haemorrhoids) and four eventually died of intestinal obstruction. Thus, as well as being painful, constipation may remain undetected for a long time and can cause death due to missed clinical symptoms [29,30]. Many factors can contribute to constipation including immobility, cerebral palsy, neurological disease, certain drugs, poor diet and lack of exercise[31, 32]. The high rate reported highlights the importance of this condition. Visual impairment was the most prevalent condition. Previous research has highlighted that sensory impairments are often not picked up by carers' or health professionals, are often misattributed to the individual's intellectual disabilities (diagnostic overshadowing), and that people with intellectual disabilities are often unable to communicate that they have a problem[32]. A high index of suspicion is, therefore, needed with regards to visual impairments, particularly as these can be detected by optometrists even in people with profound intellectual disabilities. Our study adds to UK based data by providing prevalence rates on musculoskeletal impairments, constipation and gastro-oesophageal reflux disease among people with intellectual disabilities, conditions previously unreported in the UK research literature[23]. Constipation, osteoporosis and dorsalgia were more prevalent in women, as seen in the female general population[33, 34]. However, the age-related increase in conditions typically seen in the general population is not apparent in our study in adults with intellectual disabilities. On average, the more severe the person's intellectual disabilities the younger they die[35], and the more severe a person's intellectual disabilities the higher the prevalence of many of the conditions, so older age groups have milder intellectual disabilities. A gradient was found across levels of ability for dorsalgia, with lower levels at more severe intellectual disabilities. This seems extremely unlikely, given the higher rates of cerebral palsy and bone deformities at more severe levels of intellectual disabilities, and suggests that dorsalgia is at risk of under-detection in people with communication problems. High vigilance is therefore needed for this painful condition.

Strengths and limitations

Strengths of the study are the systematic and detailed health assessments by trained health professionals, the comprehensive ascertainment of the population with intellectual disabilities, large sample size, and high participation rate. Although the study was only conducted in one area of Scotland, it is likely that the findings are generalisable to other high income countries.

Implications of the study for clinicians

In the UK, secondary health care is organized around single conditions. This can result in lack of coordination between secondary health care providers, impeding patient safety. Medical education is also focused on assessment and management of single conditions, yet management of multi-morbidity is far more complex. The most prevalent health conditions in adults with intellectual disabilities differ from those seen in the general population, so the recent work to better understand and address multi-morbidity[5] does not transfer readily to the population with intellectual disabilities. This study, therefore, starts to address an urgent need to better understand the pattern of multi-morbidity in adults with intellectual disabilities which is important because it impacts on health care. For example, osteoporosis, which can lead to multiple fractures and non-healing of bones, is treated by bisphosphonates, but people with gastro-oesophageal reflux disorder are unlikely to tolerate them; both these conditions

are in the top 20 list of conditions. People with dysphagia may be unable to take medication in tablet form for a wide range of conditions. Psychotropic drugs are commonly prescribed as mental ill-health has a point prevalence of 40.9%[36] in people with intellectual disabilities but they can make visual impairment, epilepsy, constipation, and ataxia – the top four conditions – worse. It is important to note that the top 20 physical health conditions reported are known to be painful, disabling and/or life threatening; in the main these are also conditions that are amenable to treatment, if high quality care is provided. It is vital that healthcare professionals and carers have increased awareness of the presentation and demographics of commonly occurring conditions in adults with intellectual disabilities so that they can identify and report physical health conditions in a timely manner and thus prevent unnecessary suffering.

NICE guideline 56 on multi-morbidity[37] highlights that groups of conditions where treatment is discordant pose more problems of co-ordination, and that people who are usually cared for by specialist services that tend to focus on particular types of morbidity (such as mental health in intellectual disabilities services) pose particular difficulties in management of care. Improved evidence on the multi-morbidity experienced by adults with intellectual disabilities, throughout all stages of their adulthood, is therefore crucial.

Competing interests
All authors have completed the Unified Competing Interest form (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work."

Details of contributors
DK analysed the data, jointly interpreted it, and wrote the first draft of the manuscript, JM jointly conceived the project, interpreted the data, and contributed to the manuscript, LA jointly conceived the project, interpreted the data, and contributed to the manuscript, AH jointly interpreted the data, and contributed to the manuscript, ES jointly conceived the project, interpreted the data, and contributed to the manuscript, S-AC jointly conceived the project, interpreted the data, and contributed to the manuscript. All authors approved the final version of the manuscript. S-AC is the study guarantor.

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Data sharing
No additional data available.

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Table 1. Demographics and characteristics of participants

Participants	N (1,023)	%
Gender		
Male	562	54.9
Female	461	45.1
Age (years)		
16-24	121	11.8
25-34	156	15.2
35-44	253	24.7
45-54	238	23.3
55-64	169	16.5
65-74	70	6.8
75 and above	16	1.6
Level of intellectual disabilities		
Mild	398	38.9
Moderate	248	24.2
Severe	193	18.9
Profound	184	18.0
Accommodation type		
Lives with family carer	390	38.1
Lives independently	102	10.0
Lives with paid support	467	45.7
Lives in congregate Setting	64	6.3
Deprivation category		
Most affluent	228	22.3
2	92	9.0
3	66	6.5
4	99	9.7
Most deprived	538	52.6
Ethnicity		
White	986	96.4
Non-white	37	3.6
Down Syndrome		
No	837	81.8
Yes	186	18.2

Table 2. Prevalence of physical health conditions for adults with and without Down syndrome across all ICD10 chapters

	Physical health condition	Whole cohort (n=1,023) n	Whole cohort %	Down syndrome (n = 186) n	Without Down syndrome (n = 837) n
1	Visual impairment	481	47	90 (48.4%)	391 (46.7%)
2	Epilepsy	349	34.1	24 (13%)	325 (38.8%)
3	Constipation	346	33.8	45 (24.1%)	301 (36%)
4	Ataxic/gait disorders	306	29.9	30 (16.1%)	276 (33%)
5	Hearing impairment	276	26.9	73 (39.2%)	203 (24.2%)
6	Nail disorder (e.g. ingrowing nail)	238	23.3	50 (26.9%)	188 (22.5%)
7	Epidermal thickening/xerosis	217	21.2	69 (37.1%)	148 (17.7%)
8	Cerebral palsy and other paralytic syndromes	191	18.7	8 (4.3%)	183 (21.9%)
9	Osteoporosis	189	18.5	11 (5.9%)	178 (21.3%)
10	Fungal infection	167	16.3	42 (22.5%)	125 (14.9%)
11	Hypertension	158	15.4	8 (4.3%)	150 (17.9%)
12	Bone deformity	155	15.1	27 (14.5%)	128 (15.3%)
13	Obesity	153	15	25 (13.4%)	128 (15.3%)
14	Musculoskeletal pain/dorsalgia	152	14.9	32 (17.2%)	120 (14.3%)
15	Eczema/Dermatitis	149	14.6	38 (20.4%)	111 (13.3%)
16	Gastro-oesophageal reflux disorder	148	14.5	26 (14%)	122 (14.6%)
17	Dysphagia	147	14.4	24 (12.9%)	123 (14.7%)
18	Lower respiratory tract infection	134	13	34 (18.3%)	100 (11.9%)
19	Dyspnoea/wheezing	131	12.8	27 (14.5%)	104 (12.4%)
20	Dental/oral	130	12.7	28 (15%)	102 (12.2%)

Table 3. Physical health conditions stratified by gender, level of intellectual disabilities, Down syndrome and age, with odds ratios (95% confidence intervals)

