An Examination of the Nutritional Intake and Anthropometric Status of Individuals with an Intellectual Disability

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Declaration

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of MSc is entirely my own work, and that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work.

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List of Abbreviations

BMI Body Mass Index

BMR Basal Metabolic Rate

cm Centimetres

DCU Dublin City University

DRV Dietary Reference Values

DXA Dual-energy X-ray absorptiometry

EAR Estimated Average Requirement

FFQ Food Frequency Questionnaire

FSA Food Standards Agency

FSAI Food Safety Authority of Ireland

ft Feet

g Grams

GP General Practitioner

HEI Healthy Eating Index-2005

HSE Health Service Executive

ID Intellectual Disability

IDS-TILDA Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing

kg kilograms

lb pounds

m meters

Max Maximum

Min Minimum

NCI National Core Indicators

NHANES National Health and Nutrition Examination Survey

NHIS National Health Interview Survey

NHS National Health Service

NI Northern Ireland

NIDD National Intellectual Disability Database

PwID Persons with an Intellectual Disability

Rec Research Ethics Committee

RD Registered Dietitian

RDA Recommended Dietary Allowance

SLÁN Survey of Lifestyle, Attitudes and Nutrition

SOI Special Olympics Ireland

SOPHIE Special Olympics Health Impact Evaluation

SPSS Statistical Package for the Social Sciences

STEPS STEPwise approach to Surveillance

TILDA The Irish Longitudinal Study on Ageing

UK United Kingdom

US United Sates

WHO World Health Organisation

WISP Weighed Intake Software Package

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Abstract

Edel Hoey

An Examination of the Nutritional Intake and Anthropometric Status of Individuals with an Intellectual Disability

Background The prevalence of overweight and obesity appears greater in persons with an intellectual disability (PwID) than those in the general population. This has been widely reported in the literature. Few studies have examined the nutritional intakes of PwID. The aim of this study is to describe the anthropometric status and the nutritional intakes in PwID.

Methods Adults with an ID (16-64 years) were recruited from four ID service provider organisations, in the Republic of Ireland. Almost 2000 PwID were invited to participate in the study and 131 participated in one or more parts. The Survey on Lifestyle and Attitudes to Nutrition (SLAN) 2007 questionnaire was adapted for use in this population. Interviews were carried out face to face with PwID and family members. Weight, height and waist circumference measurements were obtained. Participants were invited to complete a four day food diary, over two week and two weekend days.

Results The mean BMI of the overall study sample was 29.4kg/m^2 ±6.1. The mean BMI of men was 28.8kg/m^2 and the mean BMI of women was 30.2 kg/m^2, with 2.4% of the sample underweight, 22.6% normal weight, 28.2% overweight and 46.8% obese. Having a diagnosis of Down's syndrome (p=0.03) and greater fried food consumption (p=0.041) were associated with increasing BMI. Increasing waist circumference was associated with increasing severity of ID (p=0.04). Mean reported energy intakes were 2044kcal/day for men and 1684kcal/day for women. Mean energy intakes from sugar, fat and saturated fat are above maximum recommended intakes and few study participants met micronutrient RDAs.

Conclusion This study highlights the alarming prevalence of overweight and obesity in PwID. While under reporting of nutritional intake is suspected in the study participants this study also highlights the poor diet quality of study participants.

Key Words: intellectual disability, body mass index, obesity, diet, nutrition, associated factors

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Chapter 1: Introduction

Definition of the term 'intellectual disability'

There is no agreed term used globally to describe an intellectual disability (ID). In the Republic of Ireland the term 'intellectual disability' is used, which is defined by the WHO (2014) as 'a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development'.

In the UK the term 'learning disability' is used. The Department of Health (2001) provides the following definition for the term learning disability. 'Learning disability includes the presence of a significantly reduced ability to understand new or complex information or to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood with a lasting effect on development.'

In the US the terms 'intellectual disability' and 'developmental disability' are replacing the term 'mental retardation'. The American Association of Intellectual and Developmental Disabilities (2010) describes an ID as 'a disability characterized by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills. This disability originates before the age of 18'.

For the purpose of this thesis the term ID will be used to cover the above terms.

Prevalence of Intellectual Disabilities

Diagnostic criteria for ID worldwide varies, the worldwide prevalence is estimated as 10.37/1000 population (1%) (Maulik et al. 2011). In Europe the prevalence of ID is estimated at <1% (European Intellectual Disability Research Network 2003). In the Republic of Ireland there were 27,691 people registered on the National Intellectual Disability Database (NIDD) in 2013. The prevalence rate of ID is

therefore 6.02/1,000 population, based on the 2011 Census (Kelly and O'Donohoe 2014). The prevalence rate for moderate, severe or profound ID was 3.54/1,000 population. The prevalence rate for mild ID was 2.00/1,000 population, which may be lower than the actual figure as only individuals requiring a ID service are registered on the NIDD. There were more males than females registered on the database (ratio 1.38:1).

The exact number of persons with an intellectual disability (PwID) in Northern Ireland (NI) is not known as there is no definitive record. The 2011 NI Census recorded 40,177 individuals who were reported to have a "learning difficulty, an intellectual difficulty, or a social or behavioural difficulty which had lasted, or was expected to last, at least 12 months", which accounts for 2.22% of the resident population. This figure includes individuals with social or behavioural difficulties. The data collection method did not allow for differentiation of which type of difficulty therefore this figure is likely to be higher than the number of PwID in NI (Murphy 2014).

McConkey et al. (2003) estimated that there were 16,366 PwID in NI, using information provided from the Health and Social Care Trusts. This estimates the prevalence rate of ID as 9.7/1,000 population.

In a further attempt to estimate the number PwID in NI, McConkey (2013) identified that in 2012/2013 there were 7,198 PwID registered with a GP in Northern Ireland. This is accepted as likely to be the most accurate figure (Murphy 2014). The population of Northern Ireland according to the 2011 Census is 1.811 million; therefore the prevalence of ID is approximately 3.97/1,000 population. Individuals with a borderline/mild ID, the 'invisible population', may not obtain health and social care services and therefore may be not be included in these statistics and make up a further 1% of the population (Emerson and Hatton 2013).

There is also no comprehensive register in England. It is estimated, using population predictions and data on PwID obtaining services that there is 1.14 million PwID in England (Emerson et al. 2013).

Health Inequalities for Individuals with an Intellectual Disability

It is well recognised that health inequalities exist between PwID and the general population. Individuals with ID are twice as likely to have health problems such as neurological issues, obesity, haemorrhoids or skin problems than individuals without ID (van Schrojenstein Lantman-de Valk,H. MJ et al. 2000).

In recent decades there has been a move from institutionalized care towards enabling PwID to live in the community (Bigby 2006). With this move, the responsibility for the healthcare of PwID and their complex needs shifted to the primary care setting, with GP's taking over from specialized institutional medical teams, integrating PwID into their practice (Jansen et al. 2004). Healthcare workers often have insufficient training and knowledge of the special healthcare needs of PwID and many live on very low incomes or in poverty and specialised healthcare can be costly (Meijer, Carpenter and Scholte 2004).

Poverty, unemployment, genetic predisposition, poor communication skills, poor health related literacy, personal behaviours such as not engaging in regular physical activity, discrimination and social exclusion were identified as fundamental causes of health inequalities between individuals with an ID and the general population (Emerson 2011). Healthcare policies and health promotion activities are typically aimed at improving the health of the general population, as PwID are a unique heterozygous population specific tailored health improvement strategies are needed (Cooper, Melville and Morrison 2004).

Individuals with ID are also living longer than ever before. In Ireland in 2013 49% of those with a moderate, severe or profound ID are aged 35 years or over, compared to just 29% in 1974 (Kelly and O'Donohoe 2014). The increasing number of older adults with an ID is putting pressure on healthcare services as older individuals with ID are at risk of the typical health issues faced by the general aging population, alongside the health issues they face due to their ID (Krahn and Fox 2014). It remains the case that although the life expectancy for PwID is increasing, it remains lower than that of the general population (Coppus 2013).

Obesity and Overweight in Individuals with an Intellectual Disability

Individuals with ID are a nutritionally vulnerable group. They may have limited knowledge and understanding of nutrition and health, poor cooking skills, reduced abilities and opportunities to make informed nutritional choices, difficulties with transport to purchase food for themselves and rely on others for nutritional adequacy and provision (British Dietetic Association 2011).

It is thought that PwID are more likely to be overweight or obese than the general population. Different sample sizes, study populations, age ranges of participants and methodologies used in studies make it difficult to accurately quantify the issue of overweight and obesity in PwID. The prevalence of overweight in PwID is estimated between 28-38.2% and the prevalence of obesity is estimated between 25.6-51% (Bhaumik et al. 2008, McCarron et al. 2014, de Winter et al. 2012, Emerson 2005, Hsieh, Rimmer and Heller 2014, Stedman and Leland 2010, Yamaki 2005).

Being overweight is one of the five highest risk factors for disease burden in developed countries (World Health Organisation 2002). Obesity and overweight are some of the most preventable secondary conditions for individuals with disabilities (Rimmer, Ming-De Chen and Hsieh 2011). Obesity is associated with increased morbidity, cardiovascular disease, some cancers, type 2 diabetes mellitus (increased risk BMI $\geq$22kg/m^2 in women and $\geq$24kg/m^2 in men), physical impairment, psychological issues (including distress and depression), reduced quality of life and economic burden (Dixon 2010, Finer 2015).

It is estimated that through increased healthcare needs and indirect costs, such as absenteeism, obesity associated costs are €1,127,584,243 in the Republic of Ireland and €510,323,754 (£369,799,820) in Northern Ireland (Perry et al. 2012).

The WHO global disability action plan 2014-2021 identified that strengthening the collection of relevant and internationally comparable data on disability as a key priority (World Health Organisation 2014). Given the consequences of overweight and obesity and that they are preventable further research gaining insight into this issue in PwID is crucial.

There does not appear to be any studies, with representative samples of the whole population of PwID, which can explain why individuals with ID are more likely to be overweight and obese than individuals without ID. Given the health risk associated with overweight and obesity it is imperative that future research quantifies the prevalence of overweight and obesity in a representative sample of PwID and examines the associated factors. In particular, there appears to be a gap in our knowledge of the nutritional intake of PwID. Increased understanding of the factors associated with overweight and obesity in this population is essential in order to plan appropriate interventions to reduce the prevalence of overweight and obesity in PwID.

Study Overview

This study was carried out as part of the Special Olympics Programmes Health Impact Evaluation (SOPHIE) study. The SOPHIE study was funded by the Iris O' Brien foundation and was managed via SOI. The overall aim of the SOPHIE study was to examine the impact of Special Olympics participation on the health and wellbeing of PwID in the island of Ireland.

Much of the work carried out by this researcher was in conjunction with another MSc student, who will submit a project examining the physical activity and physical fitness of the SOPHIE study participants. Tasks including recruitment, co-ordination of the collection of data and study tool development were shared between both MSc students.

Significance of the Study

There are few studies quantifying the prevalence of overweight and obesity in PwID in Ireland. Increased understanding of the prevalence of and factors associated with overweight and obesity in this population is essential in order to develop effective prevention and intervention strategies. This study is important as it describes the anthropometric status of an Irish sample of PwID. The link between nutritional intakes and anthropometric measurements in PwID is examined, which

few studies have carried out previously. This study also highlights the difficulties in recruitment in this heterozygous population.

Aim

The aim of this study is to describe the anthropometric status and the nutritional intake in PwID.

Objectives

- Describe anthropometric status of PwID, using BMI and waist circumference measurements
- Examine the influence of variables identified in the literature on BMI and waist circumference measurements in PwID
- Describe the nutritional intake of PwID, with the use of 4 day food diaries

Chapter 2: Literature Review

In order to become analyse previous research and identify gaps in the research a literature review was carried out. The aim of this literature review is to examine and critically assess the scientific literature examining the nutritional issues faced by persons with an intellectual disability (PwID). The aim is broken down to:

1. Describe the anthropometric status of PwID
2. Examine the nutritional intake of PwID
3. Identify what methodological issues arise in assessing dietary intake and anthropometric measures in PwID

Anthropometry is defined as a measurement of the human body's composition and dimensions at various ages and levels of nutrition (Jelliffe 1996).

Prior to 2005 relatively little research was carried out examining the prevalence of obesity in PwID (Emerson 2005). With the publication of 'Obesity the Policy Challenges- the Report of the National Taskforce on Obesity' in 2005 the issue of the alarming prevalence of obesity was highlighted in Ireland. The prevalence of obesity is growing rapidly, with an increase of approximately 67% in the prevalence of obesity in Ireland between 1990 and 2000 (Irish Universities Nutrition Alliance 2001). Therefore, in order to focus on the most contemporary literature in order to describe the most up to date anthropometric status of PwID it was decided to include original research carried out in the previous 10 years in this literature review.

The following inclusion criteria were used:

a) Papers should be published between 2005 and January 2015
b) Papers should be primary research articles, published in the English language
c) Papers should refer to the population of adults with intellectual disabilities, exclusively over 18 years of age

Exclusion criteria included:

a) Papers focusing on just individuals with Prader-Willi Syndrome were excluded

b) Papers that included individuals with other disabilities such as physical disabilities, without the presence of an ID, were excluded
c) Review articles were excluded

Databases

The following databases were searched in order to provide a comprehensive search:

- **CINAHL Complete** indexes approximately 3,000 journals from the fields of nursing and allied health. In addition, this database offers access to health care books, nursing dissertations, selected conference proceedings, standards of practice and book chapters.
- **MEDLINE via EBSCO** provides authoritative medical information on medicine, nursing, the health care system and pre-clinical sciences from over 4,800 current biomedical journals.
- **Web of Science** is a multi-disciplinary citation database covering over 10,000 of the world's highest impact research journals in the areas of science, social science, arts and humanities.

Search Terms

The following search terms were used:

1. intellectual disabilit* OR learning disabilit* OR developmental disabilit* OR learning difficult* OR mental retard*
2. nutrition OR nutritional issues OR obesity OR dietary assessment OR food diary OR diet records OR anthropometry OR waist circumference OR BMI OR body mass index OR nutrition assessment OR dietary intake OR food choice OR dietary choice
3. dietary assessment OR food diary OR diet records OR anthropometry OR waist circumference OR BMI OR body mass index OR nutrition assessment OR dietary intake
4. methodological issues OR difficulties OR issues OR challenges OR barriers

Searches were carried out in the following format:

a) 1 and 2
b) 1 and 3 and 4

Using the Medline and CINAHL PLUS databases terms were searched for in abstracts, choosing the option that papers must be published in English between 2005 and the present day, with participants over 18 years of age. These options were not available in Web of Science therefore the terms were searched for in titles, published between 2005 and the present day.

Database results were screened initially by reading the title and papers thought to be relevant were exported to the reference management software *'Refworks'*. Sixty six papers were exported, the breakdown of which is described in Table 1.

Table 1 Number of papers selected from each database

Database	Papers search a (n)	Papers search b (n)	Papers selected (n)
CINAHL Complete	93	5	23
MEDLINE	233	11	32
Web of Science	54	13	11

***** The Cochrane Library was also searched but yielded no results therefore it will not be included.

Refworks identified 19 duplicates which were removed, leaving 47 papers for second round screening. Abstracts, and full articles were required, were judged against the inclusion criteria and 27 papers were excluded from the literature review that did not meet the inclusion criteria, leaving 20 papers for review.

In addition, three studies that did not meet the inclusion criteria, but had sections that were deemed to be relevant to an Irish sample were included. In total 23 papers were included for analysis in this literature review.

The 23 studies were analysed and a number of themes were identified; the prevalence of overweight and obesity in individuals with IDs, underweight in individuals with IDs, methods of assessing dietary intake in individuals with IDs, dietary intake of individuals with IDs and methods of assessing body composition individuals with IDs.

Overweight and Obesity in Adults with Intellectual Disabilities

Fifteen studies examined the prevalence of and associations with overweight and obesity in PwID. There is conflicting results between studies. Table 2 summarises the anthropometric findings of these studies.

In each study examined, unless otherwise indicated, the WHO (1995) BMI categorisation was used:

- Underweight: BMI <18.5 kg/m^2
- Normal weight: BMI 18.5-24.9 kg/m^2
- Overweight: BMI 25-29.9 kg/m^2
- Obese: BMI ≥ 30kg/m^2

The ID Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA) is the first study of it's kind in Europe (McCarron et al. 2014). It allows direct comparison between an Irish nationally representative sample of older adults over 40 years of age with an ID and the general population over 50 years of age. Given their reduced longevity, PwID over 40 years of age were included. This literature review will report on anthropometric measurements and dietary intake results.

Computer assisted interviews were completed by 708 participants or proxy reporters and physical measurements were obtained for 602 participants. BMI was calculated (kg/m^2). Mid Upper Arm Circumference (MUAC) or Ulna length were measured if height and weight could not be. Analyses of statistical significances between groups were not reported.

Of those for whom BMI was calculated 3.2% were underweight, 30.1% were normal weight and 66.7% were overweight or obese. Excluding alternative measures to height and weight, 34.8% of the sample was overweight and 42.5% was obese. Older adults in the general population were less likely to be normal weight (21%) and more likely to be overweight or obese (79%) than older PwID. Women with ID were more likely to be obese than men (69.9% compared to 62.3%). Those with a mild ID were more likely to be overweight or obese (84.9%) than those with a severe/profound ID (46.9%).

Waist circumference measurements identified that 64.6% of PwID are at substantially increased risk of cardio-metabolic disease, compared to 53% of the general population.

Anthropometric measurements were taken using the same method for participants with and without an ID, which strengthens any comparisons made between these groups. Statistical significance analysis is not reported which would have been of value, for example, whether the difference in obesity prevalence in Irish men and women with ID is significant. The overall IDS-TILDA study gathered data on the age, living arrangements etc. of study participants. Analysis of associations between anthropometric measurements and possible associated factors in this sample would have been worthwhile. The sample is representative for older PwID, a similar study in the whole population of adults with ID would be of benefit to quantify the overweight and obesity prevalence in Irish adults with ID.

McGuire et al. (2007) examined the lifestyle and health behaviours of Irish adults with ID and compared them to a sample in the general population; this literature review will examine BMI and nutritional intake findings. The study team carried out a cross-sectional postal questionnaire survey. The 2003 National Health and Lifestyle survey (SLAN), which was developed to investigate the health behaviours and status of the Irish general population, was adapted. Postal questionnaires were completed by 156 family members or paid carers of PwID, mean age 37 years (range 16-65 years). BMI was calculated from proxy reported weight and height measurements, kg/m^2.

The mean BMI of study participants was $27.7kg/m^2$ ±5.69, 37.7% were overweight, 30% were obese and 30% were normal weight. In comparison, just 13% of the general population were obese. No significant difference between the prevalence of obesity in men and women with an ID was identified (p=0.67).

The small sample size of this study limits the conclusions that can be drawn as this may not be a representative sample. Height and weight measurements were reported by proxies. There were no checks by the study team in place to ascertain the reliability or validity of the data collected; therefore these figures are likely less reliable then if the team had directly obtained physical measurements. It is possible

that proxies under or over reported physical measurements, which may have an effect on this study's results and any comparisons with the general population as measurements were directly obtained for the sample of the general population used for comparison.

Emerson (2005) reported that PwID deviate significantly from 'normal weight'. Information was collected from audits on the quality of the supported accommodation provided to 1542 adults with an ID living outside their family home, in socially deprived areas of Northern England. Height and weight were obtained from health records; it is not clear whether these were measurements directly obatined or reported. BMI was calculated (kg/m^2). A cut off of BMI $<20kg/m^2$ was used to categorise underweight. The data was compared to nationally representative BMI data on the general population, from the Health Survey for England 2001.

Of the study population, 31% were normal weight, 28% were overweight and 27% were obese. Women aged 35-44 years (p=0.042), 55-64 years (p=0.028) and 65-74 years (p=0.002) were significantly more likely to be obese than men of the same age. Men with an ID were less likely to be obese than men in the general population for all ages, except 65-74 age group, (p<0.002). Women aged 16-24 and 35-44 years with an ID were significantly more likely to be obese than women of the same age in the general population ($p<0.05$ and $p<0.001$, respectively).

Multivariate regression analysis identified associations between obesity and being female ($p<0.001$; OR=1.7), most able (adaptive behaviour) ($p<0.001$; OR=2.5) and moderately able ($p<0.01$; OR=1.8), and when controlled for personal characteristics, geographical location (p<0.05; OR=2.7) and having a greater number of community-based activities (p<0.01; OR=1.6).

Caution should be maintained in interpreting these results as it is unclear whether this is a representative sample to compare with national data on the general population and no checks were in place to ascertain the reliability or validity of the measurements collected. There was also no analysis of dietary intake therefore further investigation is required to draw conclusions about the causes of obesity in

this population. However this study appears to have followed a clear methodology and is worthwhile in highlighting future areas for research in this population.

In another English sample Bhaumik et al. (2008) conducted a population based prevalence study in which data was collected from 1119 adults with an ID registered on the Leistershire Learning Disability Register. Participants had weight and height measurements taken by a community physician as part of a health check, within two years of July 1998, followed by a home interview. BMI was calculated (kg/m^2), BMI<20kg/m^2 was used to categorise underweight.

Of the study participants 32.7% were normal weight, 28% were overweight and 20.7% were obese. Women were more likely to be obese than men (29% compared to 15%, *p=0.03*). There were no significant differences between the sexes in the prevalence of normal weight (*p=0.10)* and overweight (*p=0.08*). When compared to the general population over 25 years of age (Health Survey for England 1998), men with an ID are less likely to be obese (15% compared to 19%) and women with an ID are more likely to be obese (32% compared to 23%).

Using multivariate analysis, after adjustment for age, sex, ethnicity, Down's syndrome and smoking status, individuals living independently or with family members were identified as greater than 3 times more likely to be obese than study participants living in residential care (OR 3.28; 95%CI 2.12–5.08). Women (OR for men compared to women 0.36; 95%CI 0.25–0.53), individuals with hypertension (OR 2.67; 95%CI 1.76–4.06) and those with Down syndrome (OR 2.30; 95%CI 1.40–3.80) were also identified as more likely to be obese.

It is possible that the prevalence of obesity is underreported given that individuals with a greater level of understanding were under represented in the study sample, it has been suggested that individuals with a milder ID are more likely to be obese than individuals with more severe ID. Personal characteristics such as gender and level of ID were not controlled for. There has also been a move towards less institutionalized residences for PwID since 1998 in the UK, with less restrictive living arrangements which have been linked with an increased risk of obesity.

Gazizova et al. (2012) examined the prevalence of and associations with obesity in eighty PwID and mental illness attending routine mental illness outpatient appointments (range 18-65 years) in the UK. Weight and height measurements were taken and BMI was calculated (kg/m^2), BMI<20 kg/m^2 was used to categorise underweight.

Of the study participants 25% were normal weight, 28% were overweight and 41% were obese. The mean BMI for men was 28.6 kg/m^2 and 32.6 kg/m^2 for women. Being female (p=0.001), higher serum triglyceride concentrations (p=0.026) and lower levels of ID (p=0.003) were associated with higher BMI. A strong negative association was found between BMI and ID (P=0.003; partial correlation=-0.331). The proportion explained variance (R^2) was small, 0.241.

Data was obtained from the Health Survey for England 2008 on the general population. When compared with the general population, study participants were less likely to be a normal weight (25% compared to 37%) or overweight (28% compared to 37%) and were more likely to be obese (41% compared to 25%).

The study population and small sample size are not however representative of the population of PwID therefore caution must be maintained in interpreting these findings. Participants had a mental illness and an ID, and are more likely to take medications linked with increased bodyweight. R^2 was 0.241, therefore there are other factors linked with increased BMI that warrant further investigation. This study did not examine nutritional intake, which given the low R^2 value may have increased the R^2 value and our understanding of the factors associated with increased BMI in PwID.

Steadman and Leland (2010) reported that PwID in New Zealand are more likely to be obese than the general population. Archived, anonymized data was obtained for 141 PwID (range 25-68 years) receiving support from an ID service provider. Weight and height measurements were measured by staff from which BMI was calculated (kg/m^2).

Of the study population 17.4% were normal weight, 30.6% were overweight and 51% were obese. PwID were more likely to be obese than the general population

(51% compared to 30%, $p<0.0001$), using 2008 data on the general population from the New Zealand Ministry of Health. Both men and women with ID were more likely to be obese than the general population ($p<0.02$). Women with an ID were also significantly more likely to have BMI $\geq 35 kg/m^2$ ($p<0.001$) and $\geq 40 kg/m^2$ ($p<0.003$) compared to the general population.

Data is not available for the level of participants' ID; however 75% of the study participants receive less than 5 hours support/week suggesting they may have a mild/moderate ID which studies have associated with increased risk of obesity. The high prevalence figures for obesity may not therefore be representative of all PwID. It is reported that comparable measures to weighing scales were used by doctors where required, however the methods and frequency of this is not reported. The use of methods of assessing body composition not validated in this population may have an impact on the results of this study. A clear methodology is required in order to make reliable comparisons with other studies. The small sample size also indicates that the conclusions drawn may not be representative of all PwID in New Zealand.

In the US Stancliffe et al. (2011) found similar prevalence rates of overweight and obesity between PwID and the general population. From the 2008-9 National Core Indicators (NCI) programme, 8,911 randomly selected PwID (mean age 43.48 years, range 20-93), receiving institutional, home or community based service provision. The NCI gathers survey data in 20 US states. Height (*ft*) and weight (*lb*) data were gathered from participant records or by a proxy respondent by the NCI. BMI (kg/m^2) was calculated using the formula body mass (*lb*) *x* 703/ height^2 (ft^2). The data obtained was compared with the National Health and Nutrition Examination Survey (NHANES) sample of general population. Differences were considered significant if the 95% CI did not overlap.

Similar prevalence rates of overweight and obesity were found between PwID and the general population, with just 4 of 27 comparisons statistically significant. Women with ID were overall significantly more likely to be overweight or obese than men with ID (64.5%, 95%CI 63.0-66.0 compared to 60.5%, 95%CI 59.1-61.8). Women with ID were significantly more likely to be morbidly obese (BMI $\geq 40 kg/m^2$) than men (10.8%, 95%CI 9.6-11.8 compared to 5.1%, 95%CI 4.5-5.7).

Significantly more PwID were morbidly obese than the general population (7.6%, 95%CI 7.1-8.2 compared to 5.7%, 95%CI 4.9-6.5), in particular young women with an ID (13.3%, 95%CI 11.6-15.0). No significant difference was identified between racial groupings.

A significant association was found between increased severity of ID and lower prevalence of obesity (mild ID 41.4% obesity, 95%CI 39.7-43.0; profound ID 12.6% obesity, 95%CI 10.8-14.5). Individuals living in less restrictive environments had a higher prevalence of obesity (institution 18.6% (95%CI 16.2–21.0), foster home 27.0% (95%CI 22.8–31.2), group home 31.6% (95%CI 29.8–33.3), own home 42.8% (95%CI 39.9–45.6) and family home 37.7% (95%CI 35.7–39.7)). Individuals living in less restrictive environments are more likely to have a mild or moderate ID. No significant difference in the prevalence of obesity in individuals with a mild or moderate ID was found between different accommodation types which suggests that living arrangement may have a stronger effect on the likelihood of being obese than level of ID, however further research is needed in this area. Individuals with Down syndrome had a significantly higher mean BMI than other groupings based on aetiology of ID ($p<0.001$), however individuals with a dual-diagnosis were excluded from this analysis.

The study team did not collect physical measurements themselves. Measurements were obtained from records of proxy reporters. The study team did not verify the accuracy of these measurements and so relied on the NCI appropriately obtaining this information. Therefore the measurements may not be accurate which reduces the reliability of any comparisons with the NHANES data on the general population which was assessed directly.

Moran et al. (2005) reported that there was no significant risk for ever having obesity for individuals with mild ID compared to the general population. They carried out a retrospective observational study in the US examining participants' medical records, comparing 680 PwID (mean age 34.4 years) with 1806 age matched individuals without an ID (mean age 40.2 years). Participants were categorised as having a mild or severe ID.

Participants with a mild ID had similar prevalence rates of obesity as the age matched individuals without an ID (29.7-38.7% compared to 33.1-40.9%). Younger individuals with severe ID had much lower prevalence rates of obesity compared to the general population (20-30 years, 14.2% compared to 33.1%), however it increased over time (≥60 years of age 30.3%). Interestingly, they also identified that 15-40% of all study participants who were once obese did not remain obese.

As physical measurements were obtained retrospectively this study is reliant on practitioners correctly obtaining height and weight measurements and following appropriate protocols. There were no checks by the study team to establish the reliability and validity of measurements obtained. However physical measurements were obtained for the entire study sample by the same methods, improving the strength of comparisons made. Individuals with a severe ID are over represented in the sample; therefore caution must be maintained in interpreting these findings as they are not representative of the overall population of PwID. Individuals were categorised as having a mild or severe ID, individuals are typically categorised as having a mild, moderate or severe ID in other studies, therefore comparisons between BMI and level of ID with other studies is limited as individuals who are categorised as having a moderate ID may be categorised in this study as mild or severe. Limited variables were analysed by the study team and nutritional intake was not examined therefore further research in the future is required into the causes of overweight and obesity in this sample.

Yamaki (2005) obtained data from the US National Health Interview Survey (NHIS) between 1985 and 2000 and compared the BMI status of PwID and the general population, without an ID, aged 18-65 years. BMI was calculated from self-reported weight and height measurements, kg/m^2. Questionnaires were answered by participants and proxies. Data was grouped into 4 year categories, 1985-1988, 1989-1992, 1993-1996 and 1997-2000.

Over the time periods the prevalence of obesity in PwID increased (1985-1988 19.43% 95%CI ±2.96 compared to 1997-2000 34.6% 95%CI ±7.98). No statistically significant differences between genders were identified. PwID were significantly more likely to be obese than the general population across each time point (95%CIs did not overlap).

Unlike in the general population, the prevalence of overweight did not increase in PwID over the time periods. Gender comparisons were not significant, except men were more likely than women in 1993-1996 to be overweight (33.81% 95%CI±4.96 compared to 29.33% 95%CI±3.53). Men with ID were less likely to be overweight than men without ID (28.25-33.87% compared to 39.72-43.01%). There was a similar prevalence in overweight in women with and without ID.

The overall proportion of PwID who are a healthy weight decreased significantly over time (1997-2000 34.6% 95%CI ±7.98 compared to 1985-1988 19.43% 95%CI ±2.96). PwID were less likely to be a normal weight than those without ID at each time period (e.g. 1997-200 33.75% 95%CI±7.76 compared to 43.19% 95%CI±0.35).

Weight and height measurements were self-reported. Self-reported physical measurements are often under-reported as individuals may attempt to appear to conform to a more healthy weight. Proxy reporters may not under-report to the same extent as self-reporters however, as they are reporting on someone else's behalf but errors in recall and estimation of measurements may still occur. Data was collected using the same method for those with and without ID, which may improve the validity of comparisons.

The questionnaire was redesigned in 1997 which may have an effect on the data and comparability with the previous years. The sample size of PwID for whom data was available was small (n=49-460, depending on years) and CIs were large, reducing significant differences. This data is 15-30 years old, if the increase in obesity and decrease in normal weight continues in the trend suggested the prevalence of obesity in PwID today may in fact be higher than reported. Further investigation is indicated.

Hsish et al. (2014) investigated the prevalence of and associations with obesity in PwID in the US. Baseline data from a large scale longitudinal study was used. Mail or online surveys were completed by 1450 PwID (range 18–86 years) and caregivers familiar with them. BMI was calculated from reported weight and height measurements (kg/m^2).

Of the study participants 35.6% were normal weight, 28.9% were overweight and 38.3% were obese. Women were significantly more likely to be obese than men (p<0.001). Men were more likely to be overweight than women (31.6% compared to 25.5%) and women were more than twice as likely to be morbidly obese than men (10.9% compared to 4.5%). Individuals with severe ID were significantly less likely to be obese than individuals with borderline, mild or moderate ID (p<0.001). No significant differences were identified in obesity prevalence across the different types of accommodation.

Men with ID were more likely to be obese than men in the general population (34.3% compared to 28.3), using data from the 2010 NHIS. Women with an ID were more likely to be obese (43.2% compared to 27.7%) and morbidly obese (10.9% compared to 5.4%) than women in the general population.

Multivariate regression analysis identified significant associations between obesity and having Down syndrome (AOR=2.53, 95%CI=1.86–3.45), being female (AOR=1.40, 95%CI=1.09–1.81), the number of fizzy drinks consumed daily (AOR=1.19, 95%CI=1.01–1.40), taking medications that can include weight gain as a side effect (AOR=1.80, 95%CI=1.38–2.37), participation in moderate physical activity (AOR=0.89, 95%CI=0.79–0.99) and residing in an urban area (AOR=1.41, 95%CI=0.98–2.02). Level of ID was not included in the regression analysis as this was unknown for 23% of study participants.

PwID are a heterozygous group and vary in their ability to recall information and complete questionnaires. Often proxies are used to obtain information, however they may not be aware of everything in the participant's life and data reported may not be fully accurate. BMI was calculated from reported measurements from proxies which are not as accurate as the study team directly obtaining physical measurements. There is no way to ascertain how accurate these estimates are which limits the interpretation of these figures. The NHIS data on the general population contains self-reported heights and weights, the scientific evidence suggests under reporting of individual's own bodyweight is common therefore the prevalence of overweight and obesity in the general population may in fact be higher. Participants were asked what conditions they take medications for, not what specific

medications they take. Not all medications have the same effect therefore caution must be used in drawing conclusions from these results alone.

The study team did not control for participants' characteristics in analyses, nor did they examine associations between level of ID and BMI, which would have provided a more compete analyses of the factors associated with increased BMI in this study sample. As the level of ID is not available for 23% of study participants it is not clear if this is a representative sample of PwID.

De Winter et al. (2012) investigated the prevalence of overweight and obesity in older PwID (using measurements of BMI, waist circumference, waist to hip ratio and body fat percentage), compared this with the general population and examined any characteristic associations with being overweight or obese in older PwID. The study was part of a large cross sectional study carried out in the Netherlands, the 'Health Aging and ID' study in which 945 PwID over 50 years of age participated.

Using BMI measurements 38.2% of PwID were overweight and 25.6% were obese. Older men with an ID were significantly less likely to be overweight than older men in the general population, 39.2% (95%CI 34.7-43.7) compared to 47.7% (95%CI 45.5-50.0), but similar prevalence rates for obesity exist, 13.7% (95%CI 10.5-16.8) compared to 13.2% (95%CI 11.6-14.7). The prevalence of overweight in women with an ID was similar to older women in the general population, 37.1% (95%CI 32.6-41.7) compared to 35.3% (95%CI 33.0-37.5), but obesity was significantly higher, 38.0% (95%CI 33.5-42.6) compared to 14.8% (95%CI 13.2-16.5).

Using BMI measurements logistic regression multivariate analysis identified that being female (OR 6.1, $p<0.001$), having a less severe ID (OR 2.0, $p<0.001$), being able to eat independently (OR 3.3, $p<0.001$) and do groceries independently (OR 3.1, $p<0.001$) was significantly associated with obesity. R^2 was small was 0.21.

Waist circumference measurements indicate that 21.5% of the study population were overweight and 46% were obese. Multivariate regression analysis identified a significant association between obesity and being female (OR 5.1, $p<0.001$), able to do groceries independently (OR 2.2, $p<0.05$), physically inactive (<7500 steps per

day) (OR 3.7, $p<0.01$). and having Down syndrome (OR 3.9, $p<0.05$). R^2 was small, 0.33.

Waist to hip ratio measurements categorised 36.7% of the study population as overweight and 48% as obese. Multivariate regression analysis identified a significant association between obesity and being female (OR 5.8, $p<0.001$), older (OR 1.4, $p<0.01$), able to eat independently (OR 1.6, $p<0.01$), able to prepare a meal independently (OR 1.6, $p<0.05$) and having Down syndrome (OR 1.8, $p<0.05$). R^2 was small, 0.25.

Using body fat percentage estimates significant associations were identified between higher body fat percentage and being female ($p<0.001$) and physically inactive ($p<0.001$). $R^2=0.78$, these risk factors account for much of the risk of a high body fat percentage.

The large sample size, which was almost representative for Dutch older PwID who receive support from a service provider, gives strength to these results. BMI measurements were the only measurements in this study for which comparable data existed form the general Dutch population, reducing possible comparisons. The BMI of the general population is self-reported over the telephone, which may be underreported influencing comparisons made. The low R^2 values for BMI, waist circumference and waist to hip ratio suggest there are other factors than those identified in the present study contributing to the high prevalence of overweight and obesity in older PwID. The analyses did not control for participant characteristics nor did it examine nutritional intakes, which may have increased the explained variance in these measurements. Further research is required.

Sohler et al. (2009) examined the BMI and associated factors in 291ethically diverse PwID, over 18 years of age, living independently or with family/friends, who receive outpatient care through a medical practice in the US. Data was obtained from patient files. Weight and height were extracted, with the mean results over the study period used to calculate BMI, height/weight^2 (kg/m^2).