Physical health condition	Gender	Level of disability				Down Syndrome	Age						
	REF=Female	Mild	Moderate	Severe	Profound		16to24	25to34	35to44	45to54	55to64	65to74	75+
Vision	0.79 (0.61to1.02)	**REF**	1.12 (0.81to1.55)	**1.81 (1.27to2.57)**	**2.57 (1.79to3.70)**	1.10 (0.79to1.53)	REF	0.83 (0.51to1.35)	1.11 (0.71to1.73)	1.05 (0.67to1.65)	0.88 (0.55to1.42)	0.81 (0.44to1.48)	0.61 (0.20to1.81)
Epilepsy	1.04 (0.79to1.38)	**REF**	**1.58 (1.09to2.3)**	**1.79 (1.21to2.65)**	**4.51 (3.06to 6.65)**	**0.21 (0.13to0.34)**	**REF**	**1.74 (1.02to2.97)**	**1.68 (1.02to2.75)**	1.23 (0.74to2.02)	1.02 (0.60to1.74)	0.75 (0.37to 1.50)	0.43 (0.11to1.66)
Constipation	**1.50 (1.14to1.97)**	**REF**	1.26 (0.88to1.82)	**1.85 (1.27to2.70)**	**4.28 (2.93to6.24)**	**0.56 (0.38to0.82)**	REF	1.37 (0.81to2.34)	1.18 (0.72to1.94)	1.59 (0.97to2.59)	1.13 (0.67to1.92)	1.03 (0.52to2.01)	1.79 (0.59to5.39)
Ataxic/ Gait disorder	1.23 (0.92to1.64)	**REF**	**2.4 (1.62to3.56)**	**3.77 (2.51to5.67)**	**6.64 (4.41to10.00)**	**0.40 (0.26to0.62)**	REF	1.43 (0.81to2.54)	1.37 (0.80to2.34)	**1.78 (1.05to3.02)**	1.59 (0.90to2.78)	**2.49 (1.26to4.92)**	3.02 (0.98to9.29)
Hearing	0.97 (0.73to1.30)	REF	0.94 (0.65to1.36)	1.08 (0.73to1.61)	0.86 (0.56to1.32)	**2.46 (1.74to3.49)**	**REF**	0.71 (0.39to1.29)	0.91 (0.54to1.54)	1.22 (0.73to2.05)	1.37 (0.80to2.38)	**4.51 (2.37to8.59)**	**4.96 (1.68to14.6)**
Nail Disorder	1.24 (0.92to1.67)	REF	1.01 (0.69to1.48)	1.05 (0.7to1.58)	0.9 (0.58to1.38)	1.24 (0.85to1.80)	**REF**	**1.95 (1.02to3.73)**	1.69 (0.92to3.12)	**2.92 (1.61to5.29)**	1.79 (0.94to3.41)	**2.28 (1.07to4.85)**	3.09 (0.94to10.12)
Epidermal thickening	**1.82 (1.33to2.49)**	REF	**1.49 (1to 2.22)**	1.24 (0.79to1.93)	1.33 (0.85to2.08)	**2.74 (1.91to3.93)**	**REF**	**2.87 (1.40to5.86)**	**2.29 (1.16to4.53)**	**2.94 (1.49to5.79)**	**3.25 (1.60to6.59)**	**2.49 (1.04to5.94)**	1.68 (0.33to8.47)
Cerebral palsy	0.86 (0.61to1.22)	**REF**	**2.38 (1.41to4.04)**	**4.10 (2.44to6.88)**	**9.89 (6.04to16.20)**	**0.15 (0.07to0.32)**	REF	1.62 (0.86to3.06)	1.17 (0.63to2.14)	1.25 (0.68to2.29)	0.84 (0.43to1.63)	0.67 (0.27to1.67)	0.51 (0.10to2.53)
Osteoporosis	**2.34 (1.64to3.32)**	**REF**	**1.67 (1.01to2.82)**	**2.69 (1.61to4.48)**	**9.69 (6.02to15.60)**	**0.22 (0.11to0.43)**	REF	1.59 (0.77to3.26)	**2.11 (1.08to4.14)**	1.55 (0.78to3.08)	**2.40 (1.20to4.84)**	**2.97 (1.30to6.80)**	2.40 (0.62to9.33)
Fungal Infection	0.84 (0.59to1.19)	**REF**	0.67 (0.43to1.03)	0.77 (0.49to1.23)	**0.39 (0.22to0.70)**	**1.67 (1.11to2.53)**	**REF**	**8.90 (3.09to26.20)**	**3.78 (1.30to11.01)**	**8.21 (2.88to23.37)**	**6.40 (2.18to18.77)**	**6.74 (2.09to21.78)**	0 (0to.)
Hypertension	0.94 (0.66to1.35)	**REF**	**0.64 (0.41to0.99)**	**0.41 (0.24to0.69)**	**0.30 (0.16to0.55)**	**0.22 (0.10to0.46)**	**REF**	2.11 (0.78to5.66)	**2.52 (1.01to6.30)**	**4.49 (1.83to11.01)**	**5.32 (2.15to13.18)**	**6.18 (2.31to16.52)**	**19.13 (5.17to70.73)**
Bone deformity	1.33 (0.93to1.88)	**REF**	1.36 (0.84to2.19)	1.22 (0.72to2.06)	**2.91 (1.83to4.61)**	1.04 (0.65to1.65)	**REF**	1.22 (0.6to2.47)	1.01 (0.51to1.97)	1.58 (0.83to3.02)	1.53 (0.77to3.04)	1.40 (0.58to3.36)	**6.42 (2.03to20.31)**
Obesity	0.98 (0.69to1.40)	REF	0.97 (0.61to1.54)	1.23 (0.76to2.00)	1.27 (0.79to2.06)	0.86 (0.54to1.38)	**REF**	**0.48 (0.25to0.92)**	0.79 (0.46to1.37)	**0.45 (0.25to0.82)**	0.83 (0.46to1.50)	0.41 (0.17to1.01)	0.23 (0.03to1.86)
Musculo-skeletal	**1.88 (1.31to2.69)**	**REF**	**0.54 (0.35to0.85)**	**0.45 (0.27to0.75)**	**0.16 (0.07to0.34)**	1.14 (0.73to1.79)	REF	2.35 (0.99to5.57)	2.08 (0.92to4.70)	**3.10 (1.39to6.94)**	**3.22 (1.40to7.41)**	2.56 (0.97to6.73)	1.09 (0.12to9.57)
Eczema	0.95 (0.66to1.35)	REF	0.62 (0.38to1.0)	0.89 (0.55to1.45)	0.92 (0.57to1.50)	**1.70 (1.12to2.59)**	REF	1.04 (0.55to1.97)	0.74 (0.40to1.36)	0.890 (0.49to1.62)	0.71 (0.36to1.38)	0.81 (0.34to1.91)	0.81 (0.17to3.87)
Gastro-oesophageal reflux disorder	1.31 (0.91to1.87)	**REF**	0.85 (0.5to1.45)	1.40 (0.84to2.35)	**3.36 (2.13to5.29)**	0.95 (0.59to1.53)	REF	1.05 (0.49to2.22)	1.63 (0.84to3.18)	1.80 (0.92to3.49)	1.22 (0.58to2.55)	1.21 (0.47to3.12)	1.19 (0.24to6.01)

Dysphagia	**1.46 (1.00to2.11)**	**REF**	**2.36 (1.30to4.26)**	**3.62 (2.01to6.53)**	**10.60 (6.19to18.17)**	0.96 (0.58to1.59)	REF	1.24 (0.61to2.50)	1.17 (0.60to2.27)	1.04 (0.53to2.03)	1.39 (0.69to2.8)	1.11 (0.43to 2.85)	0.41 (0.05to3.50)
Lower respiratory tract infection	0.9 (0.62to1.31)	**REF**	0.78 (0.46to1.32)	0.75 (0.42to1.34)	**2.49 (1.57to3.96)**	**1.87 (1.20to2.92)**	REF	0.68 (0.35to1.32)	0.64 (0.35to1.17)	0.63 (0.34to1.17)	0.63 (0.32to1.23)	0.66 (0.26to1.66)	1.36 (0.35to5.35)
Dyspnoea	**2.07 (1.42to3.03)**	**REF**	0.95 (0.59to1.52)	1.03 (0.63to1.69)	**0.38 (0.19to0.75)**	1.12 (0.70to1.8)	REF	1.25 (0.54to2.88)	1.29 (0.60to2.77)	**2.43 (1.16to5.06)**	1.30 (0.57to2.94)	2.24 (0.91to5.51)	2.60 (0.61to10.96)
Dental Health	0.90 (0.62to1.31)	REF	0.89 (0.55to1.44)	1.18 (0.72to1.92)	0.66 (0.37to1.18)	1.28 (0.80to2.03)	REF	1.90 (0.92to3.95)	0.97 (0.47to2.01)	1.51 (0.75to3.04)	1.21 (0.56to2.58)	1.67 (0.69to4.05)	0 (0to.)

Numbers in bold are significant results

Figure 1. Total number of ICD-10 physical health conditions

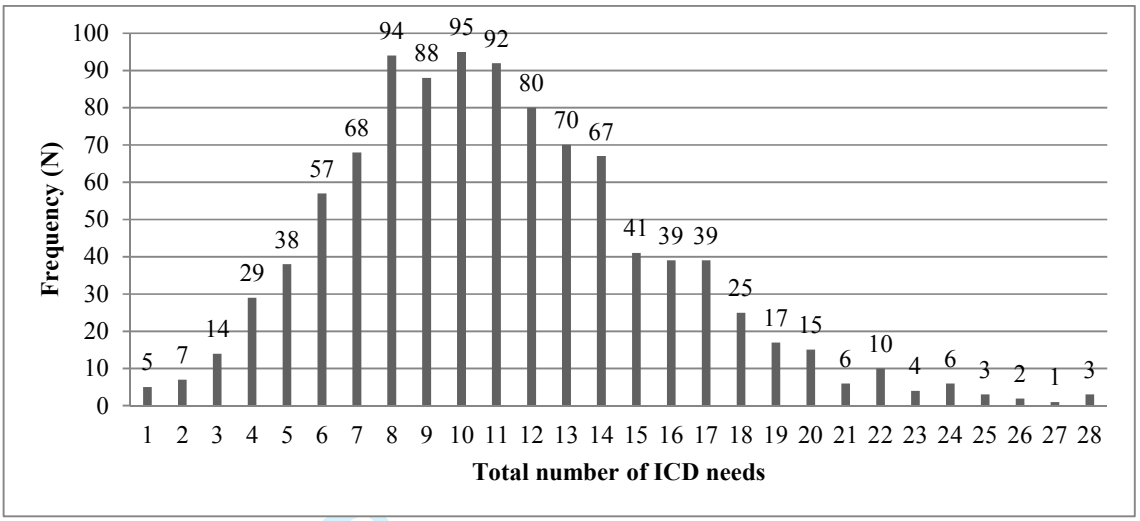


Figure 2. Mean number of physical health conditions by gender, age group and level of disabilities

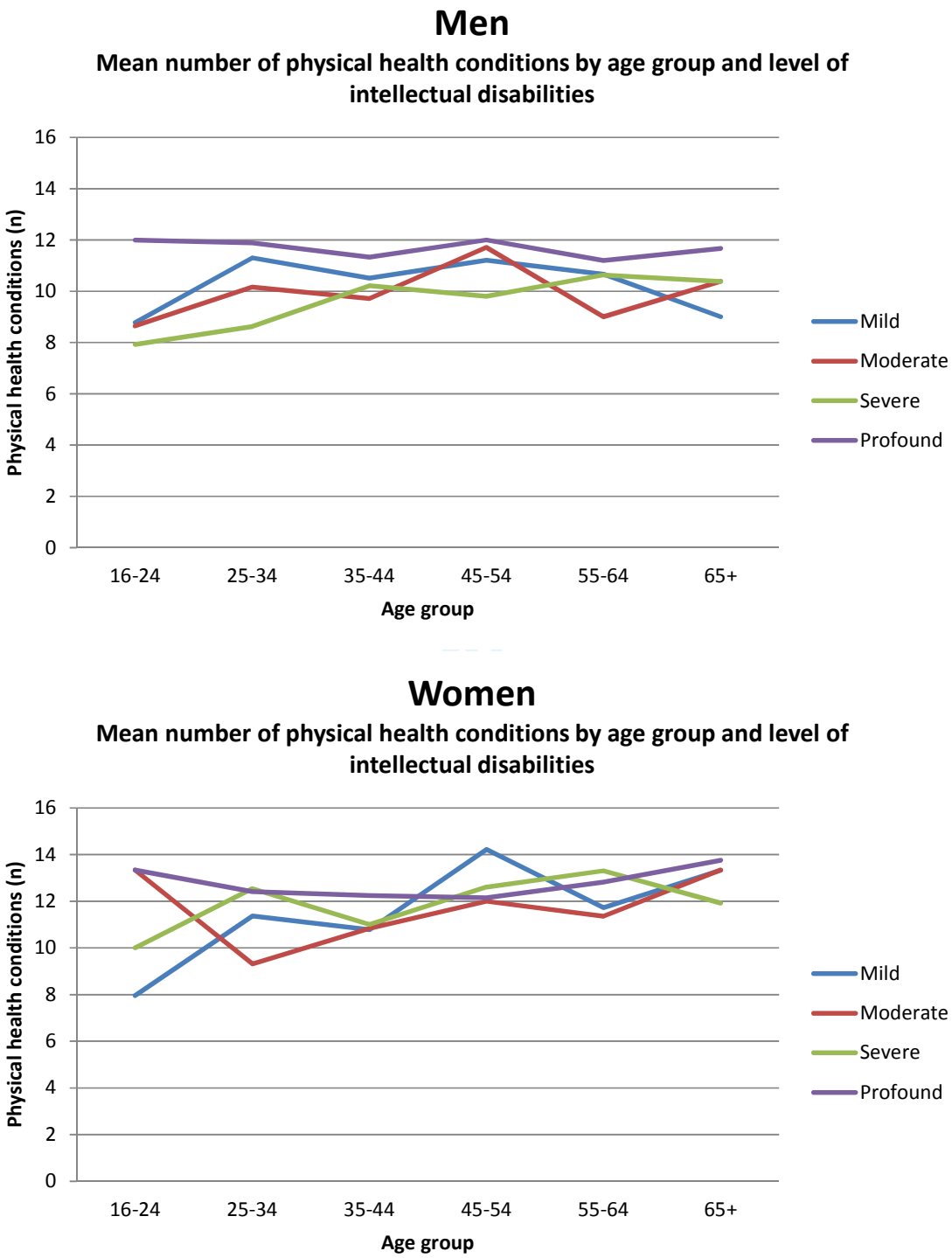


Figure 3. Extent of multi-morbidity in individuals with intellectual disabilities with and without Down Syndrome

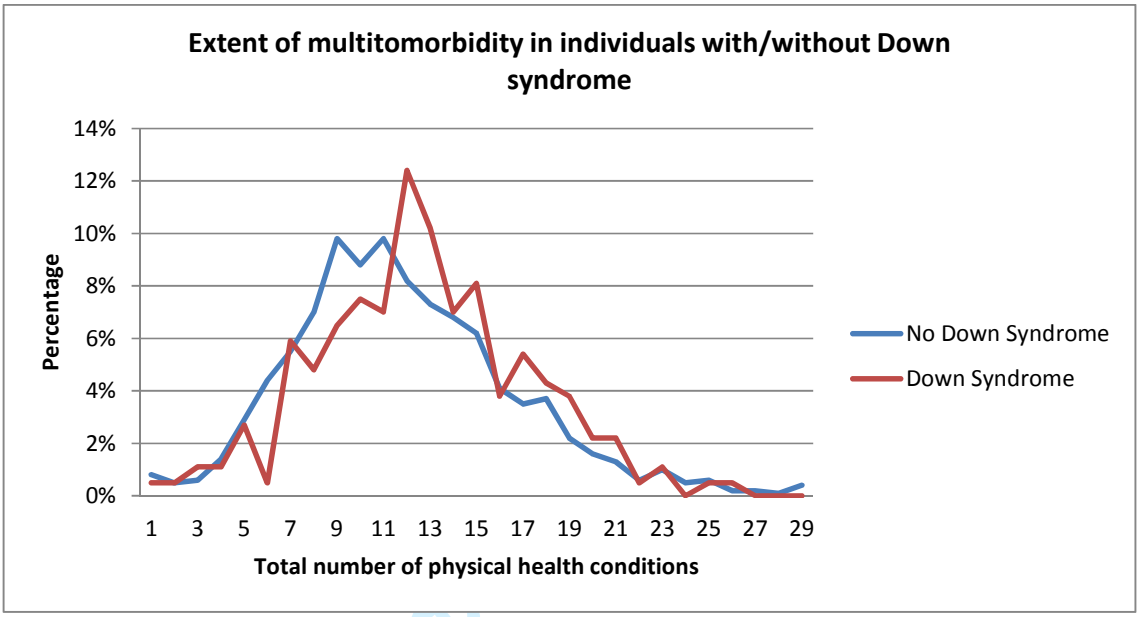
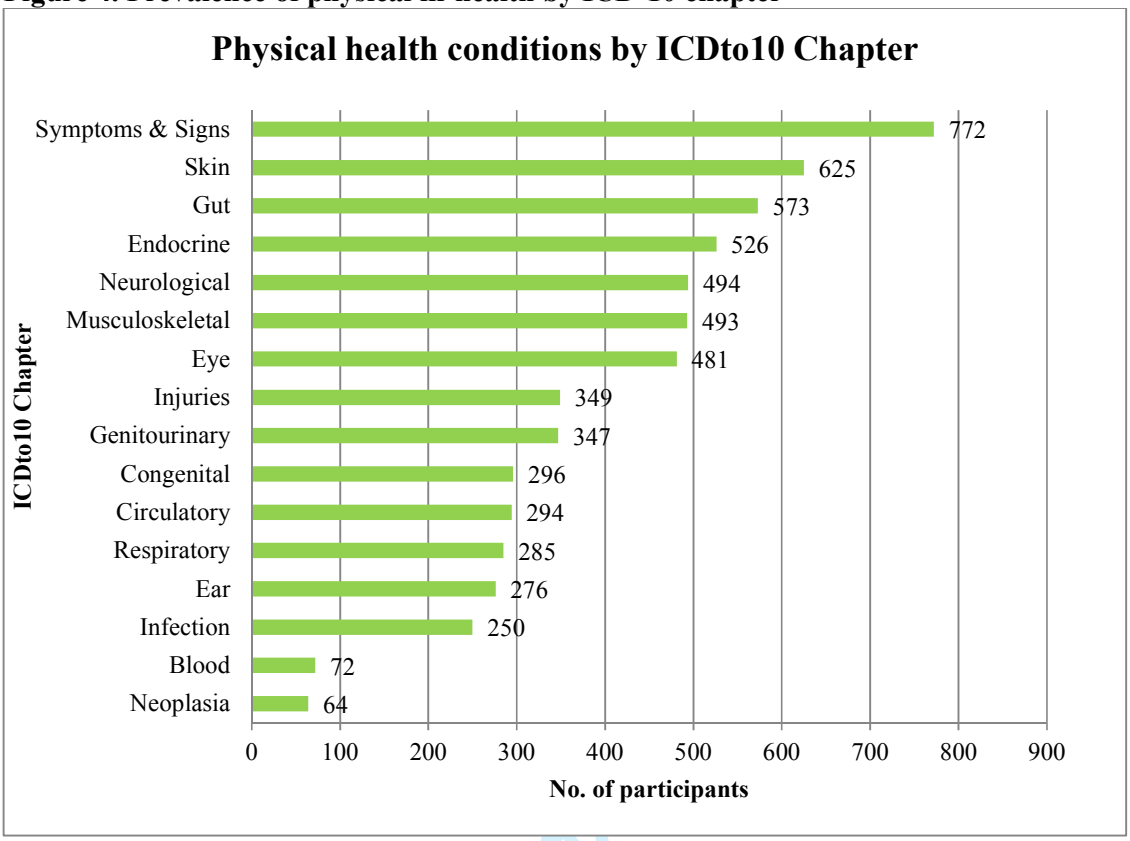


Figure 4. Prevalence of physical ill-health by ICD-10 chapter



STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	Page
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2
Objectives	3	State specific objectives, including any prespecified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	3
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	3
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	3
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	3
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	3
Bias	9	Describe any efforts to address potential sources of bias	3
Study size	10	Explain how the study size was arrived at	3
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	4
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	4
		(*b*) Describe any methods used to examine subgroups and interactions	4
		(*c*) Explain how missing data were addressed	N/A: none
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	N/A
		(*e*) Describe any sensitivity analyses	N/A
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	3
		(b) Give reasons for non-participation at each stage	3
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	11
		(b) Indicate number of participants with missing data for each variable of interest	3

Outcome data	15*	Report numbers of outcome events or summary measures	4-5, 12-18
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	12-18
		(*b*) Report category boundaries when continuous variables were categorized	13-14
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	N/A
Discussion			
Key results	18	Summarise key results with reference to study objectives	5-6
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	6
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	6-7
Generalisability	21	Discuss the generalisability (external validity) of the study results	6
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	7-8

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.