Of the study participants 24.4% had a normal BMI, 27.5% were overweight and 43.3% were obese. This is worrying given 55.3% of study participants were less

than 30 years of age and previous studies have identified an increasing risk of obesity with increasing age. Indeed the study team report increasing age increased the risk of obesity (AOR 2.71 ≥45years of age).

The current sample size is not large enough to reliably compare age categories with the NHANES. Weight and height measurements were collected from patient records and no checks were in place by the study team to verify that the correct protocol was followed and the measurements were accurate. The study population may not be representative of general population of PwID, as over half were under 30 years of age. Participants reside in an urban area with access to good healthcare facilities. Participants also live independently or with family/friends, which possibly increases their risk of obesity compared to PwID living in more institutionalized settings, and therefore may overestimate the prevalence of obesity in PwID.

Foley at al. (2013) compared the BMI of US Special Olympic (SO) athletes across three time points 2005-2006, 2007-2008 and 2009-2010. Overall the prevalence of underweight, overweight and obesity were not found to have increased over this time period. Anonymized age, sex and BMI data were obtained from free health screenings for SO athletes at state, national and international SO events and 6004 records for PwID aged 20-59 were used in this study. Weight and height measurements were obtained from participants and BMI was calculated (kg/m^2). Results were compared to published NHANES data on prevalence rates in the general US population.

Female SO athletes were significantly more likely to be obese than women in the general population, except for 20-39 year old women in 2007-2008 (p=0.088). Only 20-39 year old male SO athletes (2005–2006 and 2007–2008) were significantly more likely to be obese than men in the general population (p=0.039 and p=0.004, respectively).

Male SO athletes were significantly more likely to be overweight than female SO athletes in both age groups (p<0.001) and females were more likely to be obese than male SO athletes (p<0.001). There was no significant difference in the prevalence of overweight or obesity in women over time. There was just one

significant change in the prevalence of obesity in 40-59 year old men, 45.47% (95% CI 41.04-49.91) in 2009-2010 compared to 33.1% (95% CI 25.32-40.87) in 2005-2006.

The large sample size strengthens this study; however the study population are likely not representative of the general population of PwID. Study participants were not randomly selected and personal characteristic data was not available to verify the representativeness of the sample. Individuals who participate in SO events may also be more active and health conscious than the general population of PwID. A SO protocol exists for measuring weight and height; the study team did not verify that it was followed by those obtaining physical measurements. Different models of scales/stadiometers may have been used, which may not have been calibrated as per manufacturer's instructions. Deviations from the protocol will likely have an effect on the BMI measurements calculated and therefore the results of this study.

Temple et al. (2014) compared the BMI of SO athletes by world region and investigated whether age and sex were linked with the likelihood of being overweight or obese**.** Data was obtained by the study team from a SO database. Body weight was measured by trained personnel at SO events. Data was collected between 2003 and 2009 for 11,643 SO athletes. The mean age for men was 29.6 years (SD = 9.9) and for women 30.4 years (SD = 10.2).

Overweight and obesity in SO athletes were most prevalent in the North American, European, Latin American and African regions compared to the Asia-Pacific and East Asian regions. Comparisons were limited due to age variation differences between regions. In North America76.4% of women and 68.2% of men had a BMI $\geq$25kg/m^2. In Europe 56.6% of women and 47.7% of men had a BMI $\geq$25kg/m^2. In East Asia these percentages were much lower with 32.2% of women and 26.8% of men with a BMI $\geq$25kg/m^2. Women were identified as more likely to be overweight/obese than men (OR for men=0.59, p<0.001), excluding the Asia-Pacific and East Asian regions where female overweight/obesity was relatively lower. Age was also identified as a predictor for overweight/obesity (OR=1.058, p<0.001), except in the East Asian and Latin American regions where participation in SO for athletes $\geq$ 40 years of age is low (4% and 9% respectively).

SO have a protocol in place for measuring weight and height, as in Foley et al. (2013) the study team did not verify protocols were correctly adhered to. There was also limited information on participant's residential status, co-morbidities, aetiology of ID etc. which limits generalisation of results, despite large sample size. The participants from whom data was collected at SO events may be more active than the general population of PwID; the prevalence of obesity in the general population of PwID may be higher. Despite these limitations Temple et al. (2014) have identified that the prevalence of obesity is highest in PwID in North American and Europe, suggesting environmental and societal factors may have a role.

As suggested by previous research (Bhaumik et al. 2008, de Winter et al. 2012, Hsieh, Rimmer and Heller 2014) individuals with Down syndrome may be at increased risk of obesity compared to ID of other aetiologies. In the UK Melville et al. (2005) examined whether obesity was more prevalent in individuals with Down syndrome. This is the first study in which PwID, with and without Down syndrome, (mean age 37.2 years) were matched for age, sex and accommodation type. From the Leicestershire Learning Disability Register 247 matched pairs were identified. Data was collected in 1992-1993. Weight and height were measured in a medical examination and from these measurements BMI was calculated (kg/m^2).

Women with Down syndrome had a significantly higher BMI than the control group ($p<0.01$) and were more likely to be morbidly obese ($BMI \geq 40 kg/m^2$) than the female control group (6.8% compared to 2.6%). Women with Down syndrome were as more likely to be overweight (OR 2.17) and obese (OR 1.43) than female controls.

No significant difference in mean BMIs was found between the two male groups. Men with Down syndrome are more likely to be overweight than the control group (OR 1.6) and less likely to be obese (OR 0.85).

In the general population, 1993 Health Survey for England, 50% of women were classed as overweight, obese or morbidly obese, compared to 77.8% of women with Down syndrome and 62% of female controls. Of men in the general population 57.8% were classed as overweight, obese or morbidly obese, compared to 59.2% of men with Down syndrome and 46.9% of male controls.

No women with Down syndrome were underweight compared to 6% of the female controls and 0.7% of men with Down syndrome were underweight compared to 10.7% of the male controls. This reduces the mean BMI of the control groups and any differences between mean BMIs, increasing the OR of being overweight and obese in the individuals with Down syndrome.

Analysing and controlling for other factors that affect bodyweight such as dietary intake would have increased the reliability and accuracy of these results. It is reported that it was not possible to match study participants with Down syndrome with controls with the same level of ID. Studies have suggested the level of ID has an impact on body weight status therefore this may have an impact on the study results and any conclusions that may be drawn.

Critical Review

The prevalence of obesity differs between the fifteen studies identified in this literature review for a variety of reasons. Different sampling strategies, methodologies and varying geographical locations make comparison between studies, and across time, difficult.

It has been suggested that there may be an association between living environment and increased risk of being overweight or obese, therefore comparisons between studies with samples recruited from institutionalised and community living samples are difficult. While studies such as Sohler et al. (2009), Emerson (2005) and Stancliffe et al. (2011) describe the residential status of study participants others such as Foley et al. (2013) and Temple et al. (2014) did not collect information on the residential status of their study participants. Study participants in the study carried out by Sohler et al. (2009) reside in an urban area independently or with friends/family, the sample recruited by Emerson (2005) reside in supported accommodation outside the family home and the sample in the study carried out by Stancliffe et al. (2011) reside in institutions, group home, own and family homes. This makes it problematic in interpreting the results of these studies and applying the results to the general population of PwID as study participants' living arrangements may be associated with their BMI.

The methodology used to assess anthropometric status varies between studies. While the use of BMI has been validated for use in this population (Temple et al. 2010) many studies identified in this literature review relied on proxy reported measurements (Mc Guire et al. 2007, Stancliffe et al. 2011, Yamaki 2005 and Hsish et al. 2014). Proxy reporters may under or overestimate measurements, reducing the accurateness of measurements used in analyses and in comparison with other studies on PwID and the general population. The lack of a consistent methodology in obtaining anthropometric measurements in these studies makes it difficult to make accurate comparisons and draw accurate conclusions.

De Winter et al and Mc Carron et al. recruited representative samples of older adults with ID. This strengthens the validity of the results and the conclusions that can be drawn about older adults with ID. None of the studies identified in this literature search recruited representative samples of PwID. Gazizova et al. (2012) recruited a sample with mental illness, Foley et al. (2013) and Temple et al. (2014) recruited samples from SO events, Sohler et al. (2009) recruited a young sample from an urban setting and Steadman and Leland (2010) did not obtain participant's level of ID, therefor participant's level of ID is unknown. The results from these studies cannot be generalised as representative of all PwID as representative samples were not recruited. In order to accurately quantify the issue of overweight and obesity in this population, and therefore develop appropriate treatment and prevention strategies, future studies with representative samples are needed.

Emerson (2005) controlled for personal characteristics and found that location and the numbers of community based activities were associated with obesity. Research carried out since then has not controlled for personal characteristics, nor have they examined these factors further. In order for researchers to improve understanding of the factors associated with and causes of overweight and obesity in the population of PwID it is imperative that researchers build upon, incorporate and further develop previous research in this area.

Mc Guire et al. (2007) was the only study identified that examined the nutritional intake of study participants. Given the importance of dietary intake, and also physical activity, in being overweight (Fricker et al. 1989), it is important for future studies to examine these factors and their role in overweight and obesity in PwID.

In the studies carried out by McCarron et al. (2014) and Moran et al. (2005) a control group of the general population to compare measurements with was recruited. Mc Guire et al. (2007), Emerson (2005), Bhaumik et al. (2008), Steadman and Leland (2010), Gazizova et al. (2012), Stancliffe et al. (2011), Yamaki (2005), Hsish et al. (2014) and Sohler et al. (2009) compared their results with previously published studies, often published several years prior . Comparisons made with a control group, with the same methodologies, are often more valid than those without. The methods of obtaining physical measurements are often not the same in the studies identified in this literature search who did not recruit a control group to make comparisons with the general population. For example de Winter et al. (2012) obtained measurements directly and compared these with self-reported measurements in a sample from the general population. In order to drawn valid, accurate, reliable conclusions data should be collected using the same methodology. Caution must be maintained in making comparisons between studies using different methodologies.

Most of the studies identified in this literature search reported that PwID, particularly women with ID, are more likely to be overweight or obese compared to the general population (McCarron et al. 2014, Mc Guire et al. 2007, Emerson 2005, Bhaumik et al.2008, Steadman and Leland 2010, Gazizova et al. 2012, Stancliffe et al. 2011, Yamaki 2005, Hsish et al. 2014 and Sohler et al. 2009, de Winter et al. 2012). While the methodologies vary the consistency of these findings highlights the overwhelming issue of obesity in this population.

Moran et al. (2005) did not find that their sample were more likely to be obese than the general population. This may be attributable to their sample being over represented with individuals with a severe ID. The studies in this literature review suggest that less severe ID is associated with increased BMI, which may explain the lower incidence of obesity in this sample.

In summary, the prevalence of overweight is 22.9-38.3% and the prevalence of obesity in PwID is 20.7% to 56.7%. The variance in overweight and obesity prevalence reported in each study, which each have a different subset of study participants, highlights the impact the selection of study participants and methodology used has on the results. No studies with representative samples of the

whole population of PwID were identified and methodologies and recruitment strategies varied between studies. Further research on the anthropometric status and associated factors in PwID is clearly needed in order to provide comparable findings, with consistent validated methodologies.

Underweight in Adults with Intellectual Disabilities

Underweight has been identified as an issue in PwID. Emerson (2005) used a BMI<20kg/m^2 to classify participants as underweight, classifying 14% of participants as underweight. Men with an ID were identified as significantly more likely to be underweight at all ages (p<0.05). Women over 35 with an ID were significantly more likely to be underweight than women in the general population (p<0.001).

Multivariate regression analysis identified associations between underweight and being least able (p< 0.001; OR = 2.3), having a NHS accommodation provision (p< 0.05; OR = 2.7), fewer hours per week of scheduled day activity (p< 0.05) and living in a setting with a larger number of co-residents (p< 0.01).

Bhaumik et al. (2008) reported that in their sample 18.6% were underweight. Men were more likely than women to be underweight (*p=0.03*). Men with an ID are more likely to be underweight than men in the general population (19% compared to 2%). Women are also more likely to be underweight than the general population also (12% compared to 5%).

It was also reported that taking medications (OR 0.57; 95%CI 0.38-0.87) and having Down syndrome (OR 0.46; 95%CI 0.26-0.81) was inversely associated with being underweight. The likelihood of participants being underweight decreased with increasing age (OR 1.00 20-29 years, OR 0.58 30-39 years, OR 0.51 40-49 years, OR 0.37 ≥50 years).

A third study in a UK sample also used BMI<20kg/m^2 to classify individuals as underweight. Gazizova et al. (2012) reported 6% of their study sample was

underweight, compared to 2% of the general population (Health Survey for England 2008).

The use by these studies of BMI<20kg/m^2 to classify individuals as underweight limits comparisons with other studies. Indeed the Health Survey for England uses the WHO classification of BMI <18.5 kg/m^2 classifying underweight and BMI 18.5-24.9 kg/m^2 classifying normal weight which reduces the validity of the comparisons made with the general population. It also overestimates the percentage of study participants who are underweight and underestimates the number of study participants who are normal weight, using the WHO classification.

Using the same classification to identify underweight in these three UK studies identified different prevalence's of underweight; 6% (Gazizova et al. 2012), 14% (Emerson 2005) and 18.6% (Bhaumik et al. 2008). In the sample used by Gazizova et al. (2012) participants had a mental illness and ID. Studies suggest antipsychotic and anti-epileptic medication use may be linked to an increased BMI which may explain the lower prevalence of underweight in this sample.

Using the WHO classification in Irish samples Burke et al. (2014) reported that 3.2% of participants were underweight and McGuire et al. (2007) reported that 2.3% of participants were underweight. Sohler et al. (2009) reported that 4.8% of their US study participants were underweight. Foley et al. (2013) identified a prevalence rate of underweight in their sample of US SO athletes as 0.56-4.71%.

There are limitations in interpreting the results of these studies, such as participants not being representative all PwID. The prevalence of underweight in PwID does not appear, however, to be as high as overweight/obesity.

Methodological Issues in Assessing Body Composition in Adults with Intellectual Disabilities

There are difficulties in measuring body composition in the general population such as measurer bias, deviation from protocols, intra observer differences etc. There may be further challenges in measuring body composition in PwID such as difficulties in comprehension, balance difficulties and physical disabilities etc. The literature identified by the search terms used is discussed below.

Unless otherwise indicated, height and weight measurements taken in all studies included in this review used an electronic digital scale and rigid stadiometer. BMI was calculated using the formula weight (kg)/ height^2 (m^2).

Temple et al. (2010) investigated whether BMI is an appropriate indicator of adiposity in PwID. Forty six ambulatory individuals with a mild to moderate ID, 19-60 years of age, living in group homes participated in this study. Weight was measured using electronic digital weighing scales, with participants in light clothing, without shoes. Height was measured using a wall mounted stadiometer, with participants barefoot looking straight ahead, with their back, buttocks and head against the wall. The headboard was lowered with some pressure onto the top of participants' heads. BMI was calculated (kg/m^2).

Dual-energy X-ray absorptiometry (DXA) scans are the most accurate tool available to researchers to measure body composition but are expensive to use, BMI is a more cost and time efficient method. DXA scans were used to ascertain soft tissue composition, bone mineral density and content. Body fat percentage was calculated using manufacturer algorithms. Lean mass and fat mass were reported in grams also. The study used the following percentage body fat cut offs for obesity; 25% for men and 39% for women aged 20-39 years and 28% for men and 40% for women aged 40-59 years.

This study suggests that BMI is an appropriate indicator of adiposity in PwID; however a cut off of BMI$\geq$30kg/m^2 may not identify all obese individuals. Partial correlations of BMI with fat mass was estimated at r= 0.91, p= 0.001 and with lean mass r=0.12, p= 0.43. BMI accounted for 83% of the variance in total body fat and 68% of the variance in percentage body fat. Obesity as defined by BMI as BMI$\geq$30kg/m^2 has a sensitivity of 57.1% and a specificity of 100%. The sensitivity of BMI as a cut off for obesity improved with lower cut off points. This would identify more obese individuals but it would also falsely categorise more individuals as obese.

Linear regression analyses examined BMI as a significant predictor of fat mass for the following groups; men (R^2=0.71, p<.001), women (R^2=0.89, p<.001),

individuals with Down's syndrome (R^2=0.88, p<.001) and with ID of other aetiology (R^2=0.85, p<.001).

The aetiology of ID in this sample is not representative of the general population of PwID as individuals with Down syndrome are overrepresented. A more representative sample is required to draw firm conclusions. There would however be large cost implications in the routine use of DXA scans in research in PwID. BMI appears to be a practical and appropriate indicator of adiposity in PwID and was used by all the prevalence studies identified in this literature review.

Waninge et al. (2010) investigated whether waist circumference in the supine position can be measured reliably and validly. Standing and supine waist circumferences were measured twice, using a non-stretch measuring tape at the midway point between the 10th rib and ileac crest, for the validity study in 160 healthy adults without ID (20-65 years from all BMI categories). Participants breathed in for the first measurement and out for the second, with the mean used in analysis.

In the reliability study forty three individuals with severe motor, sensory and ID participated. Waist circumferences were measured twice in the supine position using a non-stretch measuring tape at the midway point between the 10th rib and ileac crest. The participant breathed in for the first measurement and out for the second, with the mean used. These measurements were repeated one week later. Dietary intake and whether the participant had recently defecated were noted for comparison.

There were statistically significant differences between the standing and supine waist circumference measurements (p<0.001), with the majority of supine measurements lower than standing waist circumferences. Linear regression analysis was used to develop a formula for predicting standing waist circumference from a supine measurement: corrected standing waist circumference = 1.017-1.961 x gender +1.016 x supine waist circumference (p< 0.001; R^2 =0.964).

The limits of agreement (LOA) for the 2 supine waist circumference measurements in individuals with severe motor, sensory and IDs was 8% of the mean and the intra

class correlation (ICC) was 0.98 (95%CI=0.97-0.99) indicating that supine waist measurements can be performed reliably.

The 160 participants required to detect statistically significant differences participated in the validity study. The validity study however didn't include PwID, which may influence the results. Waist circumference measurements were taken twice, breathing out and in. The WHO suggests that the waist circumference should be measured at the end of a normal expiration, which would likely give a lower result.

Waninge et al. (2009) investigated the feasibility and reliability of methods of assessing body composition in adults with severe sensory and ID. Forty five adults with severe and profound ID, most of whom had impaired vision, participated in this study.

Anthropometric measurements were taken on two separate occasions, one week apart. Dietary intake and whether the participant had recently defecated were noted for comparison.

Participants stood shoeless with their backs and heels against a wall and height was measured using a measuring tape to the nearest cm (Seca height measure 202). Participants unable to stand had their body lengths measured in the supine position (the distance between lines drawn at top of head and the participant's heels was measured) or lying on their sides (the sum of the distance measured between head to cervical spine, cervical spine to sacrum, sacrum to heel). Body lines were followed in measuring, not the shortest distance.