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THE PREVALENCE OF PHYSICAL CONDITIONS AND MULTI-MORBIDITY IN A COHORT OF ADULTS WITH INTELLECTUAL DISABILITIES, WITH AND WITHOUT DOWN SYNDROME. CROSS-SECTIONAL STUDY

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THE PREVALENCE OF PHYSICAL CONDITIONS AND MULTI-MORBIDITY IN A COHORT OF ADULTS WITH INTELLECTUAL DISABILITIES, WITH AND WITHOUT DOWN SYNDROME. CROSS-SECTIONAL STUDY

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Word count: 3,201

Abstract

Objectives: To investigate the prevalence of multi-morbidity in adults with intellectual disabilities with and without Down syndrome.

Design: Large, population-based cross-sectional study.

Setting: The geographical area of one Health Board, Scotland.

Participants: All adults (aged 16+ years) known to general practitioners to have intellectual disabilities, and adults receiving services provided or paid by intellectual disabilities health or social work services. 1,023/1,562 potential participants took part (65.5%); 562 (54.9%) men and 461 (45.1%) women, aged 43.9 years (16-83 years). 186 had Down syndrome and 837 did not.

Main outcome measures: The prevalence of ICD-10 physical health conditions and multi-morbidity detected at a comprehensive health assessment.

Results: The mean number of physical health conditions/participant was 11.04, and 98.7% had multi-morbidity. The most prevalent conditions are not only painful and/or disabling but in some cases life threatening. The five most prevalent were visual impairment, epilepsy, constipation, ataxic/gait disorders, and hearing impairment. The pattern of multi-morbidity differs to that seen in the general population and is spread across the entire adult lifecourse. The extent of multi-morbidity in the adults with Down syndrome was similar to that of the adults without Down syndrome, whilst the prevalence of individual conditions differed.

Conclusions: This robustly-designed study with a large population found an extremely high prevalence of multi-morbidity in adults with intellectual disabilities across the entire adult lifecourse. This increases complexity of medical management that secondary health care services and medical education are not yet geared towards, as these tend to focus on single conditions. This is in addition to complexity due to limitations in communication and understanding. As the physical conditions within their multi-morbidity also differ from that seen in the older general population, urgent attention is needed to develop the care pathways and guidelines that are required to inform and so improve their health care.

Key words: intellectual disabilities, Down syndrome, multi-morbidity, comorbidity, physical health, health inequalities

Strengths and limitations of this study

- This is the first study to have reported on multi-morbidity in people with intellectual disabilities across the adult lifecourse, where each individual had their health assessed by trained professionals.
- The health assessments were systematic and detailed.
- The study is population-based, large, and the participation rate was high.
- A limitation is that the study was only conducted in one area of Scotland.

Introduction

People with intellectual disabilities have different health needs, shorter life expectancy, and other health inequalities compared to the general population[1-4]. Despite this, there is surprisingly little reported on their prevalence of physical ill-health and multi-morbidity (two or more conditions in addition to intellectual disabilities) and few studies have been population-based and conducted on a large scale. Multi-morbidity is important as its management is more complex than that of single conditions, with risks of drug-drug interactions, drug-disease interactions, and disease-disease interactions. However, health care systems, and care pathways, are focused on management of single conditions. In the general population, awareness has recently been raised on the importance of multi-morbidity, which becomes increasingly prevalent over the age of 50 years[5].

Only five studies were identified that investigated multi-morbidity amongst adults with intellectual disabilities. Three studies reported high rates of multi-morbidity; 71% in 695 older persons with intellectual disabilities[6], 80 % in 1,047 older persons receiving paid support[7] and 40.6% in 8,014 adults with intellectual disabilities[8]. However, these studies are limited as two included only older adults[6,7], one of which relied on self/proxy-reporting of known health conditions out of a list of 12[6], the other included 20 conditions[7], and the third which was across the adult lifecourse reported data extracted electronically from primary care case records on 38 conditions, therefore only included conditions that had previously been presented to the GP[8]. Two further studies reported lower rates of multi-morbidity (though still higher than in the general population): 22.9% in 14,751 adults with intellectual disabilities aged 18-84 years (versus 13.3% of other people)[9]. and 10% in 299 adults with proxy measures of mild intellectual disabilities, aged 16-49 years (versus 5% of other people)[10]. The former of these included just 19 long-term conditions (selected on the basis of the UK GP

contract, i.e. evidenced to be of importance for the general population), and relied on extraction of information on the 19 conditions that had previously been presented to the GP. The latter reported whether people were known to have any of only 15 health conditions, and focused only on adults with mild intellectual disabilities, who are therefore less dissimilar from the general population than are people with more severe intellectual disabilities[10]. These sampling and methodological differences account for the lower reported rates of multi-morbidity in these two studies than in the other three. Only one of these five studies conducted individual health assessments (and only for some of the conditions included in the study)[7], and all five reported on only a limited number of pre-selected conditions.

There is lack of consistency in reports on the prevalence of single physical health conditions in people with intellectual disabilities, due to the differences in methods used and populations studied. Reported prevalence rates for vision problems, for example, range from 18% to 99%[11-14], gastro-oesophageal reflux disease ranges from 33% to 50%[2,15-17] untreated dental caries range from 18% to 84%[18-20] and obesity ranges from 21% to 35% [21-24]. Thus, findings are conflicting. Conceivably, prevalence of physical health conditions may vary by country, due to differences in lifestyle, availability, affordability, and organisation of health care. There is a lack of studies carried out in the United Kingdom (UK) on the physical health of people with intellectual disabilities[25]. No UK based data were found on the prevalence of musculoskeletal impairments, constipation, or gastro-oesophageal reflux disease among people with intellectual disabilities. A recent systematic review of systematic reviews of the health or health care of people with intellectual disabilities, also found significant gaps in research on physical health conditions[26].

In summary, little is known about the extent of multi-morbidity, and prevalence of physical health problems in adults with intellectual disabilities. This paper reports findings from a large-scale population-based study which was conducted to address this. The aims of this study were to identify in adults with intellectual disabilities with, and without, Down syndrome:

1. the extent of multi-morbidity
2. the prevalence of physical ill-health
3. the top 20 most prevalent physical health conditions, and their associations with age, gender, level of intellectual disabilities, and Down syndrome.

Methods

The study was given ethical approval by the NHS Greater Glasgow Primary Care Trust – Community & Mental Health Research Ethics Committee (project number 0144). Individual consent to participate was taken from each person with intellectual disabilities, as far as that person had decision making capacity to consent, with consent given by the nearest relative/welfare guardian when the participant lacked such capacity, in keeping with Scottish law. Additionally, for individuals who did not have decision-making capacity to consent, the study was explained to them in keeping with their communicative abilities, and their views sought and respected.

Participants

The adult population (aged 16 years and over) of people with intellectual disabilities living within the geographical area of Greater Glasgow Health Board, Scotland, were identified and recruited to a cohort study between 2002-2004. All persons known to general practitioners (GPs) to have intellectual disabilities, persons receiving health, social care, residential, occupational and support services provided by intellectual disabilities health or social work services, or any other support hours or services funded through social work or disability allowances were approached to take part in the study[27]. The general practitioners were financially incentivised to identify their population, and 100% in the area did so. The ascertainment rate was similar to the adult rate reported in a recent meta-analysis on prevalence of intellectual disabilities[28]. Only participants within the strict study boundary were included. Of the 1,562 potential participants identified, consent was gained for 1,023 adults to take part (65.5%).

Measures and procedure

Six nurses reviewed primary care case records, using a structured format and data collection form. They then completed a comprehensive semi-structured health interview and targeted physical examination, and followed a phlebotomy protocol, with the person with intellectual disabilities and their carer, using the *C21st Health Check* (http://www.gla.ac.uk/researchinstitutes/healthwellbeing/research/mentalhealth/research/projects/ucedd/). Physical examination included measurement of height and weight, waist circumference, three recordings of blood pressure, pulse rate, pulse rhythm, communication assessment, oral examination, vision, hearing, peak flow, inhailer technique (if used), and feet and nail assessments, followed by urinalysis, a phlebotomy protocol, and referral protocol. Most of the physical examination was protocolled, e.g: vision was assessed by first asking a series of nine questions to help detect any possible problems (e.g. for persons unable to self-report, carers were asked whether the person screws up his/her eyes when in bright sunlight), then measuring vision using Kay's pictures at 33 cm and 3 m, and referring persons with possible visual impairment to the University Visual Sciences Department for more detailed, specialist assessment; hearing, likewise, was assessed through a series of questions, then otoscopy, and if the tympanic membrane could be visualized, examination using Warblers at 1/2 m at the level of 30 db/500 Hz, 30 db/1,000 Hz, 30 db/2,000 Hz, and 30 db/4,000 Hz, with referral for specialist assessment if there was any suggestion of possible hearing impairment. If the tympanic membrane could not be visualized because of impacted cerumen, drops were first used, to clear it. Blindness or low vision was only recorded if it was not corrected by spectacles/best possible correction; and hearing loss was only recorded if it was not corrected by hearing aids. Findings were discussed with one of three general practitioners who specialised in intellectual disabilities, and who classified all the physical health conditions using the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision[29]. The complete assessment process took about 4 hours per participant and conditions were recorded if present at the time of assessment (as opposed to historical conditions).