Body weight was measured shoeless, in swimming costumes on electronic scales. Participants unable to stand were weighed in their wheelchairs and their bodyweight was calculated. BMI was calculated (kg/m^2).

Waist circumference was measured twice at the midway point between the 10th rib and ileac crest, using the measuring tape. Participants breathed in for the first measurement and out for the second, with the mean used. Skinfold measurements were measured using callipers (Model HSK-BI, Baty International) at 4 points on

their right side, standing straight (triceps, biceps, subscapular and suprailiac). Measurements were taken twice, with the mean used for analysis. With participants sitting with their knees flexed at 90 degrees the tibia length was measured using measuring tape.

Feasibility was considered adequate if 95% of measurements were possible. Reliability was considered adequate if the LOA were <10% of the mean of the first measurement and the ICC value is >0.8 and 95% CI is ≤0.04.

There was no significant difference between any of the measurements taken at time point 1 and 2. Height, weight, BMI, tibia length and waist circumference measurements were considered reliable (LOA 2.1-5.5%, ICC 0.97-0.99) and feasible (over 95% successful). The LOAs for skinfold measurements were not considered reliable (LOA 27-80%) or feasible (82% successful). Difficulties were reported in taking these measurements, as participants may not have understand why they are feeling a pinch and therefore struggled to remain still. They also report that the level of stress caused to most participants was not acceptable.

The study team identified that the mean height measured was significantly different to the calculated using the Stevenson formula ($p<0.01$). Height was measured using a measuring tape; stadiometers are more rigid and likely obtain more accurate measurements which may explain some of the differences between height measured and height calculated.

The sample size was small and participants had severe/profound ID therefore this study is not representative of all PwID. It does however identify that skinfold measurements are not appropriate in individuals with severe/profound ID.

De Winter et al. (2012) investigated the prevalence rates of obesity and overweight in their study sample of PwID using three different methods. BMI categorised 38.2% of the population as overweight and 25.6% as obese, waist circumference measurements categorised 21.5% as overweight and 46.0% as obese and waist to hip ratio measurements categorised 36.7% as overweight and 48.0% as obese. Given the large differences in the prevalence of overweight and obesity identified

with these measurements further research appears to be indicated into the validity of these measures in PwID.

No studies were identified that investigated the validity of measurements reported by proxy reporters, which given the difficulties in gathering information from this complex heterozygous population appears to be indicated. Analysing the available evidence height, weight, BMI and waist circumference measurements appear to be feasible and reliable in the population of PwID.

Dietary Intake of Adults with Intellectual Disabilities

McGuire et al. (2007) compared their Irish study participants' intake to the general population using the 'Food Pyramid'. PwID were more likely to comply with the ideal sugar and fat intake (≤3 servings per day) than the general population (72.5% compared to 17%). However they were less likely to achieve the recommended daily intake of carbohydrate, fruit and vegetable, dairy and protein than the general population, with just 25.9%, 42.2%, 9.5 and 17.1%, respectively, achieving ideal intakes.

Individuals with mild or moderate ID had a higher level of choice in their dietary intake than individuals with a severe or profound ID (2.6 and 2.7 compared to 2.2 and 1.4 out of a possible score of 4) but the effect on nutritional intake was not examined.

The method of collecting data used in this study, using proxies, is likely to have underestimated participants' nutritional intake given that 30% of the sample were obese, therefore caution must be maintained in interpreting these results.

With the same method Burke et al. (2014) reported that the majority of participants with ID achieved recommended intakes of carbohydrate, dairy and protein sources (approximately 80-90%). Fruit and vegetable intake was lower with approximately 70% achieving recommended intakes. Sweets and snacks recommendations were met by 46% of participants (52% in 2011). Comparisons with the general population were not reported.

Fast food was consumed once a week or more by 28.8% of participants, 1-3 times a month by 25.8% of participants and 45.4% rarely or never consumed fast food. Men with an ID were more likely than women to consume fast food once a week or more (34.7% compared to 24.2%). PwID living independently were least likely to consume fast food once a week or more compared to those living in community or residential settings (20.5%, 35.1% and 25.3%, respectively), suggesting there may not be a link between independence and unhealthier food choices. Further investigation is certainly indicated.

Ptomey et al. (2013b) compared the dietary intake of 70 community residing, overweight and obese adults with mild to moderate ID (mean bodyweight 103.5±89.6kg, mean age 33.9±11.5years), who had volunteered for a weight loss study to the Healthy Eating Index-2005 (HEI-2005). The HEI-2005 provides a score of how well individuals meet the 2005 Dietary Guidelines for Americans, assessing fruit and vegetable, whole grain, fat and sodium intake etc.

The diet quality of PwID was found to be poorer of that of the average American, who "needs improvement". The mean HEI-2005 score for study participants was 46.7±11.5, indicating "poor" diet quality, with no significant difference between the score for men and women. This is lower than the average American score of 58.2, indicating "needs improvement".

The mean energy intake was 1928kcal ±891 (2331.5kcal ±1059.4 for men and 1728.1kcal ±719.3 for women). As participants' bodyweight increased, the consumption of whole grains ($p<0.05$), all fruits ($p<0.05$), whole fruits ($p<0.01$), all vegetables ($p<0.05$) and dark green and orange vegetables ($p<0.01$) significantly decreased. Mean dietary intakes of vitamins A, D and E were below the Estimated Average Requirement (EAR) and the dietary intake of fibre was below the recommended daily amount (RDA) for both male and female participants. Women's calcium intake and men's vitamin K intakes were also lower than recommended.

The mean fruit and vegetable servings consumed per day was 4.5 ±3.6. Caution must be used interpreting this figure as in the US (unlike Europe) potatoes are included in vegetable portions; potatoes contributed 0.4±1.2 servings and chips

contributed 0.3±0.8 servings to the total fruit and vegetable intakes. Fruit juice contributed 0.7±1.7 servings also. Just 24.5% of the study participants consumed the recommended intake of whole fruits. Intakes of sugar sweetened beverages were also high with participants consuming a mean daily intake of 0.9±0.3 servings/day.

It was reported that "additionally, men were deficient in vitamin K, and women were deficient in calcium". The EAR designed to meet requirement for 95% of population, in order to make a diagnosis of deficiency clinical assessment is required. Participants were not randomly selected and their dietary intakes may not be reflective of all PwID as participants were volunteers for a weight loss study therefore may be more motivated to consume healthier diets than general population of PwID, therefore it's possible that the actual dietary quality of PwID is in fact lower than reported here.

Draheim et al. (2007) reported that both men and women reported a high dietary fat intake (>30% of energy from fat), 71.4-85.6% and 70.1-79.2%, respectively. Fruit and vegetable intake was low with ≥5portions of fruit and vegetables consumed by just 0-4.4% of men and 0-6.4% of women with ID.

There was no significant differences identified in vegetable intake between the 3 residential settings (group homes, with a family member or semi-independently) for men, with and without adjustment for age and the presence of Down syndrome. Women who lived in group homes scored higher in the fruit and vegetable screen than women living with a family member or semi-independently. After adjustment for age and sex there was no significant difference in the mean dietary fat and fruit and vegetable screener scores between individuals with or without Down syndrome.

There are limitations in the representativeness of the study sample. Initial screening was carried out by the service agencies on interested participants, therefore individuals were not randomly selected to participate in the study and the sample may not be representative of all PwID. Participants living in group homes were significantly older than participants living with family members and semi-independently. The studies included in this literature review suggest that increasing

age has an impact on bodyweight status. It is also possible that increasing age has an effect on nutritional intake.

In summary, there is scope for improved nutritional intake data collection and comprehensive analyses of the macronutrient and micronutrient intake in PwID.

Methodological Issues Assessing Dietary Intake in Adults with Intellectual Disabilities

There are many challenges in collecting accurate comprehensive data on the nutritional intake in the general population, including under-reporting, over-reporting, day-of-the-week effects, incorrect portion size estimates etc. There are additional challenges in the population of PwID. PwID may have varying levels of poor concentration, comprehension and memory skills. Proxy reporters may be used but they may not have knowledge of all food and beverage items consumed by the individual. There is currently no validated method to collect dietary data from the population of PwID. There is a dearth of literature examining dietary assessment methods in PwID. Those identified by the search terms used are discussed below.

McGuire et al. (2007) assessed the nutritional intake of study participants using the SLAN questionnaire with a Likeheart scale. Respondents indicated how often the study participants consumed fruit and vegetables, carbohydrate sources, meat, fish and poultry, dairy and fat sources, sweets and snacks and beverages. Using this method, data collected was directly comparable to the general population. Intakes, however, were reported by proxies. Use of such retrospective methods, where participants tick the quantity they typically consume, reduces burden on respondents but also reduces the quality of the data on participant's dietary intake. These results may not give comprehensive data on total nutritional intake and results cannot be broken down on a nutrient basis.

Interestingly, the study team reported a higher prevalence of obesity but lower intake of sugar and fat in PwID compared to the general population, which suggests total nutritional intake was not captured. Proxies may be more aware of main

mealtime eating occasions than snacking occasions. There are possibly other influencing factors on obesity, such as lower activity levels, in PwID.

A Likeheart scale was designed to examine level of choice in 5 areas including food. The method used to collect dietary intake does not allow for comparison of nutrient intake with these tools, for example nutrient intake on a meal basis cannot be compared with the level of freedom of choice.

This method was also used by Burke et al. (2014) in the IDS-TILDA study. This method allows for comparison with the general population but has many limitations as discussed. An additional question on the frequency of fast food consumption was added. The quantity and type of fast food was not obtained and therefore does not allow for analysis of nutritional content.

Ptomey et al. (2013b) assessed dietary intake using 3 day food records, with 2 week and 1 weekend day, completed by study participants with support from their caregivers. These were reviewed by a Registered Dietitian (RD) with the participants using portion size guides and models. Data was analysed using Nutrition Data System for Research (NDSR) (2008 version), which was used to calculate diet quality scores using the HEI-2005, as a percentage per 1000kcal. The HEI-2005 provides a score of how well individuals meet the 2005 Dietary Guidelines for Americans. Scores >80 indicate "good" diet quality, scores of 51-80 indicate "needs improvement" and scores ≤50 indicate "poor" diet quality.

Calculating diet quality scores allows for comparisons with the general population. The 3 day food records likely gather more accurate and representative information about the nutritional intake of participants than the methods used by other studies in this review. Participants are, however, reliant on support from their caregivers to accurately complete the records, who may not always be present particularly at snack times which participants may not recall and therefore under report.

The study participants are not representative of all PwID as individuals with severe or profound ID were excluded. Individuals with mild/moderate ID are likely more able to complete food diaries than individuals with severe/profound ID, this method requires further investigation with a more representative sample.

Draheim et al. (2007) examined the fruit and vegetable and fat intake of 325 individuals with a mild to moderate ID (range 19-65years) in the US. The Block Screening Questionnaire for Fat Intake (which is used to calculate a fat score, from which the percentage of fat in dietary intake is estimated) and the Behavioural Risk Factor Surveillance System's Fruit and Vegetable Module (which is used to calculate a fruit and vegetable score, from which the mean number of fruit and vegetables consumed daily is estimated) were used. It is reported that these were selected due to the reduced cognitive functioning and attention span of PwID. They were found to be moderately reliable (SEM ±2.1 to 2.6), when repeated over 2 weeks with a subset of 12 participants, which was accepted given the difficulties in collecting accurate dietary intake data in PwID. Participants provided information, with care providers present as required. Food Frequency Questionnaires were also completed during an interview with the participant and their carer but results were not reported.

While the short instruments limit the burden on participants they also limit the quality of data obtained. Dietary intakes of fat and fruit and vegetables were calculated from scores generated, it would be more accurate to obtain an estimate of total daily nutritional intake (using retrospective or prospective methods). Important distinctions between types of dietary fat were not made.

Humphries et al. (2008) investigated whether the use of photographs improves dietary recalls in 9 adults (range 35-61years) with mild to moderate ID living in group homes or semi independently in the US. Using the NHANES method 24 hour recalls were carried out. The participants were allowed to have 'support persons' with them; however they were not allowed to assist with the dietary recall. The first 24 recall was carried out at Interview 1.

After one year training was provided with a 35mm Olympus TRIP AF50 camera. Mats with 1 inch grids were used as the background of photographs. The following day participants photographed all food consumed before and after each eating occasion over 24 hours. The next day the participants completed a 24 hour recall, without photographs (Interview 2). The participants then completed another 24 hour recall, with the photographs present as memory and communication aids (Interview 3).

The NHANES reliability criteria were used to assess the reliability of the 24 hour recalls. All of the 24 hour recalls, without the photographs, were deemed to be unreliable using the NHANES criteria. Reliability did not improve after the taking of photographs (Interview 2) but did improve with the photographs present (Interview 3), from 'indiscernable/poor' to 'good/excellent'. Photographs also aided communication between interviewer and study participant, particularly if the interviewer had difficulties with comprehension of what the PwID was saying.

The sample size was however small. Data on missed photographs and whether prompts were required was not reported. Many PwID have difficulties remembering to take photographs, which appears to be one of the biggest issues with their use in this population. Further investigation is required.

In the US Ptomey et al. (2013a) investigated whether using photographs in 24 hour recalls improved estimated intakes of 23 adults with mild to moderate ID (mean age 26.4 years, range 18-60years, BMI 35.5kg/m^2 ±5.7). Apple iPad 2s were provided to participants 2 days prior to the 24 hour recall, with training. Participants were encouraged to take before and after photographs of their oral intake with a fiduciary marker (5x5cm checked squares) for 24 hours prior to their home visit from a trained RD. A reminder to take photographs was programmed into the iPad.

A 24 hour recall was carried out by the RD following 5 steps; the participant lists oral intake without interruptions, participants were asked about commonly forgotten foods, the timing of intake was obtained, descriptions of foods and quantities consumed were queried using three dimensional models. Photographs were then used by the RD and participant to discuss their intake and any items different to the 24 hour recall without photographs were recorded. Both intakes were entered into and analysed by NDSR software (version 2011).

Photographs were taken for 66.5% ±30.4 of eating occasions. Forgetting an item consumed (45.9%), missing details (29.6%) and incorrect portion sizes estimates (21.4%) were the most common differences. Significant increases of 28.5% in energy (p=0.002), 19.1% in carbohydrate (p=0.003), 23% in protein (p=0.029) and 41.4% in fat (p=0.006) intakes were reported with the use of photographs.

While significantly higher intakes were reported with photo assisted recalls, limited comparisons can be made as not all food and beverages consumed within the 24 hour period were photographed, the most common reason being participants did not feel comfortable photographing their intakes in public. This may have implications for the future use of photographic methods if PwID are not comfortable photographing dietary intakes in public. The mean energy intake with 24 hour recall was 497.2kcal ±86.7 and with photographs was 625kcal ±85.7. The mean BMI of study participants was 35.5kg/m^2 which suggests much of participants' oral intake was not captured with either method.

Participants had mild to moderate ID; the general population of PwID contains individuals with a range of severity of ID. Participants of this study are also likely to be more motivated than general population as they were enrolled in a healthy lifestyle intervention. The conclusions that can be drawn about the application of this method to the wider population of PwID are limited.

Elinder et al. (2012) aimed to validate personal digital photography in PwID. Eighteen Swedish adults (aged 23-60) with a mild to moderate ID from community residences or their own flat, who receive daily support from staff, participated in the study.

Participants and staff were trained on how to use the camera, a Canon PowerShot A480. The study participants took the photos before starting to eat and drink, with reminders from staff when required. A researcher directly observed each participant for one 8-11 hour day. The researcher recorded each food and drink item consumed, the time and when staff reminders were needed to take photos.

This study assessed the frequency of 'indicator' foods from the groups 'fruit and berries', 'vegetables', 'non-core foods and beverages' such as confectionary, soft drinks and alcohol and 'beverages excluding water'. Lunch and dinner were compared to the 'plate model'; 37.5% carbohydrate dense foods, 37.5% vegetables and 25% protein rich foods. 'Dietary diversity' was assessed using points given to participants when they consumed any amount of food from 9 different food groups.

Participants required prompting from staff to take photos on 40% of occasions, with this 15% of observed occasions were not photographed. Almost perfect agreement (ICC>0.8) was found between photographed dietary intake and observed intake for the indicator foods, meal quality and dietary diversity, except fruit and berries (ICC 0.71). Inter-rater reliability was lowest (ICC 0.66) for meal quality. Photographs were take at 91% of breakfasts, 69% of lunches, 100% of dinners and 83% of in between meals consumed. Most participants had lunch and in between meal snacks in activity centres, which may explain the reduced number of photographs taken.

The study team concluded that in individuals with mild to moderate ID, with daily staff support, personal digital photography was a reliable, feasible and valid method of assessing dietary quality. Adequate staff provision is essential however, given that reminders were required on 40% of occasions. Nutritional content was not investigated which provides researchers with valuable knowledge of the macronutrient and micronutrient intakes of PwID. Photographic methods alone may not be able to differentiate between cooking methods or foods that appear similar e.g. full fat milk and skimmed milk. Participants were not requested to take photographs after eating occasions, this is necessary as the whole portion size may not be consumed, which without taking into consideration over estimates nutritional intake. Participants were observed on a day which suited the observer which may not reflect habitual intake.

The difficulty in remembering to take photographs appears to be one of the main limitations with digital photography in PwID. Participants in this study had to have the ability to understand the study to participate, which is not possible with many PwID, and still required prompting on 40% of occasions. With only 60% of eating occasions photographed in a study with individuals with a mild to moderate ID, without prompting, this would likely be less in a general sample of individuals with different types and severities of ID.

In conclusion there is currently a gap in our knowledge of the optimum data collection methods in PwID. There is no validated method for assessing dietary intake in the general population of PwID. Study samples are often not representative which limits the applications of their results in this population. At present each research team uses their judgement in choosing dietary assessment

tools. In order to obtain an accurate assessment of nutritional intakes the use of proxy reporters, with the individual with an ID, appears to be necessary. Methods using food diaries appear to be the most comprehensive in gathering dietary intake data.

Summary

In summary, there are high rates of overweight and obesity in PwID. PwID are more likely to be overweight or obese than the general population. Directly obtained BMI measurements appear to be feasible and reliable measures of fat mass in this population. Future studies with validated, consistent methodologies and representative samples are required to accurately quantify this issue in this population.

Little comprehensive data is available on the nutritional intake of PwID. There is no validated method for assessing dietary intake in the general population of PwID. Study samples are often not representative which limits the applications of their results in this population. Future studies should investigate the optimum methods of obtaining nutritional intake data and investigate the link between nutritional intakes and anthropometric measures in PwID.