The level of intellectual disabilities of each participant, in keeping with the ICD-10 Classification of Mental and Behavioural Disorders - Clinical descriptions and diagnostic

guidelines[30], was derived from recorded assessments, or on the basis of the score gained on the health check. A record was made of whether or not each person had Down syndrome.

Definition of multimorbidity

There is no standard definition for multimorbidity. A recent NICE guideline on multimorbidity reflected that whilst multimorbidity is most commonly defined simply as having 2 or more long-term conditions, this type of definition is not necessarily helpful when providing clinical care[31] Hence in the NICE guideline, the term multimorbidity refers to the presence of 2 or more long-term health conditions, which can include: defined physical and mental health conditions such as diabetes or schizophrenia; on-going conditions such as learning disability; symptom complexes such as frailty or chronic pain; sensory impairment such as sight or hearing loss and; alcohol and substance misuse. The guideline coverage is for adults with 2 or more long-term physical health conditions, and/or adults with 1 or more mental health conditions and at least 1 physical health condition. Given that the focus of this study is exclusively on adults with intellectual disabilities, we have used a tighter criteria for multimorbidity of intellectual disabilities plus at least two physical health conditions.

Analysis

Relevant data from the health check were entered into the Statistical Package for Social Services Version 22[32].The number of individuals, age, gender, level of intellectual disabilities, and accommodation type were analysed using descriptive statistics. Social deprivation category was based on quintiles of the Carstairs deprivation score. This ranges from 1 (most affluent) to 5 (least affluent)[33]. Frequency data were derived to identify the prevalence of multi-morbidity, and physical health conditions across all ICD-10 chapters. Twenty binary logistic regressions were conducted to determine if there were any associations between each of the 20 dependent variables (each of the twenty most prevalent physical health conditions) and the independent variables of age group, gender, level of ability, and Down syndrome.

Results

Demographics

The sample comprised 562 men (54.9%) and 461 women (45.1%) with a mean age of 43.9 years (range 16–83). 186 (18.2%) had a diagnosis of Down Syndrome; 91 men (48.9%) and 95 women (51.1%) with a mean age of 41.1 years. Table 1 describes the demographics and characteristics of the study sample.

-Insert table 1 about here –

The extent of multi-morbidity experienced by adults with intellectual disabilities

The highest number of current physical health conditions experienced by an individual was 28. There was a mean number of 11.04 coexisting conditions per participant (*SD* = 4.7) (figure 1). 99.2% of participants (n = 1,015) had at least one condition and 98.7% (n = 1, 010) had two or more conditions (figure 1). Only 8 participants (4 males, 4 females) had no physical health conditions. Multi-morbidity was highly prevalent across the whole of the

adult lifecourse (figure 2). Figure 2 displays the mean number of physical health conditions by gender, age, and level of intellectual disabilities, showing high rates across all groups.

-Insert figures 1 and 2 about here –

The extent of multi-morbidity was similar for the adults with, and without, Down syndrome (figure 3). A gradient across the extent of neighbourhood deprivation was not seen for multi-morbidity (figure 4).

-Insert figures 3 and 4 about here -

The prevalence of physical ill-health by ICD-10 Chapter

Participants were only counted once if they had more than one condition within each ICD-10 chapter (see figure 5). The most prevalent conditions reported were from the ICD-10 chapters on symptoms & signs, n = 772 (75.5%); diseases of the skin and subcutaneous tissue, n = 625 (61.09%); diseases of the digestive system, n = 573 (56%); endocrine, nutritional and metabolic diseases, n = 526 (51.4%); diseases of the nervous system, n = 494 (48.3%); diseases of the musculoskeletal system and connective tissue, n = 493 (48.2%); and diseases of the eye and adnexa, n = 481 (47%). ICD-10 codes within the symptoms and signs chapter include physical health conditions such as ataxic gait and dysphagia.

-Insert figure 5 about here -

Top 20 most prevalent physical health conditions

Physical health conditions in order of prevalence were: visual impairment, epilepsy, constipation, ataxic/gait disorders, hearing impairment, nail disorder, epidermal thickening/xerosis, cerebral palsy and other paralytic syndromes, osteoporosis, fungal infection, hypertension, bone deformity, obesity, musculoskeletal pain/dorsalgia, eczema/dermatitis, gastro-oesophageal reflux disorder, dysphagia, lower respiratory tract infection, dyspnoea/wheezing and dental/oral (table 2). For adults with Down syndrome, these conditions were also common, but the most prevalent conditions were visual impairments, hearing impairments, xerosis, nail disorder, and constipation, with the first four of these conditions being more prevalent than in the adults without Down syndrome. Some conditions were much less common than in the adults without Down syndrome – epilepsy, hypertension, ataxia, cerebral palsy, and osteoporosis (table 2). Whilst constipation was prevalent in the adults with Down syndrome, it was less so than for the adults without Down syndrome. For both the adults with intellectual disabilities and adults with Down syndrome, these patterns differ from the general population in whom the most prevalent physical health conditions have been reported to be, in order, hypertension, painful condition, asthma, coronary heart disease, irritable bowel, dyspepsia and diabetes[8].

-Insert table 2 about here-

Table 3 shows the results of the 20 regressions with the top 20 most prevalent physical health conditions as the dependant variables. It presents the odds ratios for gender, age, level of intellectual disabilities, and presence of Down syndrome in independently predicting each of the 20 conditions. Women experienced some conditions more frequently than men, notably: constipation, epidermal thickening/xerosis, osteoporosis, dyspnoea/wheezing, and musculoskeletal pain/dorsalgia. For most conditions, there is not an association with age, however, epilepsy and hearing impairment appear to be less prevalent in older age groups, and osteoporosis and hypertension more prevalent in older age groups. Several of the conditions showed a gradient across level of ability, being more prevalent the more severe the intellectual disabilities, including visual impairment, epilepsy, constipation, ataxia, cerebral palsy, osteoporosis, bone deformity, gastro-oesophageal reflux disorder, and dysphagia; whilst for hypertension and dorsalgia the relationship with ability level was reversed.

- Insert table 3 about here –

Discussion

Principal findings and interpretation

It is believed that this is the first study to have reported on multi-morbidity in people with intellectual disabilities across the adult lifecourse, in a large population-based sample where each individual had their health comprehensively assessed. A full range of physical health conditions were comprehensively assessed, rather than a shorter list of pre-selected conditions, or only conditions that had already been presented to primary care, or proxy-measures for conditions. An extremely high prevalence of multi-morbidity was reported, at 98.7%. As expected, the percentage was much higher than in previous studies due to this methodology. The extent of multi-morbidity was similar for both the adults with, and without, Down syndrome, though, as expected, there were some differences in the pattern of conditions. The pattern of multi-morbidity also differed from the general population, hence findings from the general population are not transferrable; multi-morbidity amongst people with intellectual disabilities requires specific study[31]. Multi-morbidity was prevalent across the entire adult lifecourse, unlike the general population in whom it increases over the age of 50[5], hence health care availability is equally essential at all ages. Unlike the general population, a gradient across the extent of neighbourhood deprivation was not seen for multi-morbidity, as found in previous studies with adults with intellectual disabilities [8,34], hence focussed services are needed in all neighbourhoods.

With regards to single conditions, visual impairment was the most prevalent condition. Previous research has highlighted that carers' or health professionals are often not aware of sensory impairments[35], these are often misattributed to the individual's intellectual disabilities (diagnostic overshadowing)[35], and that people with intellectual disabilities are often unable to communicate that they have a problem[36]. A high index of suspicion is, therefore, needed with regards to visual impairments, particularly as these can be detected by optometrists even in people with profound intellectual disabilities. Epilepsy was the second most prevalent condition. Epilepsy amongst people with intellectual disabilities has previously been reported as much higher than for the general population, with seizures commonly multiple and resistant to drug treatment[26, 37]. Uncontrolled epilepsy can be

disabling and have serious negative consequences on both quality of life and mortality[2].It is therefore essential for all health care practitioners to be aware of the prevalence and management of a complex and potentially life threatening condition in the intellectual disabilities population. Constipation was the third most prevalent physical health condition. This has been reported as common in adults with intellectual disabilities in institutional settings[38], but has received little research attention in population-based cohorts. Evenhuis[39], reported on the occurrence of constipation in 70 individuals over a 10-year period (mean age 70 years, range 60–92) in a Dutch residential care centre and found that 57% suffered from chronic constipation and 56% were permanently taking laxative treatment. Eight people with chronic constipation had serious side effects (rectal prolapse, diverticula of colon, intestinal obstruction, megacolon and haemorrhoids) and four eventually died of intestinal obstruction. Thus, as well as being painful, constipation may remain undetected for a long time and can cause death due to missed clinical symptoms [39,40]. Many factors can contribute to constipation including immobility, cerebral palsy, neurological disease, certain drugs, poor diet and lack of exercise[36,41,]. The high rate reported highlights the importance of this condition. Our study also adds to UK based data by providing prevalence rates on musculoskeletal impairments, constipation, and gastro-oesophageal reflux disease among people with intellectual disabilities, conditions previously unreported in the UK research literature[25].

Constipation, osteoporosis and dorsalgia were more prevalent in women, as seen in the female general population[41-42]. However, the age-related increase in conditions typically seen in the general population is not apparent in our study in adults with intellectual disabilities. On average, the more severe the person's intellectual disabilities the younger they die[43], and the more severe a person's intellectual disabilities the higher the prevalence of many of the conditions, so older age groups have milder intellectual disabilities. A gradient was found across levels of ability for dorsalgia, with lower levels at more severe intellectual disabilities. This seems extremely unlikely, given the higher rates of cerebral palsy and bone deformities at more severe levels of intellectual disabilities, and suggests that dorsalgia is at risk of under-detection in people with communication problems. High vigilance is therefore needed for this painful condition.

The conditions in table 2 are listed as per the top 20 in the population with intellectual disabilities. It is important to note that this list would be different if it was ordered by the top 20 for the adults with Down syndrome. For example, 24.2% of the participants with Down syndrome had a thyroid disorder, which is more common than several of the other conditions listed in table 2.

We are unclear why the figures appear to show slightly higher rates of multimorbidity in the 45-54 year group for men with moderate intellectual disabilities and women with mild intellectual disabilities, and the apparent high rate for young women with moderate intellectual disabilities.

Strengths and limitations

Strengths of the study are the systematic and detailed health assessments by trained health professionals, the comprehensive ascertainment of the population with intellectual disabilities, large sample size, and high participation rate. Of the 5 adult studies out of 52 studies included in a recent meta-analysis on the prevalence of intellectual disabilities[28]

moderate to profound intellectual disabilities was reported to account for 65-66% of the adults with intellectual disabilities in these studies, compared with 61% in ours, i.e. our rates are similar. Although the study was only conducted in one area of Scotland, it is likely that the findings are generalisable to other high income countries. One drawback of detailed health assessments is that looking for more conditions will result in more conditions being identified. This is both a strength – as conditions are frequently overlooked in this population – but also contributes to the high prevalence of multi-morbidity that was identified. We did not include mental health conditions in this study, as this information has been previously published elsewhere[27]. Previously published intellectual disabilities papers on multi-morbidity varied in terms of whether/the extent to which they included mental health.

Implications of the study for clinicians

In the UK, secondary health care is organized around single conditions. This can result in lack of coordination between secondary health care providers, impeding patient safety. Medical education is also focused on assessment and management of single conditions, yet management of multi-morbidity is far more complex. The most prevalent health conditions in adults with intellectual disabilities differ from those seen in the general population, so the recent work to better understand and address multi-morbidity[5] does not transfer readily to the population with intellectual disabilities. This study, therefore, starts to address an urgent need to better understand the pattern of multi-morbidity in adults with intellectual disabilities which is important because it impacts on health care. For example, osteoporosis, which can lead to multiple fractures and non-healing of bones, is treated by bisphosphonates, but people with gastro-oesophageal reflux disorder are unlikely to tolerate them; both these conditions are in the top 20 list of conditions. People with dysphagia may be unable to take medication in tablet form for a wide range of conditions. Psychotropic drugs are commonly prescribed as mental ill-health has a point prevalence of 40.9%[27] in people with intellectual disabilities but their side effects include visual disturbance, lowered seizure threshold, constipation and ataxia – the top four conditions. It is important to note that the top 20 physical health conditions reported are known to be painful, disabling and/or life threatening and can significantly impact on quality of life; in the main these are also conditions that are amenable to treatment, if high quality care is provided. It is vital that healthcare professionals and carers have increased awareness of the presentation and demographics of commonly occurring conditions in adults with intellectual disabilities so that they can identify and report physical health conditions in a timely manner and thus prevent unnecessary suffering.

NICE guideline 56 on multi-morbidity[31] highlights that groups of conditions where treatment is discordant pose more problems of co-ordination, and that people who are usually cared for by specialist services that tend to focus on particular types of morbidity (such as mental health in intellectual disabilities services) pose particular difficulties in management of care. Improved evidence on the multi-morbidity experienced by adults with intellectual disabilities, throughout all stages of their adulthood, is therefore crucial. The findings have the potential to support policy and practice change to ensure comprehensive continuity of care in the lives of people with intellectual disabilities especially as more and more begin to live to old age.

Improving healthcare provision can only contribute to making the lives of people with intellectual disabilities better.

Competing interests

All authors have completed the Unified Competing Interest form (available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years, no other relationships or activities that could appear to have influenced the submitted work."

Details of contributors

DK analysed the data, jointly interpreted it, and wrote the first draft of the manuscript, JM jointly conceived the project, interpreted the data, and contributed to the manuscript, LA jointly conceived the project, interpreted the data, and contributed to the manuscript, AH jointly interpreted the data, and contributed to the manuscript, ES jointly conceived the project, interpreted the data, and contributed to the manuscript, S-AC jointly conceived the project, interpreted the data, and contributed to the manuscript. All authors approved the final version of the manuscript. S-AC is the study guarantor.

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Data sharing

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Table 1. Demographics and characteristics of participants

Participants	N (1,023) %	Without Down Syndrome N (837) %	With Down syndrome N (186) %
Gender			
Male	562 (54.9%)	471 (56.3%)	91 (48.9%)
Female	461 (45.1%)	366 (43.7%)	95 (51.1%)
Age (years)			
16-24	121 (11.8%)	101 (12.1%)	20 (10.8%)
25-34	156 (15.2%)	128 (15.3%)	28 (15.1%)
35-44	253 (24.7%)	192 (22.9%)	61 (32.8%)
45-54	238 (23.3%)	184 (22%)	54 (29%)
55-64	169 (16.5%)	148 (17.7%)	21 (11.3%)
65 and above	86 (8.4%)	84 (10%)	2 (1.1%)
Level of intellectual disabilities			
Mild	398 (38.9%)	321 (38.4%)	77 (41.4%)
Moderate	248 (24.2%)	198 (23.7%)	50 (26.9%)
Severe	193 (18.9%)	159 (19%)	34 (18.3%)
Profound	184 (18%)	159 (19%)	25 (13.4%)
Accommodation type			
Lives with family carer	390 (38.1%)	289 (34.5%)	101 (54.3%)
Lives independently	102 (10%)	94 (11.2%)	8 (4.3%)
Lives with paid support	467 (45.7%)	404 (48.3%)	63 (33.9%)
Lives in congregate Setting	64 (6.3%)	50 (6%)	14 (7.5%)

Deprivation category			
Most affluent	228 (22.3%)	179 (21.4%)	49 (26.3%)
2	92 (9%)	71 (8.5%)	21 (11.3%)
3	66 (6.5%)	49 (5.9%)	17 (9.1%)
4	99 (9.7%)	84 (10%)	15 (8.1%)
Most deprived	538 (52.6%)	454 (54.2%)	84 (45.2%)
White	986 (96.4%)	803 (95.9%)	183 (98.4%)
Non-white	37 (3.6%)	34 (4.1%)	3 (1.6%)
Mean number of physical health conditions	11.04 (100%)	10.89 (100%)	11.68 (100%)

Table 2. Prevalence of physical health conditions for adults with and without Down syndrome across all ICD10 chapters

	Physical health condition	Whole cohort (n=1,023) n	Whole cohort %	Down syndrome (n = 186) n	Without Down syndrome (n = 837) n
1	Visual impairment	481	47	90 (48.4%)	391 (46.7%)
2	Epilepsy	349	34.1	24 (13%)	325 (38.8%)
3	Constipation	346	33.8	45 (24.1%)	301 (36%)
4	Ataxic/gait disorders	306	29.9	30 (16.1%)	276 (33%)
5	Hearing impairment	276	26.9	73 (39.2%)	203 (24.2%)
6	Nail disorder (e.g. ingrowing nail)	238	23.3	50 (26.9%)	188 (22.5%)
7	Epidermal thickening/xerosis	217	21.2	69 (37.1%)	148 (17.7%)
8	Cerebral palsy and other paralytic syndromes	191	18.7	8 (4.3%)	183 (21.9%)
9	Osteoporosis	189	18.5	11 (5.9%)	178 (21.3%)
10	Fungal infection	167	16.3	42 (22.5%)	125 (14.9%)
11	Hypertension	158	15.4	8 (4.3%)	150 (17.9%)
12	Bone deformity	155	15.1	27 (14.5%)	128 (15.3%)
13	Obesity	153	15	25 (13.4%)	128 (15.3%)
14	Musculoskeletal pain/dorsalgia	152	14.9	32 (17.2%)	120 (14.3%)
15	Eczema/Dermatitis	149	14.6	38 (20.4%)	111 (13.3%)
16	Gastro-oesophageal reflux disorder	148	14.5	26 (14%)	122 (14.6%)
17	Dysphagia	147	14.4	24 (12.9%)	123 (14.7%)
18	Lower respiratory tract infection	134	13	34 (18.3%)	100 (11.9%)
19	Dyspnoea/wheezing	131	12.8	27 (14.5%)	104 (12.4%)
20	Dental/oral	130	12.7	28 (15%)	102 (12.2%)

Table 3. Twenty regression analyses showing the independent associations of gender, level of intellectual disabilities, Down syndrome, and age, with the top 20 physical health conditions [odds ratios (95% confidence intervals)