Table 2 Anthropometric measurements reported in studies included in literature review

Study	Country	Sample Size	Level of ID	Age (years)	Anthropometric Method Used	How obatined	%Under-weight	%Normal weight	%Over-weight	%Obese
Bhaumik et al 2008[a]	UK	1119	mixed		BMI	directly measured	18.6	32.7	28	20.7
Burke et al. 2014	Ireland	602	mixed	≥40	BMI, MUAC, UL	directly measured	3.2	30.1	34.8[b]	32.5[b]
de Winter et al 2012	Netherlands	945	mixed	≥50	BMI	directly measured			38.2	25.6
					waist circumference	directly measured			21.5	46
					waist-hip-ratio	directly measured			36.7	48
Emerson 2005[a]	UK	1542	mixed	16->75		obtained from records				
Foley, Lloyd & Temple	US	6004	mixed	20-59	BMI	obtained from records	0.6-2.9	14.8- 27.6	23.7-31.7	38.1-56.7
Gazizova et al. 2012[a]	UK	100	mixed	18-65	BMI	directly measured	6	25	28	41
Hsieh, Rimmer & Heller	US	1450	mixed	18-86	BMI	reported	4.1	28.7	38.3	28.9
McGuire, Daly & Smyth 2007	Ireland	156	mixed	16-65	BMI	reported	2.3	30	37.7	30
Melville et al. 2005[c]	UK	247	mixed (DS)	20-69	BMI	directly measured	0	22.2	37.6	40.1
Moran et al. 2005	US	680	mixed	20-60	BMI	obtained from records				22.2-41.7
Sohler et al. 2009	US	291	mixed	18-≥45	BMI	obtained from records	4.8	24.4	27.5	43.3
Stancliffe et al. 2011	US	8911	mixed	20-93	BMI	obtained from records	33.6		32.6	33.6
Stedman & Leland 2012	New Zealand	141	less severe	25-68	BMI	directly measured	1	17.4	30.6	51
Temple, Foley & Lloyd 2014[d]	Europe	11643	mixed	19-65	BMI	obtained from records	4.4-4.7	39-47.5	26.3-31.4	16.4-30.3
Yamaki 2005[e]	US	650	mixed	18-65	BMI	self reported		33.8	22.9	34.6

***** Blank spaces indicate data not reported in studies

[a]BMI <20 used to classify underweight

[b] classified using height and weight measurements only

[c] Data on study participants with Down's syndrome is reported, DS denotes Down's syndrome

[d]1997-2000 data on European SO participants reported

[e]Data from 1997-200 is reported

Chapter 3: Methodology

Overview and Research Design

The focus of this thesis is to describe the anthropometric status and the nutritional intake in PwID. Data was collected as part of the SOPHIE study. A mixed methods approach was employed in the overall SOPHIE study, which is reported elsewhere. The data collected, which is relevant to this project, is of a quantative nature. The work reported in this thesis includes the recruitment of participants, data collection methods, pilot testing and data handling and analysis.

Participants were recruited from ID service provider organisations. Questionnaires were completed face to face with study participants, accompanied by a family member. Physical measurements were obtained including weight, height and waist circumference. Information on dietary intake was gathered using 4 day food diaries.

Participants and Recruitment

Ethical Issues

Ethical approval for this study was obtained from the Ethics Committees of Dublin City University (REC reference: DCUREC/2013/148, approved on the 3rd July 2013), the Office for Research Ethics Committees Northern Ireland (REC reference: 13/NI/0186, approved on the 8th January 2014), St Michael's House (approved 13th November 2013). The other ID service provider organisations did not have an ethics committee and accepted DCU ethical approval.

The main ethical issues identified were possible poor comprehension, literacy and verbal communication skills which were accommodated in the following way; assent was obtained from the PwID and consent was obtained from a family member. Consent was required from a family member as the Assisted Decision-Making (Capacity) Bill 2013 is not yet law in Ireland. Assent/consent forms were developed in an easy read format for PwID in consultancy with an ID advocacy group with experience advising research teams (See Appendix A). Each step of data

collection was explained to participants using the consent forms on the day of data collection by a member of the research team. Participants and their family members marked which aspects of the study they agreed to and signed consent forms before participating in the study. Participants who were unable to marked an 'X' witnessed by two researchers. All family members were asked to sign a consent form on their own behalf and on behalf of their family member with an ID (See Appendix A). All participants were informed that they may pull out at any stage, say no to any part of the study and that all information provided would be confidential.

Setting

Five ID service provider organisations agreed to facilitate access to a sampling frame from a large urban and rural geographical spread; Centre A (urban), Centre B (rural), Centre C (urban and rural) Centre D (urban), in the Republic of Ireland, and Centre E, (urban and rural) in Northern Ireland.

Suitable venues were arranged to meet with participants and family members i.e. local service provider location or appropriate local venues were hired by the study team. Tables were arranged with a suitable distance between them to allow privacy.

Participant Profile

The overall SOPHIE study aimed to recruit up to 400 PwID from ID service provider organisations. Participants were required to have a family member with them to participate in the study. PwID of all levels of ID, residential settings and ages above 16 years of age were invited to participate in this study.

Inclusion Criteria

- People with an intellectual disability, ambulant or non-ambulant, over 16 years of age
- Verbal communication skills sufficient to provide information about themselves, or a family member willing to provide this information
- Ability to provide assent or a family member willing to provide informed consent
- Registered with a service for PwID or SOI

Exclusion Criteria

- Verbal communication skills not sufficient to provide information about themselves and/or no family member to provide this information
- Not registered with a service for PwID or SOI
- Individuals without the ability to provide assent or a family member willing to provide informed consent

Recruitment from Intellectual Disability Service Provider Organisations

Each participating ID service provider appointed a 'link person' to liaise with the study team. The number of service users over 16 years of age registered with each service provider organisation was shared with the research team. Anonymized or minimal data was shared with the research team to allow for recruitment, adhering to data protection laws.

The overall SOPHIE study aimed to recruit PwID, age and sex matching those who do and do not take part in SOI. Initially when recruitment began, individuals who participate in SOI were identified by service provider staff and anonymous identifiers were entered into a Microsoft Excel spreadsheet. Research Randomizer software was used to randomly select PwID who take part in SOI to invite to participate in the study. Study information in an easy read format for PwID, an information sheet and frequently asked questions sheet was developed and distributed to selected PwID either in the post or through service provider staff (Appendix B).

In the overall SOPHIE study it was intended to age (±2 calendar years) and sex match study participants who take part in SOI with PwID who do not take part in SOI. When recruitment began PwID who take part in SOI were recruited initially. Anonymous identifiers for PwID who do not take part in SOI, in the same organisation, were used to select PwID who do not take part in SOI to invite to participate. Often there was more than one match. In this case Research Randomizer software was used to randomly select PwID who do not take part in SOI to invite to participate. This was a time-consuming process as it involved going

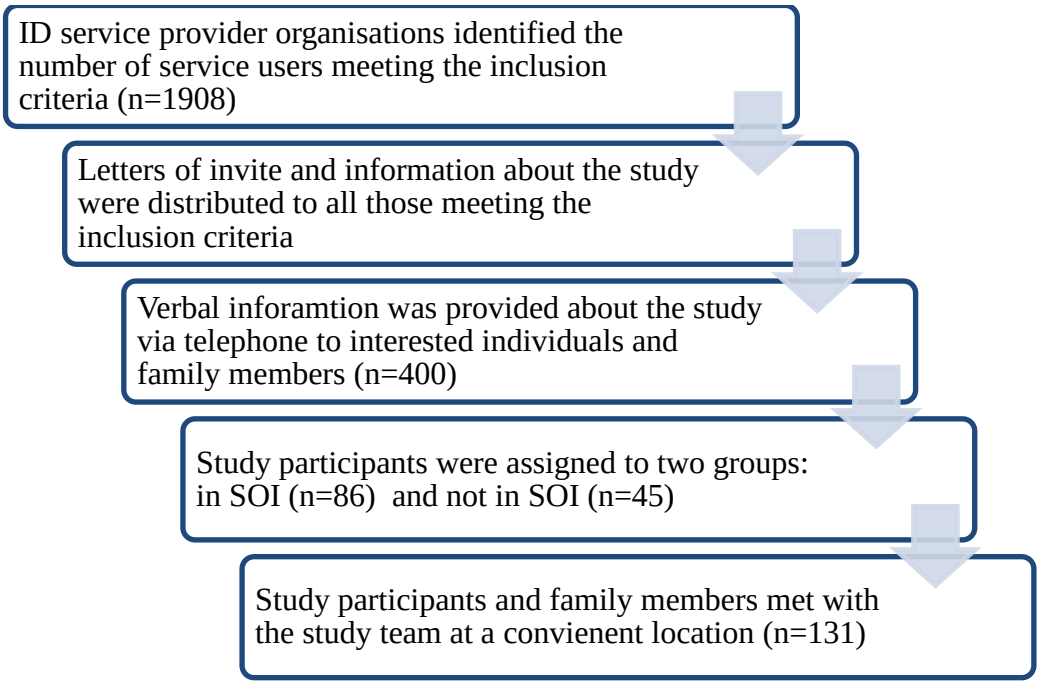
back and forth with the link person to arrange distribution of study information packs. Often more than five matched individuals were invited, each one week apart, with no success. This method was used in the first service provider organisation that participants were recruited from, Centre A. In Centre B a strategy was successfully developed whereby all PwID who meet the inclusion criteria would be invited to participate in the research. Participants would be retrospectively age and sex matched. This method was used thereafter and is outlined in figure 1.

The method of contact allowed by the research team was determined by the service provider organisations. Written material was distributed and consent was obtained for the study team to contact service users and their family members over the telephone or interested service users and their families were invited to contact the study team. Verbal information about the study was provided over the telephone. On average 2-3 calls were made to each study participant and family member. If members of the research team were not successful in making contact after the 4th call, potential participants were removed from the list. This involved making approximately 6,000 phone calls, which was shared by two MSc students.

As recruitment was slower than expected local media campaigns were commenced with advertisements placed in local newspapers and a radio interview.

Participant recruitment from Northern Ireland was unsuccessful. Two individuals expressed interest however given the logistics involved it was deemed not feasible to travel to allow them to participate in the SOPHIE study. Additional resources were put into recruitment in NI including arranging a UK telephone number and organising transport for study participants with the service provider organisations, however this was unsuccessful.

Figure 1: Recruitment process from Intellectual Disability Service Provider Organisations B-E



Data Collection Methods

Primary Participant Questionnaire

PwID often have reduced cognitive and language skills, limiting the reliability and validity of self-reported answers to research instruments (Emerson, Felce and Stancliffe 2013). Often proxy reporters are used in research in the population of PwID. A ‘proxy’ reporter answers questions on behalf of another person they are familiar with, whereas a ‘self-reporter’ answers on their own behalf (BenÃ-tez Baena, Padilla GarcÃ-a and Ongena 2012). Proxy reporters are of use in reporting observable information, for e.g. how often an individual sees their GP or how often they play soccer, but there are limitations in the use of proxy reporters in subjective topics, for e.g. how a person is feeling (Emerson, Felce and Stancliffe 2013).

Survey instruments may be adapted, for example the use of plain language and less complex scales, which can improve the validity and reliability of responses but the comparisons that can be made with the general population are also reduced

(Emerson, Felce and Stancliffe 2013). The population of PwID are a heterozygous group and vary in their abilities, an adapted instrument may be appropriate for individuals with a mild to moderate ID but may not be suitable for an individuals with a severe/profound ID (Emerson, Felce and Stancliffe 2013). There is little investigation of the best tools for each subgroup of PwID, while strategies are suggested in the literature further research is required to improve methods of questioning in PwID (Finlay and Lyons 2011).

The SOPHIE study sought to examine the health status and health service utilisation of PwID. A comprehensive questionnaire was required. As there is currently no validated instrument capturing information on the health status of the population of PwID it was decided that in order to collect accurate, comprehensive data and to make comparisons with the general population in Ireland the Survey of Lifestyle, Attitudes and Nutrition (SLÁN) 2006 questionnaire would be adapted (see Appendix C for SOPHIE study primary participant questionnaire). Adaptations relevant to the population of PwID were included from the NIDD, SOI and the expertise of the study team. This method has not been validated in PwID, however it was deemed to be the most appropriate method in order to obtain comprehensive information from study participants. Face to face interviews were carried out between members of the study team with study participants, who were encouraged to answer all questions they were able to do so reliably. A family member who knows them well was also present to act as a proxy reporter, when required. It was endeavoured at all times to obtain information directly from the PwID themselves. The reliability of answers was checked with family members or paid carers.

Additional contextual questions around food were developed by the researcher with a Likert scale examining autonomy with regards to food choice, cooking skills and food purchasing etc.

Dietary Intake

As reported in the literature review chapter of this thesis there is currently no validated method for collecting data on the nutritional intake of PwID. Difficulties with concentration, comprehension and memory skills are common in PwID. The

use of proxy reporters appears to be indicated to improve the accuracy of data obtained.

Food diaries require the respondent to record a detailed description of food and drink items consumed and the time of consumption for an agreed period of time. Estimated food diaries require respondents to estimate portion sizes, often using household measures, whereas weighed food diaries are the most accurate requiring respondents to weigh all items consumed (Gibson 2005). Recording periods of 7 days are considered the most accurate on estimating usual dietary intake but places a high burden on the respondent, therefore often periods ranging from 2 to 5 days are used (Gibson 2005). Given the challenges in collecting dietary data in this population and the need for proxy reporting in various locations it was decided that a 4 day estimated food diary, including 2 weekend days, was the most appropriate dietary assessment tool to gather detailed contextual and nutritional intake data in study participants.

Permission was obtained to adapt the ROOTS 4 day food diary. A video of instructions was developed, however this was not requested by any participants. Written instructions were developed and included at the beginning of food diaries. Verbal instructions were also provided (see Appendix D). Given the complexity of completing food diaries family members or service provider staff acted as proxy reporters. Reporters were requested to estimate portion sizes using household measurements such as measuring cups, spoons, or glasses, or by calculating weight or volume as indicated on packaging labels. Portion sizes not clearly recorded were estimated using the Food Portion Sizes (Food Standards Agency 2002).

Reporters were encouraged to contact the researcher if they had difficulties completing food diaries. Where possible the researcher, a RD, collected and reviewed food diaries for errors face to face with reporters. If this was not possible food diaries were posted and on review if errors were identified the researcher contacted reporters via telephone.

Anthropometric Data

As concluded in the literature review section of this thesis height, weight, BMI and waist circumference measurements appear to be feasible and reliable in the population of PwID.

"The WHO STEPwise approach to Surveillance (STEPS) is a simple, standardized method for collecting, analysing and disseminating data in WHO member countries" (World Health Organisation 2014). Section 3: Guide to Physical Measurements (Step 2) was adapted to suit the study population (see Appendix E for protocols). All measurements were taken twice and the mean was used for analysis (see Appendix F for data collection sheet).

Height (m) and weight (kg) were measured to the nearest 0.1m and 0.1 kg, respectively, using a stadiometer (Leicester Height Measure) and calibrated digital weighing scales (TANITA HD-305 and TANITA WB-100MA). BMI was calculated using the Quetelet formula (weight (kg)/ height^2 (m^2).

Waist circumference was measured to the nearest 0.1 cm using an anatomical measuring tape. Measurements were taken at the midpoint between the lower margin of the last palpable rib and the top of the iliac crest (hip bone) at the end of a gentle expiration, with participants' arms relaxed at their sides. Waist circumference measurements were taken behind a 3 sided portable screen to allow participants privacy.

Pilot Testing

A pilot study was carried out at the outset of the project to test the feasibility of the instruments and physical measurement collection. Pilot studies are an important stage of the research process in order to examine the usefulness of a planned method (Leon, Davis and Kraemer 2011).

A group of 10 Special Olympic athletes, with an ID, and their family members participated in the pilot study. Study instruments were administered and physical measurements were obtained, including weight, height and waist circumference.

Feedback was obtained and relevant amendments were made to study instruments. The collection of physical measurements was feasible and acceptable to participants. Changes were also made to the planned structure of data collection. It was intended to administer each instrument to the participants at the same time and move together with the supervision of researchers however it was identified that each family were unique and varied in their speed and ability to answer questions. One to one assistance is required to complete the study instruments, at each individual's own pace. This was implemented and taken into consideration when planning data collection events.

Members of the research team working in the area of ID provided training to the research team in interviewing PwID to minimize potential sources of error and to improve the overall research experience for study participants. Training was provided to members of the team, a physical activity expert and nurse, who would also be taking physical measurements by the author, a Registered Dietitian.

Data Handling and Analysis

Data Storage

Data was locked and stored securely at all times. Each participant was given a unique identification code and all data obtained was identified using this code. Consent forms and a master log linking participant identification codes with confidential data were stored securely in a separate location.

Data Entry and Cleaning

Questionnaire data was entered into Microsoft Excel. When all relevant data was entered each record was manually checked for errors by a team of two researchers. Data cleaning was carried out in SPSS.

Food diary data was entered into the nutritional analysis software WISP (Version 4.0, Weighed Intake Software Package; Tinuviel Software, Warrington, UK). When all relevant data was entered each record was manually checked for errors and amended where required. Incomplete food diaries (n=10) were excluded from analysis. The analysis was exported to Microsoft Excel.

Data Processing

To facilitate analysis ID diagnosis was recoded into a new variable of interest: diagnosis of Down's syndrome and ID or other aetiology. Living arrangements were recoded to living at home (family home) or not. Participants were divided into three groups according to their age, in similar groups as the 2007 SLAN study (Harrington et al. 2008), 16-29 years, 30-44 years and 45-64 years. This allowed for comparison with a nationally representative Irish sample. Data collected in 2006-2007 on anthropometric measurements and nutritional intakes in the general Irish population will be used for comparison with study participants throughout this study. BMI was classified using WHO (1995) classifications as follows; underweight: BMI<18.5kg/m^2, normal weight: BMI18.5-24.9kg/m^2, overweight: BMI25-29.9kg/m^2, obese: BMI≥30kg/m^2. WHO (2011) waist circumference cut-off points for risk of metabolic complications were used; waist circumference >94 cm for men and >80 cm for women indicating increased risk and waist circumference >102 cm for men and >88 cm for women indicating substantially increased risk. Recommendations for intakes of nutrients were obtained from the Food Safety Authority of Ireland (1999, 2005, 2011) and the UK Dept. of Health (1991).

Nutrients of interest in the Irish population identified from the Scientific Recommendations for Healthy Eating Guidelines in Ireland (Food Safety Authority of Ireland 2011) and include energy, % energy from fat, % energy from saturated fat, % energy from sugar, fibre, iron, calcium and vitamin D. Data is available for the general Irish population intakes of energy, percentage energy from fat, fibre, iron, calcium and vitamin D (Harrington et al. 2008).