Physical health condition	Gender	Level of disability				Down Syndrome	Age					
	REF=Male	Mild	Moderate	Severe	Profound	REF: Without	16to24	25to34	35to44	45to54	55to64	65+
Vision	0.79 (0.61to1.02)	**REF**	1.12 (0.81to1.55)	**1.80 (1.27to2.57)**	**2.57 (1.78to3.70)**	1.10 (0.79to1.53)	REF	0.83 (0.51to1.35)	1.11 (0.71to1.73)	1.05 (0.67to1.65)	0.88 (0.55to1.42)	0.77 (0.43to1.36)
Epilepsy	1.04 (0.79to1.38)	**REF**	**1.57 (1.09to2.3)**	**1.78 (1.21to2.62)**	**4.49 (3.06to 6.65)**	**0.21 (0.13to0.34)**	**REF**	**1.74 (1.02to2.97)**	**1.68 (1.02to2.75)**	1.23 (0.74to2.02)	1.02 (0.60to1.74)	0.68 (0.35to 1.30)
Constipation	**1.50 (1.14to1.97)**	**REF**	1.26 (0.88to1.82)	**1.85 (1.27to2.70)**	**4.30 (2.95to6.28)**	**0.56 (0.38to0.82)**	REF	1.38 (0.81to2.34)	1.18 (0.72to1.94)	1.59 (0.97to2.59)	1.13 (0.67to1.92)	1.15 (0.62to2.15)
Ataxic/ Gait disorder	1.23 (0.92to1.64)	**REF**	**2.40 (1.62to3.56)**	**3.79 (2.51to5.67)**	**6.66 (4.42to10.03)**	**0.40 (0.26to0.62)**	REF	1.43 (0.81to2.54)	1.37 (0.80to2.34)	**1.78 (1.05to3.03)**	1.59 (0.90to2.78)	**2.59 (1.36to4.91)**
Hearing	0.97 (0.73to1.30)	REF	0.94 (0.65to1.36)	1.08 (0.73to1.61)	0.86 (0.56to1.32)	**2.46 (1.74to3.49)**	**REF**	0.71 (0.39to1.29)	0.91 (0.54to1.54)	1.22 (0.73to2.05)	1.37 (0.80to2.38)	**4.59 (2.49to8.46)**
Nail Disorder	1.24 (0.92to1.66)	REF	1.01 (0.69to1.49)	1.05 (0.70to1.59)	0.9 (0.59to1.39)	1.24 (0.85to1.80)	**REF**	**1.95 (1.02to3.73)**	1.70 (0.92to3.12)	**2.92 (1.61to5.29)**	1.79 (0.94to3.41)	**2.41 (1.20to4.94)**
Epidermal thickening	**1.83 (1.34to2.50)**	REF	**1.49 (1to 2.21)**	1.23 (0.79to1.92)	1.32 (0.85to2.07)	**2.74 (1.91to3.93)**	**REF**	**2.87 (1.40to5.86)**	**2.29 (1.16to4.53)**	**2.94 (1.49to5.79)**	**3.25 (1.60to6.59)**	**2.34 (1.01to5.40)**
Cerebral palsy	0.86 (0.61to1.22)	**REF**	**2.38 (1.41to4.04)**	**4.10 (2.43to6.86)**	**9.86 (6.02to16.15)**	**0.15 (0.07to0.32)**	REF	1.62 (0.86to3.06)	1.17 (0.63to2.14)	1.25 (0.68to2.29)	0.84 (0.43to1.63)	0.63 (0.27to1.47)
Osteoporosis	**2.34 (1.64to3.32)**	**REF**	**1.68 (1.01to2.82)**	**2.67 (1.61to4.44)**	**9.66 (6.01to15.54)**	**0.22 (0.11to0.43)**	REF	1.59 (0.77to3.26)	**2.11 (1.08to4.13)**	1.55 (0.78to3.08)	**2.40 (1.20to4.84)**	**2.85 (1.30to6.27)**
Fungal Infection	0.85 (0.60to1.20)	**REF**	0.66 (0.43to1.03)	0.76 (0.48to1.20)	**0.39 (0.22to0.69)**	**1.68 (1.11to2.53)**	**REF**	**9.00 (3.09to26.20)**	**3.77 (1.29to10.99)**	**8.22 (2.89to23.39)**	**6.40 (2.18to18.79)**	**5.33 (1.66to17.11)**
Hypertension	0.93 (0.65to1.33)	**REF**	**0.65 (0.42to1.00)**	**0.43 (0.25to0.72)**	**0.31 (0.17to0.57)**	**0.22 (0.10to0.46)**	**REF**	2.11 (0.78to5.66)	**2.52 (1.01to6.30)**	**4.49 (1.83to10.98)**	**5.31 (2.15to13.16)**	**7.74 (2.99to19.99)**
Bone deformity	1.31 (0.92to1.85)	**REF**	1.37 (0.85to2.21)	1.27 (0.76to2.13)	**2.96 (1.87to4.70)**	1.03 (0.65to1.64)	**REF**	1.22 (0.6to2.47)	1.01 (0.52to1.98)	1.58 (0.83to3.02)	1.53 (0.77to3.04)	2.06 (0.95to4.47)
Obesity	0.99 (0.69to1.40)	REF	0.97 (0.61to1.54)	1.23 (0.76to2.00)	1.27 (0.79to2.06)	0.86 (0.54to1.38)	**REF**	**0.48 (0.25to0.92)**	0.79 (0.46to1.37)	**0.45 (0.25to0.82)**	0.83 (0.46to1.49)	0.37 (0.16to0.88)
Musculo-skeletal	**1.89 (1.32to2.70)**	**REF**	**0.54 (0.35to0.85)**	**0.45 (0.27to0.74)**	**0.16 (0.07to0.34)**	1.14 (0.73to1.79)	REF	2.35 (0.99to5.57)	2.08 (0.92to4.70)	**3.10 (1.39to6.95)**	**3.22 (1.40to7.41)**	2.31 (0.90to5.96)

Eczema	0.95 (0.66to1.35)	REF	0.62 (0.38to1.0)	0.89 (0.55to1.45)	0.92 (0.57to1.50)	**1.70 (1.12to2.59)**	REF	1.04 (0.55to1.97)	0.74 (0.40to1.36)	0.890 (0.49to1.62)	0.71 (0.36to1.38)	0.81 (0.36to1.81)
Gastro-oesophageal reflux disorder	1.31 (0.91to1.87)	**REF**	0.85 (0.5to1.45)	1.40 (0.84to2.35)	**3.36 (2.13to5.29)**	0.95 (0.59to1.53)	REF	1.05 (0.49to2.22)	1.63 (0.84to3.18)	1.80 (0.92to3.49)	1.22 (0.58to2.55)	1.21 (0.50to2.93)
Dysphagia	**1.46 (1.01to2.12)**	**REF**	**2.35 (1.30to4.25)**	**3.58 (1.99to6.44)**	**10.50 (6.13to17.98)**	0.96 (0.58to1.59)	REF	1.24 (0.61to2.50)	1.17 (0.60to2.27)	1.04 (0.53to2.03)	1.39 (0.69to2.8)	0.94 (0.38to 2.32)
Lower respiratory tract infection	0.9 (0.62to1.30)	**REF**	0.78 (0.46to1.32)	0.76 (0.43to1.34)	**2.51 (1.58to3.99)**	**1.87 (1.20to2.92)**	REF	0.68 (0.35to1.32)	0.64 (0.35to1.17)	0.63 (0.34to1.17)	0.63 (0.32to1.23)	0.78 (0.34to1.78)
Dyspnoea	**2.07 (1.42to3.03)**	**REF**	0.95 (0.59to1.52)	1.03 (0.63to1.69)	**0.38 (0.19to0.75)**	1.12 (0.70to1.8)	REF	1.25 (0.54to2.88)	1.29 (0.60to2.77)	**2.43 (1.16to5.06)**	1.30 (0.57to2.94)	2.30 (0.98to5.44)
Dental Health	0.90 (0.62to1.31)	REF	0.88 (0.54to1.42)	1.15 (0.70to1.88)	0.65 (0.3to1.16)	1.28 (0.80to2.04)	REF	1.90 (0.92to3.94)	0.97 (0.47to2.01)	1.51 (0.75to3.04)	1.21 (0.56to2.58)	1.31 (0.54to3.15)

Numbers in bold are significant results

Figure 1. Total number of ICD-10 physical health conditions

Figure 2. Mean number of physical health conditions by gender, age group and level of disabilities

Figure 3. Extent of multi-morbidity in individuals with intellectual disabilities with and without Down Syndrome

Figure 4. Number of physical health conditions by neighbourhood deprivation

Figure 5. Prevalence (%) of physical ill-health by ICD-10 chapter

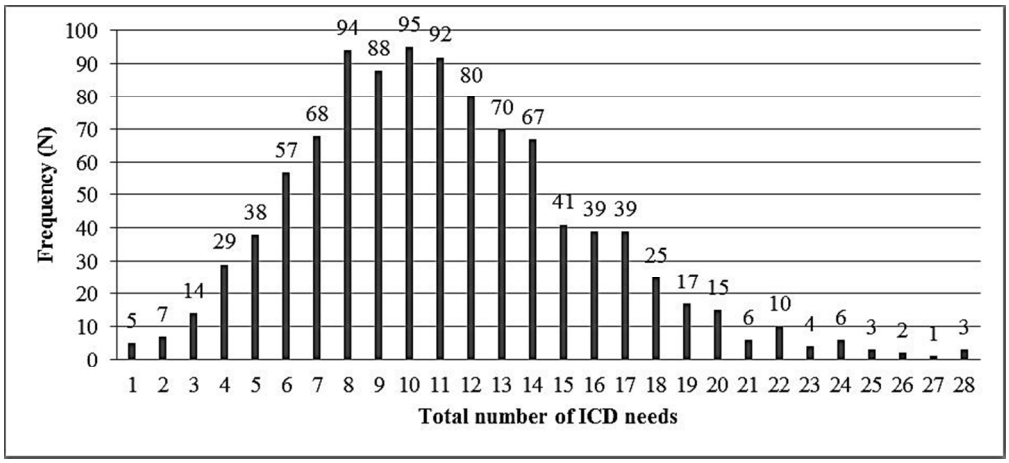

Figure 1. Total number of ICD-10 physical health conditions

79x36mm (300 x 300 DPI)