Data Analysis

Data were analysed using IBM SPSS Statistics 21.0. Missing data was coded as 999. A significance level at a *p* value of .05 was used for all analyses. Where participants had incomplete data for a given variable, participants were excluded from analysis of this variable only.

Descriptive statistics were calculated via means, standard deviations, minimums, maximums, percentages, medians and percentiles, where appropriate. Independent sample T tests were used to examine the difference between two means. With Chi-square analysis it was tested if there were any association between contextual information around food, fizzy drink and fried food consumption and BMI classification. To explore associations between BMI and waist circumference with age, gender, level of ID, diagnosis of Down's syndrome or other ID, living at home or not and participation in SOI a series of regression analyses were performed. Variables that showed significant associations in univariate analyses (independent variables entered individually) were entered into a multivariate model (independent variables entered simultaneously).

Chapter 4: Results

This chapter describes the results of this study. Response rates, anthropometric measurement, contextual dietary intake and nutritional intake data are described.

Response Rates and Descriptive Characteristics

Table 3 demonstrates response rate by region and in total. It was intended to recruit a representative sample of PwID to this study; however response rates were poorer than anticipated. The main reasons for declining to participate reported were having no family member willing or able to participate with the PwID, family illness, busy schedules, competing priorities, burden of care, that participation could not be facilitated in the families own home and lack of interest.

Table 3 Number of individuals invited to participate and response rates from each service provider organisation

Service	Location	Invited (n)	Total (n)	Total (%)
Centre A	Urban	723	34	4.7
Centre B	Rural	432	38	8.8
Centre C	Urban and Rural	500	46	9.2
Centre D	Urban	185	13	7.0
Centre E	Urban and Rural	68	0	0.0
Total		1,908	131	6.9

The characteristics' of study participants are described in Table 4. The majority of participants had a mild or moderate ID, participated in SOI and lived at home with family members. Down's syndrome was the most frequent reported ID diagnosis.

Table 4 Characteristics of the study participants

	Total Sample		Completed Anthropometry		Completed Food Diary	
	n	**%**	**n**	**%**	**n**	**%**
Gender						
Male	77	59	71	58	49	57
Female	54	41	52	42	37	43
Age Category (years)						
16-29	57	44	54	44	41	48
30-44	48	37	44	36	27	31
45-64	26	20	25	20	18	21
Level of ID						
Mild	60	48	56	48	39	47
Moderate	60	48	58	49	39	47
Severe	6	5	4	3	5	6
ID Diagnosis						
Down's Syndrome	56	44	55	46	42	49
Cerebral Palsey	7	6	5	4	4	5
Autism	14	11	13	11	8	9
Non specific ID	31	24	29	24	19	22
Other	19	15	17	14	12	14
Living Arrangements						
Living at home	105	80	98	80	75	87
5 day community group home	1	1	1	1		
7 day community group home	6	5	6	5	3	4
5 day residential centre	7	5	7	6	5	6
7 day residential centre	6	5	5	4	2	2
Other	6	6	6	6	1	1
Geographical Location						
In open country	39	30	39	32	28	33
In a village	20	16	17	14	12	14
In a town (1,500 +)	13	10	11	9	7	8
In a city (other than Dublin)	22	17	21	17	12	14
In Dublin / Belfast City	35	27	33	27	26	31
Member of SOI						
Yes	86	66	84	68	60	70
No	45	34	39	32	26	30
BMI Categories						
Underweight	3	2	3	2	3	4
Normal Weight	28	23	28	23	21	25
Overweight	35	28	35	29	24	29
Obese	58	47	57	46	35	42

* Because of rounding errors some percentages may add up to slightly more or less than 100%.

Anthropometric Measurements

Table 5 describes the mean, SD and range of the anthropometric measurements collected in this study. The mean BMI of the overall study sample was 29.4kg/m^2 ±6.1. The mean BMI of men was 28.8kg/m^2 ±5.8 and the mean BMI of women was 30.2 kg/m^2 ±6.5, which are not significantly different (p=0.223).

Table 5 Distribution of anthropometric measurements obtained

		Mean	SD	Min	Max
Total	Height (m)	1.60	0.13	1.28	1.99
	Weight (kg)	74.8	19.0	32.1	124.7
	BMI (kg/m²)	29.4	6.1	16.3	47.9
	Waist (cm)	93.3	14.8	64.0	130.0
Male	Height (m)	1.65	0.13	1.42	1.99
	Weight (kg)	78.5	20.3	45.0	124.7
	BMI (kg/m²)	28.8	5.8	16.3	43.7
	Waist (cm)	95.6	15.1	64.0	129.0
Female	Height (m)	1.52	0.11	1.28	1.72
	Weight (kg)	69.8	15.7	32.1	115.8
	BMI (kg/m²)	30.2	6.5	16.6	47.9
	Waist (cm)	90.1	13.9	66.0	130.0

BMI classification (World Health Organisation 1995) categorises 2.4% of the sample as underweight, 22.6% as normal weight, 28.2% as overweight and 46.8% as obese.

Obesity can be categorised as obese class I (BMI 30-34.9kg/m^2), obese class II (BMI 35-39.9kg/m^2) and obese class III (BMI ≥40kg/m^2). Of the study participants 26% were in obese class I, 17.9% in obese class II and 2.4% in obese class III.

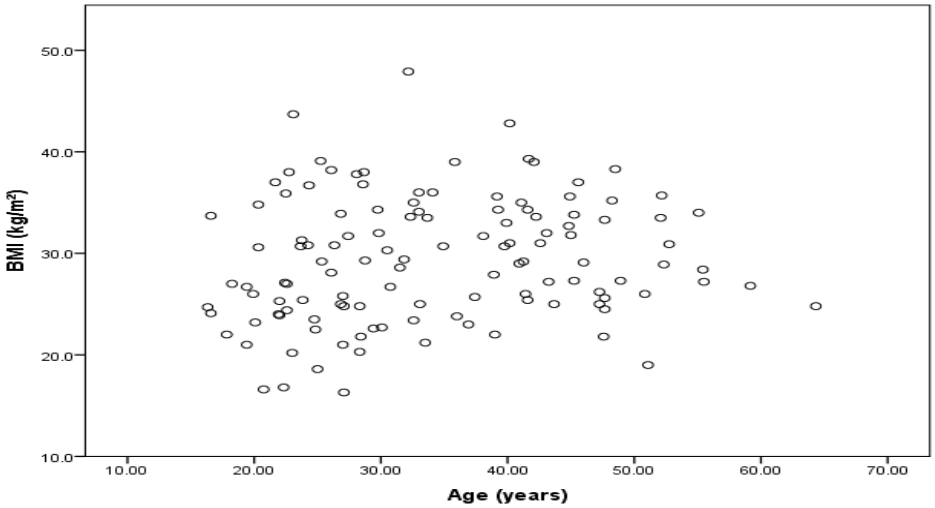
Table 6 describes the distribution of BMI by gender, age category, level of ID, diagnosis, living arrangement and SOI participation.

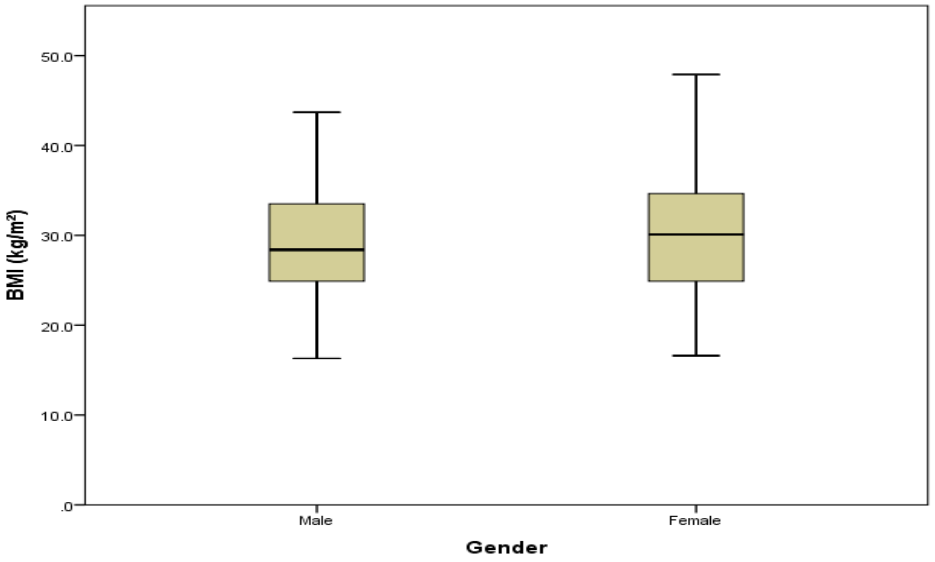
Table 6 Distribution of BMI by gender, age category, level of intellectual disability, diagnosis, living arrangement and Special Olympics participation

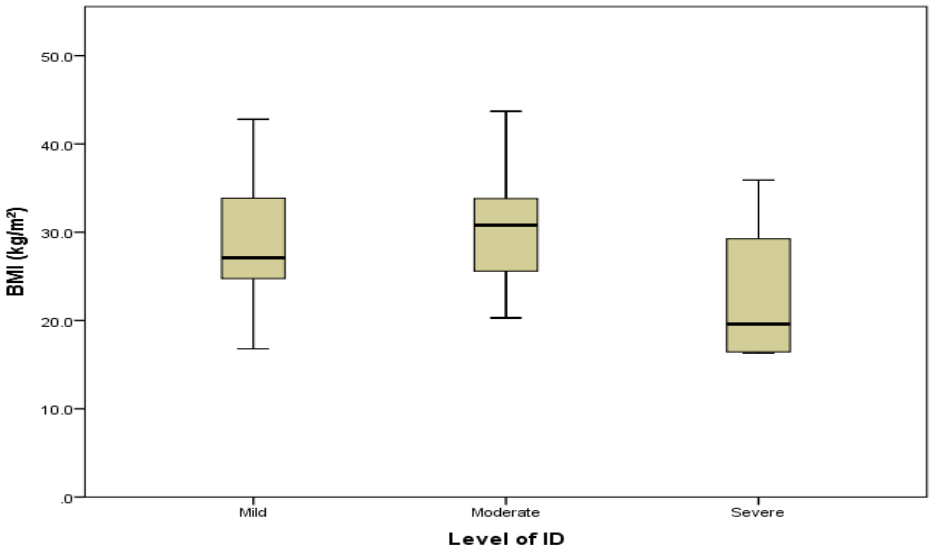
			Percentiles	
	Mean	**Median**	**25**	**75**
Gender				
Male	28.8	28.4	24.8	33.5
Female	30.1	30.1	24.9	34.8
Age Category (years)				
16-29	28.1	26.9	23.4	33.8
30-44	31.1	31	26.2	34.8
45-64	29.3	28.4	25.8	33.7
Level of ID				
Mild	28.6	27.1	24.7	34
Moderate	30.4	30.8	25.6	33.9
Severe	22.9	19.6	16.4	32.6
ID Diagnosis				
Down's Syndrome	31	30.7	26	35.7
ID Other Aetiology	27.7	27.1	24.1	31.7
Living Arrangements				
Living at home	28.9	28.8	24.5	33.8
Not living at home	31.1	30.9	25.9	36.3
Member of SOI				
Yes	29.4	29.1	24.7	34.3
No	29.4	29.1	25.6	33.7

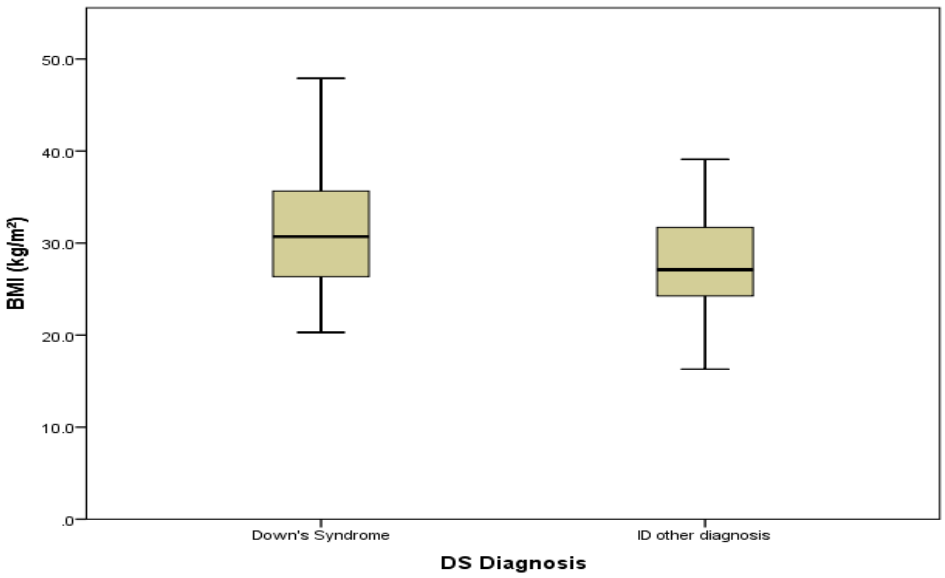
Graphs of association between BMI and age, gender, ID severity, Down's syndrome diagnosis, living arrangement and SOI participation are shown in figure 2. There mean BMI of those with Down's syndrome appears to be higher than of those without a diagnosis of Down's syndrome, which will be examined using regression analyses.

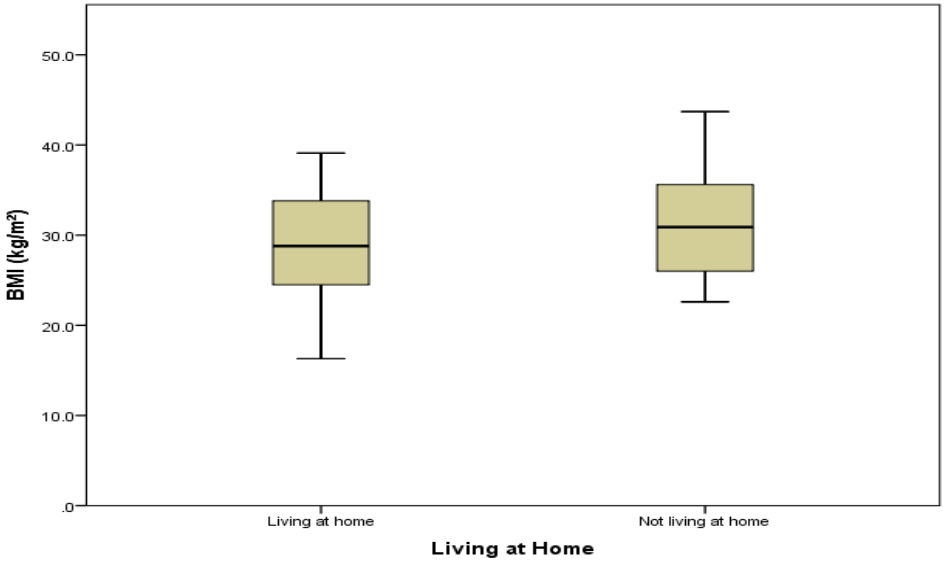
Figure 2: Distribution of BMI by age, gender, ID severity, Down's syndrome diagnosis, living arrangement and SOI participation.

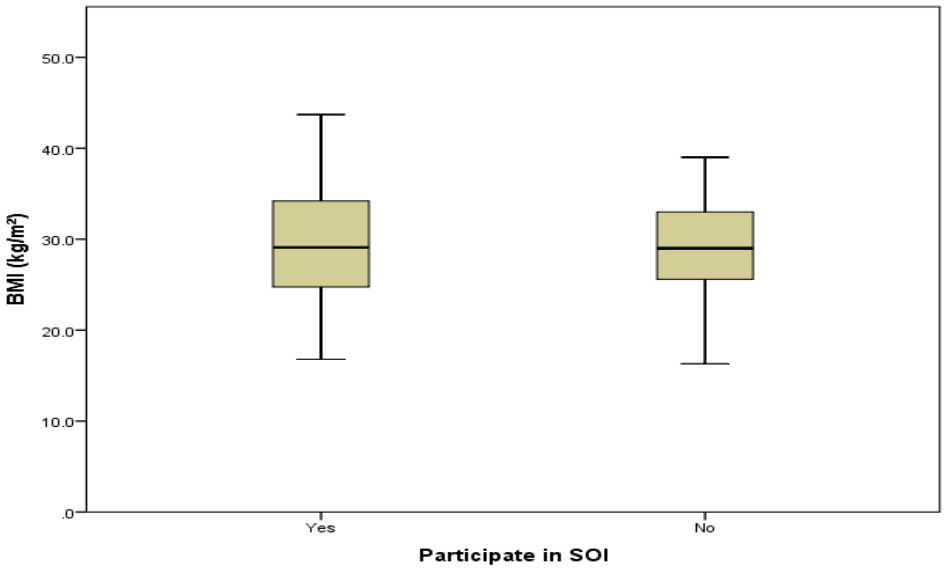







BMI (kg/m²)
50.0
40.0
30.0
20.0
10.0
.0
Down's Syndrome
ID other diagnosis
DS Diagnosis


BMI (kg/m²)
50.0
40.0
30.0
20.0
10.0
.0
Living at home
Not living at home
Living at Home


BMI (kg/m²)
50.0
40.0
30.0
20.0
10.0
.0
Yes
No
Participate in SOI

Results of univariate linear regression are displayed in table 7. Univariate analysis identified a significant positive association between having a diagnosis of Down's syndrome and BMI.

Table 7 Linear Regression Analysis with BMI

	Univariate			
	B	Sig.	95% CI	
Age	0.08	0.122	-0.20	0.18
Being female	1.37	0.223	-4.42	3.58
Lower level of ID	0.31	0.753	-3.83	2.22
Daignosis of Down's Syndrome	-3.36	0.003	-4.31	-1.20
Living at home	2.46	0.075	-0.25	5.17
Participation in SOI	0.08	0.948	-2.23	2.38

Note: B represents unstandardized regression co-efficient, R^2= 0.075

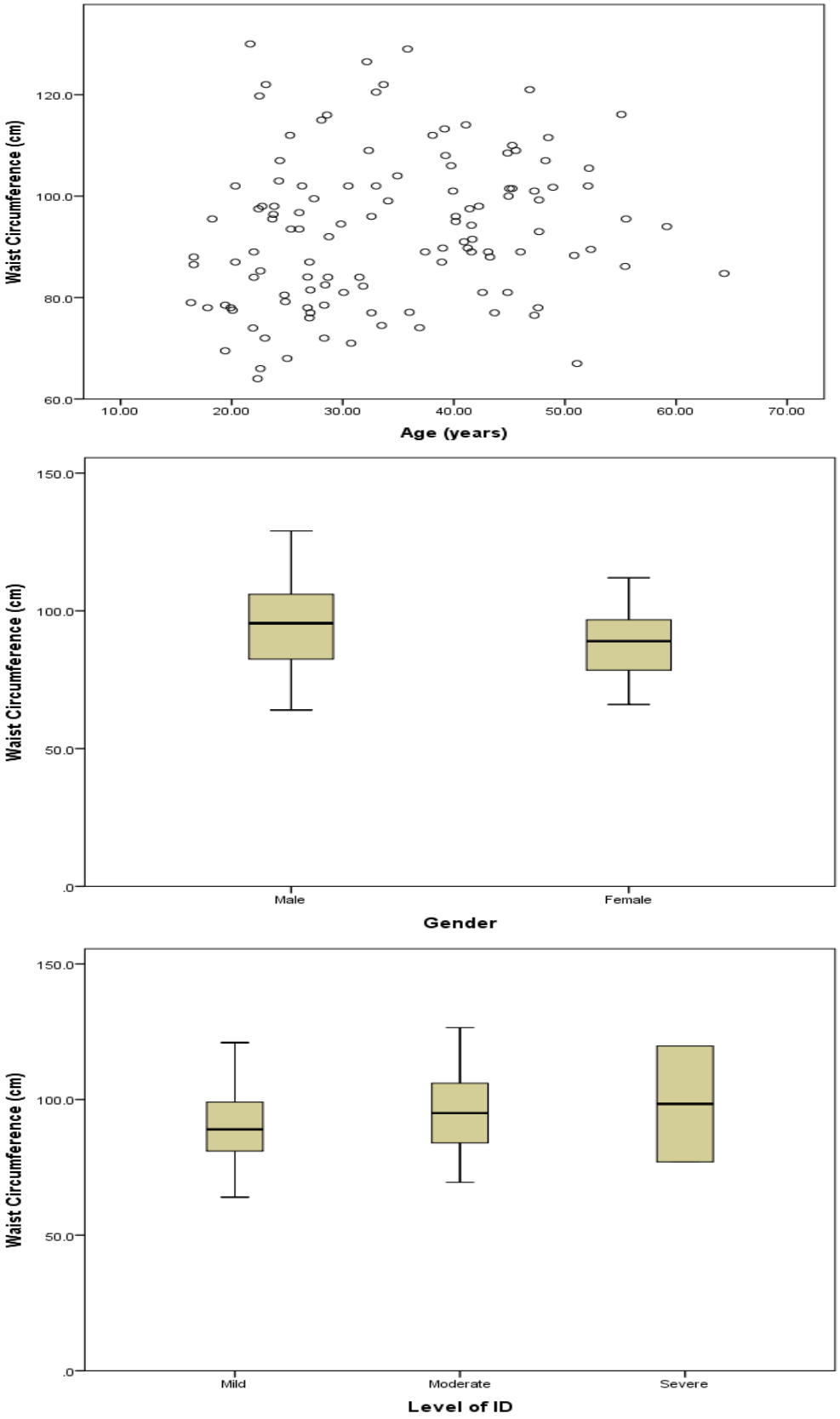
Table 8 shows the distribution of waist circumference by gender, age category, level of ID, diagnosis, living arrangement and SOI participation. The mean waist circumference of men is significantly higher than women, 95.6cm compared to 90cm (p=0.045).

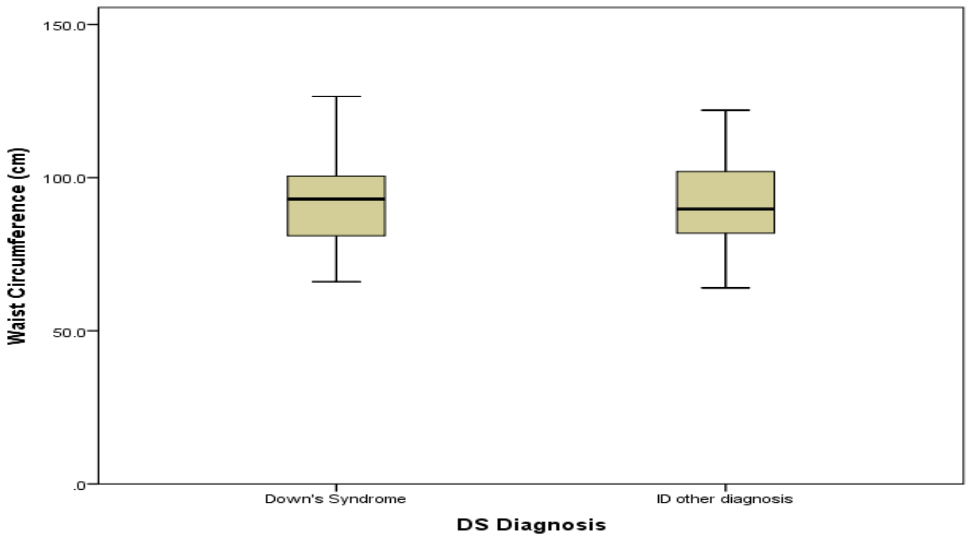
Table 8 Distribution of waist circumference by gender, age category, level of intellectual disability, diagnosis, living arrangement and Special Olympics participation

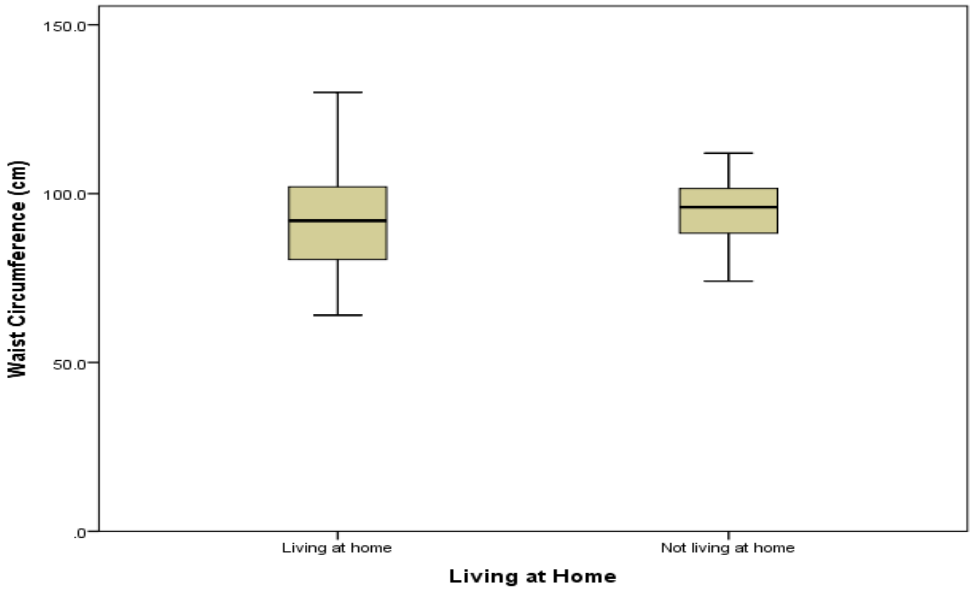
			Percentiles	
	Mean	Median	25	75
Gender				
Male	90.6	95.5	82.4	106.5
Female	90.1	89	78.5	97.4
Age Category (years)				
16-29	89.5	87	78	98
30-44	95.8	95	84	106
45-64	97	100	88.5	106.6
Level of ID				
Mild	90.4	89	80.5	99.1
Moderate	95.9	95	82.8	106.5
Severe	98.4	98.4	77	
ID Diagnosis				
Down's Syndrome	92.4	93	81	101
ID Other Aetiology	92.8	89.8	81.5	102
Living Arrangements				
Living at home	92.8	92	79.9	102
Not living at home	95.8	96	87.7	102.3
Member of SOI				
Yes	92.2	92	80.5	102
No	96	95	87	107

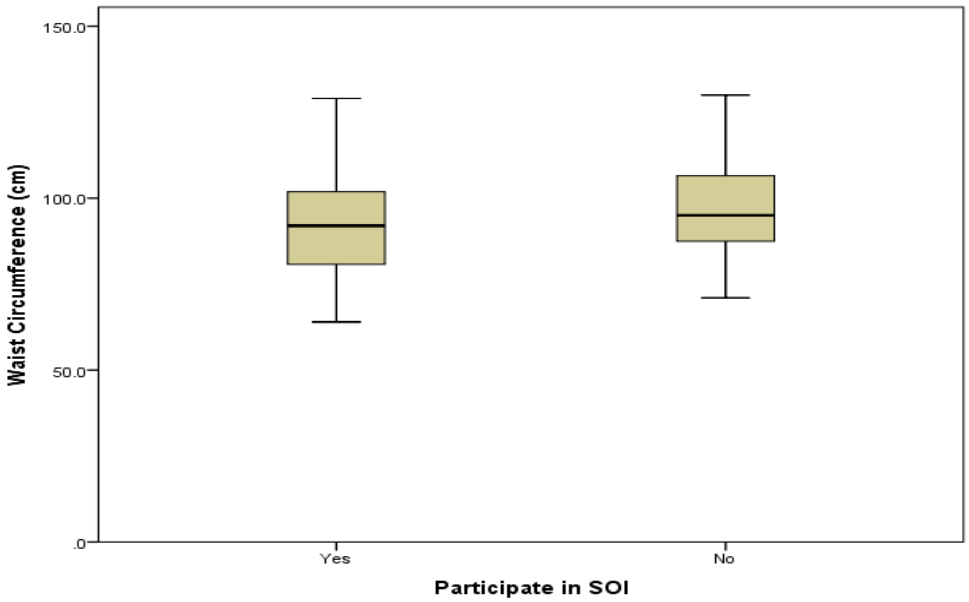
Graphs of association between waist circumference and age, gender, ID severity, Down's syndrome diagnosis, living arrangement and SOI participation are shown in figure 3. The mean waist circumference of men, those with a more severe ID and those with Down's syndrome appears to be increased. Statistical associations will be examined using regression analyses.

Figure 3: Distribution of waist circumference by age, gender, ID severity, Down's syndrome diagnosis, living arrangement and SOI participation.




150.0
100.0
50.0
.0
Waist Circumference (cm)
Down's Syndrome
ID other diagnosis
DS Diagnosis


150.0
100.0
50.0
.0
Waist Circumference (cm)
Living at home
Not living at home
Living at Home


150.0
100.0
50.0
.0
Waist Circumference (cm)
Yes
No
Participate in SOI

Results of univariate and multivariate linear regression are displayed in table 9. Univariate analysis identified a significant association between waist circumference and increasing age, being male and increasing severity of ID. Multivariate analysis identified a significant association between increasing waist circumference and increasing severity of ID. The association between increasing age (p=0.053) and being male (p=0.06) with waist circumference was almost significant.

Table 9 Linear Regression Analysis with Waist Circumference

Univariate				
	B	Sig.	95% CI	
Increasing age	0.26	.039	0.01	0.50
Being male	-5.54	.045	-10.96	-0.12
Higher severity of ID	4.86	.041	0.20	9.53
Diagnosis of Down's syndrome	0.50	.858	-5.06	6.07
Living at home or not	2.90	.399	-3.89	9.68
Participation in SOI	3.72	.196	-1.95	9.39
Multivariate				
	B	Sig.	95% CI	
Increasing age	0.178	0.053	-0	0.485
Being male	-0.17	0.06	-10.6	0.214
Higher severity of ID	0.188	0.04	0.212	9.313

Note: B represents unstandardized regression co-efficient, R^2= 0.102

Contextual Data from Questionnaires

When asked about their weight 41% of study participants said they were ‘about the right weight’, 33.6% said they were ‘too heavy’, 8.4% said they were ‘too light’ and 16.8% said they were ‘not sure’. Approximately half were actively managing their weight. When asked ‘in the past 12 months doctor, nurse or other health professional advised you to lose, maintain, or gain weight?’ 18.8% of participants reported ‘yes, lose weight’, 3.1% reported ‘yes, maintain current weight’, 1.6% reported ‘yes, gain weight’ and 76.6% reported ‘no’.

When asked ‘do you make your own food choices?’ 13.1% of participants reported ‘always’, 14.6% ‘usually’, 45.4% ‘sometimes’, 13.1% reported ‘rarely’ and 13.8% reported ‘never’. For those who do not choose themselves, family members (80%) and paid care workers (19.2%) made their food choices.

Most participants rated their cooking skills as poor (40%), with just 6% reporting their cooking skills as very good. Meal preparation was mostly carried out by family members (62%), staff (19%), study participants without support (9%) and study participants with support (9%). Meal cooking was similarly mostly carried out by family members (68%), staff (20%), participants with support (6%) and participants without support (5%).

Food shopping was mostly done by family members (64%), staff (18%), study participants without support (15%) and study participants with support (2%). One quarter of participants reported they always or usually plan what foods are bought for them, however 42% reported they rarely or never plan what foods are bought for them.

Most participants (76%) had consumed snacks the day before being interviewed. Almost half (44%) of study participants reported that they had one snack, 33% had two, 10% had three, 13% had more than four snacks.

Fizzy drinks were consumed by most study participants, 15% reported ‘daily’, 7% reported ‘4-6 times a week’, 31% reported ‘1-3 times a week’, 20% reported ‘less than once a week’ and 28% reported ‘never’. Fried food was also consumed by study participants, 5% of participants reported’ daily’, 2% reported ‘4-6 times a week’, 37% reported ‘1-3 times a week’ and 53% reported’ less than once a week’.

The association between contextual nutritional intake data from questionnaires and BMI categories was examined. There was only one significant positive association, between fried food consumption and increasing BMI category ($p=0.041$).

Nutritional Intake

Table 10 summarises participants’ overall nutritional intake and includes recommended nutrient intakes. Mean intakes of energy (1890kcal), fibre (18g), calcium (928mg), vitamin D (2.2µg), folate (284µg) and vitamin E (7mg) were below recommendations. Iron intakes (10mg) for women are also below

recommendations. Mean % energy intakes from sugar (23%), fat (37%) and saturated fat (16%) are above maximum recommended intakes.

Table 10 Distribution of study population's nutritional intake and comparison with recommendations

Nutrient	Mean	SD	Min	Max	Rec.
Energy (kcal)	1889.5	467.0	832.0	3028	2200 (1800)[a]
Protein (g)	77.5	18.7	41.9	142.6	55.5 (45) [b]
Carbohydrate (g)	230.4	63.4	89.4	439.0	
Sugars (g)	108.0	47.9	35.1	296.9	
Energy from Sugar	22.6%	7.2%	9.4%	22.6%	≤10% [a]
Total Fat (g)	79.0	26.7	27.6	141.0	
Energy from Fat	37.1%	5.8%	21.7%	37.1%	20-35% [a]
Saturates (g)	34.0	13.6	9.5	68.5	
Energy from Sat Fat	15.9%	3.7%	6.1%	15.9%	≤10% [a]
Monounsaturates (g)	24.2	9.0	7.3	47.8	
Polyunsaturates (g)	11.1	5.4	3.3	29.5	
Fibre (g)	17.8	6.6	5.5	44.9	≥25[a]
Sodium (g)	2.7	9.4	0.1	7	1.6[c]
Calcium (mg)	927.8	340.3	337.0	2172	1000[d]
Iron (mg)	10.8	3.4	4.5	25.01	10 (14)[d]
Vitamin D (µg)	2.2	1.5	0.4	9.39	5[d]
Folate (µg)	284.2	108.4	147.0	713	300[d]
Vitamin C (mg)	150.7	166.4	17.0	1157	60[d]
Vitamin E (mg)	7.4	3.3	2.7	16.6	10 (8)[d]
Thiamin (mg)	1.8	0.6	0.8	3.7	1 (0.8)
Riboflavin (mg)	1.9	0.7	0.7	4.4	1.6 (1.3)[d]
Niacin (mg)	21.1	5.8	7.9	36.4	17 (13)[b]
Vitamin B6 (mg)	2.1	0.6	1.0	4.8	1.4 (1.2)[b]
Vitamin B12 (mg)	4.8	2.4	1.2	14.8	1.4[d]

*Recommended amounts per day, unless given in other terms. If that for women is different from that for men, it is given in parenthesis. Where there was a range the mean value was used for comparison.

[a] Recommendations are goals from the Food Safety Authority of Ireland (2011)

[b] Recommendations are RNI from the UK Dept. of Health (1991)

[c] Recommendations are RDA from Food Safety Authority of Ireland (2005)

[d] Recommendations are RDA from Food Safety Authority of Ireland (1999)

Analysis of variance tests showed that males' intake of energy (p=0.001), protein (p=0.012), fat (p<0.001), % energy from fat (p=0.003), % energy from saturated fat (p=0.005), sodium (p=0.001) and iron (p=0.005) were significantly higher than females' intakes.

The mean reported energy intake of study participant's was 2044kcal/day for men and 1684kcal/day for women. Correlations between energy intake (kcal) and BMI and waist circumference were not significant, (r= - 0.182, p=0.1 and r= -0.022 and p=0.845, respectively).

Participants' mean percentage energy from fat was 37%. The mean percentage energy from fat was 39% for men and 34.7% for women, with 36% of participants meeting recommendations of ≤35% energy from fat.

Participants' mean percentage energy from saturated fat was 15.9%. The mean percentage energy from saturated fat was 16.9% for men and 14.6% for women. Just 5.8% of study participants met the recommendations of ≤10% energy from saturated fat.

The mean percentage energy from sugar of study participants' was 22.6%. The mean percentage energy from sugar of men was 21.7% and of women was 23.8%. Just 2.3% of study participants had ≤ 10% energy from sugar.

Study participants' mean fibre intake per day was 17.8g. The mean fibre intake for men was 18.8mg/day and for women was 16.6mg/day, with 10.5% of study participants getting the recommended 25g/day.

Study participants' mean iron intake per day was 10.8g. The mean iron intake for men was 11.7mg/day and for women was 9.5mg/day. More men than women met iron RDAs, 65.3% compared to 40.5%, respectively.

Study participants' mean calcium intake per day was 928mg. The mean calcium intake for men was 980mg/day and for women was 859mg/day. The RDA for calcium was met by 35.9% of study participants.

Study participants' mean vitamin D intake per day was 2.2 µg. The mean fibre intake for men was 2.5µg/day and for women was 2.5µg/day. Just 3.5% of study participants met the RDA for vitamin D.

Chapter 5: Discussion

Anthropometric Measurements

The aim of this study is to describe the anthropometric status and the nutritional intake of PwID. While a representative sample of the population of PwID was not recruited the results of this study highlight the alarming prevalence of obesity in this sample of PwID.