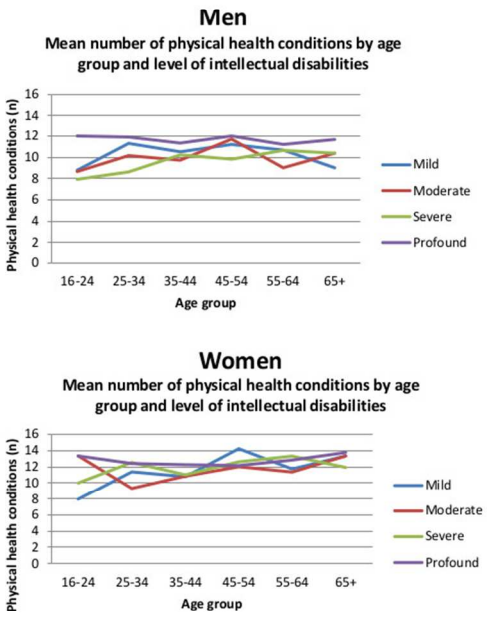

Figure 2. Mean number of physical health conditions by gender, age group and level of disabilities

69x98mm (300 x 300 DPI)

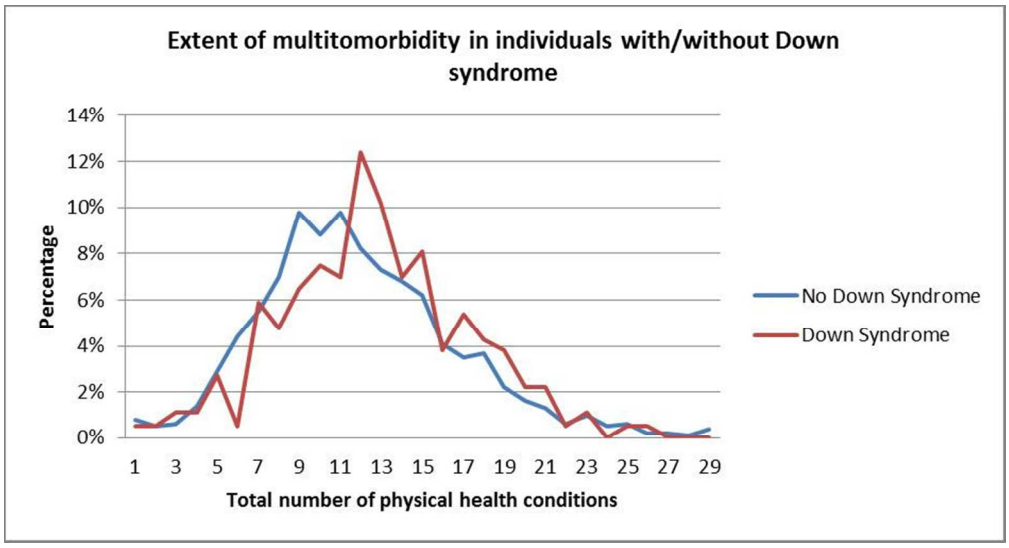

Figure 3. Extent of multi-morbidity in individuals with intellectual disabilities with and without Down Syndrome

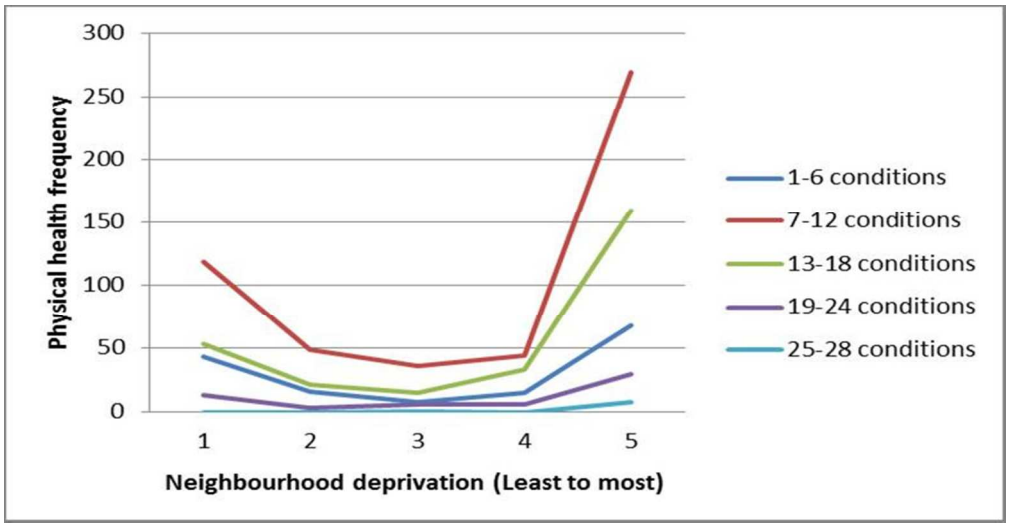

Figure 4. Number of physical health conditions by neighbourhood deprivation

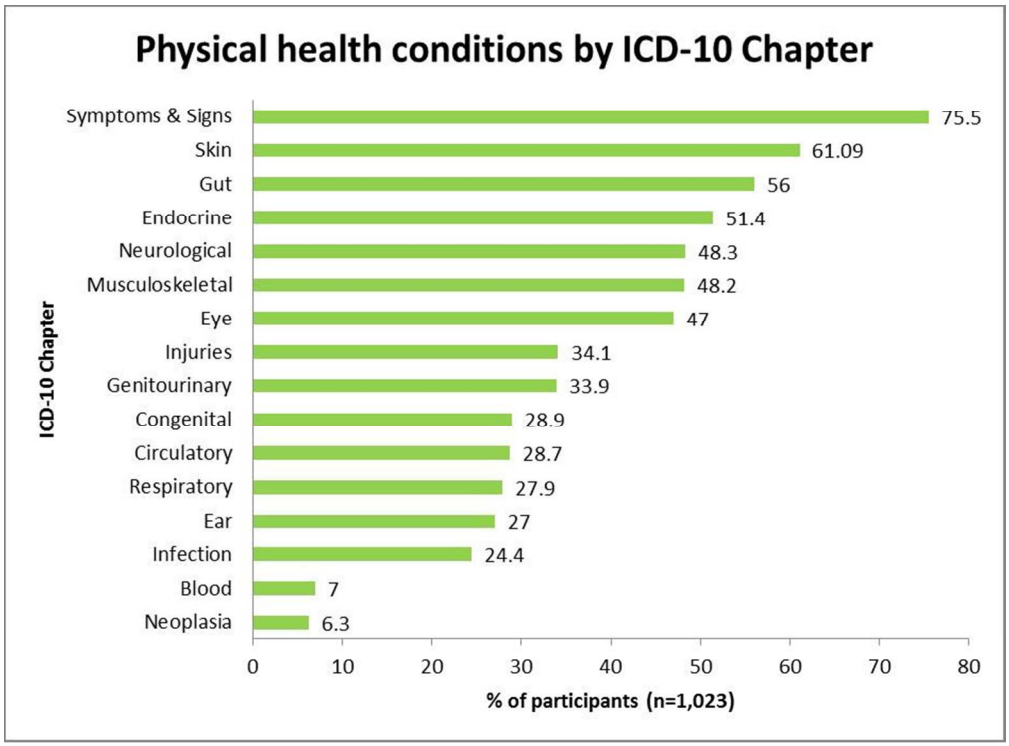

Figure 5. Prevalence (%) of physical ill-health by ICD-10 Chapter

STROBE Statement—Checklist of items that should be included in reports of ***cross-sectional studies***

	Item No	Recommendation	Page
Title and abstract	1	(*a*) Indicate the study's design with a commonly used term in the title or the abstract	1
		(*b*) Provide in the abstract an informative and balanced summary of what was done and what was found	1
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	2
Objectives	3	State specific objectives, including any prespecified hypotheses	3
Methods			
Study design	4	Present key elements of study design early in the paper	3
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	3
Participants	6	(*a*) Give the eligibility criteria, and the sources and methods of selection of participants	3
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	3
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	3
Bias	9	Describe any efforts to address potential sources of bias	3
Study size	10	Explain how the study size was arrived at	3
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	4
Statistical methods	12	(*a*) Describe all statistical methods, including those used to control for confounding	4
		(*b*) Describe any methods used to examine subgroups and interactions	4
		(*c*) Explain how missing data were addressed	N/A: none
		(*d*) If applicable, describe analytical methods taking account of sampling strategy	N/A
		(*e*) Describe any sensitivity analyses	N/A
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	3
		(b) Give reasons for non-participation at each stage	3
		(c) Consider use of a flow diagram	N/A
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	11
		(b) Indicate number of participants with missing data for each variable of interest	3

Outcome data	15*	Report numbers of outcome events or summary measures	4-5, 12-18
Main results	16	(*a*) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	12-18
		(*b*) Report category boundaries when continuous variables were categorized	13-14
		(*c*) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	N/A
Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	N/A
Discussion			
Key results	18	Summarise key results with reference to study objectives	5-6
Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	6
Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	6-7
Generalisability	21	Discuss the generalisability (external validity) of the study results	6
Other information			
Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	7-8

*Give information separately for exposed and unexposed groups.

Note: An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at http://www.plosmedicine.org/, Annals of Internal Medicine at http://www.annals.org/, and Epidemiology at http://www.epidem.com/). Information on the STROBE Initiative is available at www.strobe-statement.org.