The prevalence of obesity in the study sample is broadly consistent with previous studies. In this sample 28.2% of participants were overweight and 46.8% were obese. Previous studies have estimated the prevalence of overweight in PwID at between 28-38.2% and the prevalence of obesity at between 25.6-51% (Bhaumik et al. 2008, McCarron et al. 2014, de Winter et al. 2012, Emerson 2005, Hsieh, Rimmer and Heller 2014, Stedman and Leland 2010, Yamaki 2005).

In a representative sample of the general population 2% are underweight, 38% are normal weight, 38% are overweight and 23% are obese. While less of the current sample of PwID are overweight (28.2%) compared to the general population, worryingly the prevalence of obesity is double (46.8%).

Individuals with a diagnosis of Down's syndrome were at increased risk of obesity compared to other PwID in the study. This has been found in previous studies (Hsieh, Rimmer and Heller 2014, Melville et al. 2005, Sohler et al. 2009). There is no comprehensive register in Ireland of the prevalence of Down's syndrome, therefore it is difficult to estimate whether the prevalence of Down's syndrome in this sample is representative. In the US the National Down Syndrome Society recognise that individuals with Down's syndrome are at increased risk of overweight/obesity and provide an online weight management resource (National Down Syndrome Society 2015). No similar tool by Down Syndrome Ireland was identified. Only 7.5% of the variance in BMI is explained by a diagnosis of Down's syndrome, which is small. There are therefore other variables influencing BMI in this study sample.

Greater fried food consumption was associated with increasing BMI category (p=0.041). Hsieh, Rimmer and Heller (2014) reported no significant association between increasing fast food consumption and BMI category (AOR = 0.97, 95% CI = 0.80–1.17) in their sample of PwID. However, Hsieh, Rimmer and Heller (2014) reported a significant association between increasing fizzy drink consumption and BMI category (AOR = 0.97, 95% CI = 0.80–1.17), which was not found in this study population (p=0.158). No other studies examining these variables were identified. The differing results highlight the importance of recruiting representative samples of PwID in research studies.

Previous studies have also identified an association between obesity and being female (Emerson 2005, Hsieh, Rimmer and Heller 2014), increasing age (de Winter et al. 2012, Emerson 2005), independent living (Bhaumik et al. 2008, de Winter et al. 2012, Stancliffe et al. 2011) and having a less severe ID (de Winter et al. 2012, Stancliffe et al. 2011). Associations between these variables and BMI were not significant in the study sample. This may be due to differing sample sizes, characteristics' of study participants and non-representativeness of study samples. Future research strategies to recruit representative samples of PwID are needed to investigate the factors associated with overweight and obesity in this population.

Increased waist circumference measurements were associated with increasing severity of ID (p=0.04). The associations between increasing waist circumference and age (p=0.053) and being male (p=0.06) were almost significant. Only 10.2% of the variance is explained by the multivariate model, which is small. There are therefore other variables influencing waist circumference in this study sample. In previous research with PwID BMI measurements are typically taken over waist circumference, few studies were identified that obtained waist circumference measurements in PwID. De Winter et al. (2012) obtained waist circumference measurements in a Dutch sample of older PwID. Significant associations were identified between waist circumference and being female, having Down's syndrome and low levels of physical activity. Different study populations and samples are likely responsible for the differing findings between this and the current study. No other studies examining associations with waist circumference measurements in PwID were identified by the researcher for comparison.

Using waist circumference cut offs (World Health Organisation 2011) in this sample 36.2% of men and 55.1% women are at substantially increased risk of metabolic complications. In samples of older PwID De Winter et al. (2012) reported that 24% of male and 64.3% of female study participants had a waist circumference that classifies them at substantially increased risk of metabolic complications. These results are lower than men in the current sample but higher for women. Burke et al. (2014) reported that 64.6% of their sample was at substantially increased of metabolic complications, which is higher than this sample. The increased prevalence of substantially increased risk of metabolic complications in these two studies may be due to the sample of PwID being over 40 years of age. Further research in a representative sample of PwID is certainly indicated.

Waist circumferences were lower in the sample of PwID than the general population, 95.6cm compared to 99.5cm for men and 90.1cm compared to 90.5cm for women, respectively. This is surprising given that the prevalence of obesity twice as high in the sample of PwID compared to the general population. This may be attributable to differences in measurement techniques. The protocol for obtaining waist circumference measurements in the general population was searched for, unsuccessfully.

It is worrying that 75% of the study sample is overweight or obese and only 33.6% said they were 'too heavy'. Almost half of participants reported that they are actively trying to manage their weight yet 76.6% reported no doctor, nurse or other health professional had advised them to lose, maintain, or gain weight. This is surprising given the major issue of overweight and obesity in this population. There is currently no national Irish policy relating to nutrition in PwID. The National Taskforce on Obesity (2005) as part of Framework for Obesity Prevention for the general population of Ireland stated that 'the health services should recognise maintenance of a healthy weight as an important health issue, and measurement of height, weight, waist circumference and calculation of BMI should be part of routine clinical healthcare practice in primary care and in hospitals'. There is certainly room for improvement in the implementation of this policy in this population.

Contextual Nutritional Intake Information

This study highlights the lack of autonomy PwID have around their nutritional intakes. Just 28% of study participants 'always' or 'usually' make their own food choices and 25% 'always' or 'usually' plan what foods are bought for them. Mc Guire et al. (2007) also reported poor levels of food choice in an Irish sample of PwID. A score of choice relating to individual's diet (the highest score possible is 4, with a higher score denoting a greater level of choice) was used, with study participants scoring between 1.4 and 2.7 (McGuire, Daly and Smyth 2007).

This study also highlights the major role played by family members on the nutritional intake of PwID. When participants did not make their own food choices 80.2% reported it was a family member who chose for them. Family members also prepared 62.3% of participants' meals, cooked 68% of participants' meals and did the food shopping for 64.3% of participants. This must be taken into consideration in order for weight management strategies in this population to be successful.

In this sample there were surprisingly no significant associations between BMI category and who chose, prepared, cooked, planned or shopped for food items. De Winter et al. (2012) reported an association between being overweight and obese and food shopping independently. Similarly they did not report a significant association between food preparation and being overweight and obese. Hsieh et al. (2014) reported an association between fizzy drink consumption and obesity, which was not present in this sample. Further research into contextual dietary factors and overweight and obesity in PwID is indicated with a representative sample.

Participants were more likely to buy their own snacks (36%), with or without support, than their overall food shopping (17%). Snacks may contribute a substantial amount of energy, fat and sugar to study participants' nutritional intakes. The most commonly consumed snacks were biscuits/cakes (49%). Most participants had 1-2 snacks per day (77%). The study participants appear to have more control over their snack food choices, choosing energy dense food items such as biscuits/cakes, which is worrying.

Given the alarming prevalence of overweight and obesity in this population improved services and support for those actively trying to manage their weight

appears indicated. Successful strategies will need to take into consideration contextual information such as who chooses and prepares meals etc. and snack consumption.

Nutritional Intake of Study Participants'

The nutritional intake of the study participants was assessed using four day food diaries. While each study participant was invited to complete a food diary, just 49 food diaries were completed appropriately to be included in analysis.

There has been little comprehensive research into the dietary intake of PwID. Comparisons with other studies are often limited given different methodologies used. Comparisons with two Irish studies (McCarron et al. 2014, McGuire, Daly and Smyth 2007) are limited as they used a Likert scale of how often food items are consumed. Few studies were identified using comprehensive dietary assessment methods such as food diaries in this population. Comparisons can be made however with recommended nutrient intakes.

Limited comparisons can also be made with the general population (Harrington et al. 2008). The method used to quantify the dietary intake of the general population was through a Food Frequency Questionnaire (FFQ). FFQs aim to estimate the frequency foods or food groups are consumed with a list of foods and frequency-of-use response categories (Gibson 2005). FFQs are not as comprehensive as food diaries therefore the comparisons with the general population must be interpreted with caution.

Energy intakes reported in food diaries did not correlate with BMI or waist circumference ($r = -0.182$, $p=0.1$ and $r = -0.022$ and $p=0.845$, respectively), suggesting under reporting of nutritional intakes. While there does appear to be under reporting in the food diaries completed, the data does highlight the poor diet quality of this sample of PwID. Very few study participants are meeting micronutrient RDAs and the energy contributed from fat, saturated fat and sugar is much higher than recommended in most study participants.

The mean reported energy intake of study participant's was 2044kcal/day for men and 1684kcal/day for women which is less than reported in the general population,

2384kcal/day for men and 2173kcal/day for women. It is also lower than the reported intake of 70 overweight and obese US adults with mild to moderate ID through three day food records by Ptomey et al. (2013b). The mean reported energy intake per day was 2332kcal for men and 1728kcal for women. Reported mean energy intakes are lower for men and women than recommended energy intakes, 2200kcal/day and 1800kcal/day respectively. Recommendations for inactive males and females aged 19-50 years were used for comparison.

The energy intakes reported by the study participants' may be lower than recommendations, those reported in other studies and the general population due to the method of collecting dietary intake data used in this study not capturing all of study participants' dietary intakes rather than a true lower dietary intake in this group of PwID. Given that the prevalence of obesity is double that of the general population in this sample and reported energy intakes were 340kcal/day for men and 489kcal/day for women lower than those in the general population, under reporting is likely in study participants' nutritional intake.

The mean percentage energy from fat was 39% for men and 34.7% for women, with 36% of participants meeting recommendations of ≤35% energy from fat. Draheim et al. (2007) reported a similarly high prevalence of high fat diets; 70-87% of participants had ≥30% energy from fat. Ptomey et al. (2013b) reported their participants had a mean intake of 33% energy from fat, which is slightly lower than this sample's intake. Men's intake in the general population (36%) was lower than male study participants. Women's intake in the general population (35%) was similar to female study participants'.

Just 5.8% of study participants met the recommendations of ≤10% energy from saturated fat. The mean percentage energy from saturated fat was 16.9% for men and 14.6% for women. Ptomey et al. (2013b) reported their participants had a mean intake of 11.2% energy from saturated fat, which is slightly lower than this sample's intake.

Alarmingly just 2.3% of study participants met the recommendations of ≤10% energy from sugar. The mean percentage energy from sugar of men was 21.7% and of women was 23.8%. This alarming given that the WHO (2015) has suggested there may be additional health benefits of ≤5% energy from free (added) sugars.

Study participants' mean iron intake per day was 10.8g. Male study participants' mean intake exceeded the RDA; however female study participants' mean intake was lower than the RDA for women. More men than women met iron RDAs, 65.3% compared to 40.5%, respectively. Mean iron intakes were lower in the study population than the general population, 11.7mg/day compared to 13.5mg/day for men and 9.5mg/day compared to 13.2mg/day for women, respectively. Mean iron intakes were also lower in the study population compared to the participants in the study carried out by Ptomey et al. (2013b) reported higher mean iron takes in their US sample, 15.8g/day for men and 16.6g/day for women in their sample.

Study participants' mean fibre intake per day was 18.1g. Just 10.5% of study participants consumed the recommended 25g/day. Mean fibre intakes were lower in the study population than the general population, 18.8mg/day compared to 26.4mg/day for men and 16.7mg/day compared to 26.9mg/day for women, respectively. Fibre intakes were higher in men and similar in women in the current study compared to Ptomey et al. (2013b), whose mean intake per day was 15.1g for men and 16.8g for women.

Study participants' mean calcium intake per day was 928mg. The RDA for calcium was met by 35.9% of study participants. Mean calcium intakes were lower in the study population than the general population, 980mg/day compared to 1041mg/day for men and 859mg/day compared to 906mg/day for women, respectively. Calcium intakes were similar in men and higher in women in the current study compared to those in Ptomey et al. (2013b), whose mean intake per day was 1017mg for men and 791mg for women.

Study participants' mean vitamin D intake per day was 2.2µg. Worryingly, just 3.5% of study participants met the vitamin D RDA. Mean vitamin D intakes were lower in the study population than the general population, 2.5µg/day compared to 3.8µg/day for men and 2.5µg compared to 3.5µg/day for women, respectively. Mean vitamin D intakes were also lower in the study population compared to the participants in the study carried out by Ptomey et al. (2013b) whose mean intake per day was 5.6µg for men and 3.9µg for women.

Overall the reported nutritional intake of most study participants did not meet dietary guidelines. Given that reported nutritional intakes and BMI and waist

circumference measurements do not correlate it is likely that the four day food diaries, completed by proxy reporters, did not capture the total dietary intake of study participants. Therefore, nutritional intakes which appear lower than recommendations may in fact meet these. However, reported intakes of energy from sugar, fat and saturated fat which are greater than recommendations for most study participants may in fact be even greater than those reported in food diaries. This may explain

Strengths and Weaknesses

Few studies exist examining the anthropometric and nutritional status of PwID in Ireland. While the findings of this study may not represent the overall population of PwID they highlight the alarming prevalence of obesity and poor diet quality in this sample of PwID. This study is beneficial in raising awareness of these issues in PwID.

By adapting the SLAN questionnaire direct comparisons can be made between study participants and the general population. Anthropometric measurements were obtained by the same methods as the general population sample, which allows for more reliable comparisons than if they were obtained using different methods.

The use of food diaries to obtain data on the nutritional intake of study participants', which was analysed using the WISP programme, allowed for detailed macro and micronutrient analyses. The researcher was unable to identify any previous studies investigating the dietary intake of PwID on a nutrient basis.

The sample recruited to this study was lower than planned. The uptake for the overall study was just 6.9%. The SOPHIE study was designed to assess the impact of SOI participation on PwID and their family members, therefore PwID could only participate if they had a family member at the interview also. This had an impact on recruitment as PwID who wanted to participate but didn't have a family member to participate with them were excluded from the study. The main barrier to participation in this study appeared to be the competing priorities including burden of care on family members of PwID.

Difficulties in recruitment in the population of PwID have been documented. Lennox et al. (2005) reported an uptake of PwID of 26.5%. They identified barriers to recruitment including heavy ID staff caseloads, high demands and burdens of care faced by family members and non-essential tasks such as taking part in research became a low priority, ethical constraints on directly approaching potential study participants and suspicion towards researchers from ID staff.

Nicholson et al. (2013) identified barriers to recruitment in PwID, including difficulties for potential participants in understanding the future benefits of research, concerns about being able to answer questions, lack of interest and family and carer attitudes influence on PwID. Future research should take into consideration the barriers identified and develop strategies to overcome these. For example, uptake may improve if PwID do not need a family member present to participate in a research study.

Given the complexities of collecting information on this heterozygous population there are few validated tools for collecting health related information on PwID. The overall SOPHIE study aimed to collect comprehensive information about the health and wellbeing of PwID, therefore required proxy reporters for the study participants who were unable to answer questions themselves. While participants were encouraged to answer all questions themselves, often assistance from their family member was required. While this allows for the collection of more comprehensive data it reduces the opportunity for PwID to answer questions themselves. While this has been suggested as appropriate for objective questions (Emerson, Felce and Stancliffe 2013) it reduces the independence and autonomy of the PwID. At present in order to obtain comprehensive data in PwID, however, some proxy reporting does appear to be indicated. The extent to which proxies reported for study participants was not analysed in this study. This would have been of benefit in order to reflect on whether the questionnaire used was appropriate in order to get responses from PwID themselves.

The sample recruited is not representative of the general population of PwID in Ireland. For example those with a severe ID are underrepresented. Given that those with a severe ID are underrepresented and level of ID may be linked with BMI it's

possible that the true prevalence of underweight is higher and overweight and obesity is lower than reported in this study.

Given that 71% of the sample who completed the food diaries were overweight or obese and no significant correlation was found between energy intake and anthropometric measurements, there appears to almost certainly be under reporting of nutritional intakes in food diaries. This may not be deliberate underreporting. One possible cause may be that proxy reporters are likely present for main meals but it's possible that proxy reporters aren't always present for snacks consumed, which may account for some of the under-reporting observed. Snack foods are often high in energy, fat and sugars but low in nutritive value. Therefore the energy, fat and sugar content of the samples diet may be higher than reported.

The high possibility of under reporting limits the validity of statistical analysis of associations with dietary intake in this sample. Future investigation of the optimum method of collecting dietary intake data in this population is required in order to obtain accurate, complete information on the dietary intake of this population. This is essential in order to develop strategies to tackle the obesity epidemic in this population.

Comparisons were made, where possible, with the general population. It is a limitation of this study that a control group was not included. The use of a control group would have allowed for more reliable comparisons to be made, as data would have been collected using the same methods.

Conclusion

The results presented in the current study are consistent with the literature in showing the alarming prevalence of overweight and obesity in PwID. Increased BMI was associated with a diagnosis of Down's syndrome and greater fried food consumption. Increased waist circumference was associated with being male, increasing severity of ID and increasing age. The results of this study also highlight the lack of autonomy PwID have in the choice, procurement and preparation of their dietary intake and the major role played by family members of PwID in their dietary intake. The diet quality of this sample of PwID was poor. While

underreporting is suspected, very few study participants met micronutrient RDAs and the energy contributed from fat, saturated fat and sugar is much higher than recommended in most study participants.

Recommendations

- Future research should focus on developing strategies to recruit representative samples of PwID.
- Further research, with a representative sample of PwID, examining the anthropometric status and nutritional intake of PwID is essential.
- Further research is crucial into the most reliable method for assessing dietary intake in PwID.
- Further research is needed into the optimum methods of obtaining information from PwID
- Further research into the impact of contextual dietary factors such as food choice and nutritional intake is indicated.
- Researchers should use consistent methodologies in order to develop our knowledge base of the nutritional issues faced by PwID
- Future research examining factors associated with overweight and obesity in this population should include nutritional intake data
- Healthcare professionals working with PwID should be aware of the issue of overweight and obesity in this population.

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Appendices

Appendix A Consent Forms

PRIMARY PARTICIPANT CONSENT FORM

Special Olympics Programmes Health Impact Evaluation

I give consent/assent to take part in the following areas of the research study

Please tick where agreed

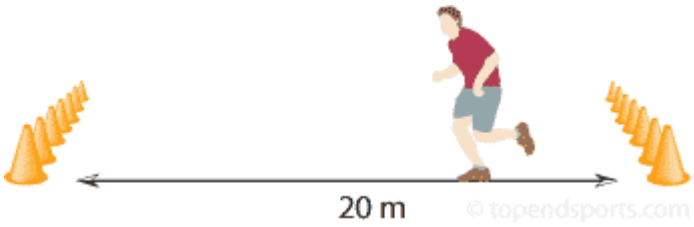
☐ Complete the health, diet and physical activity questionnaire



☐ Have weight, height and waist circumference measured in private



☐ Complete a short fitness test with trained researchers



A small number of you will also be asked to do the following 3 things:

☐ Keep a food and drink diary for four days

☐ Wear an activity monitor for one week

☐ Take part in a focus group discussion led by 2 trained researchers

Participants name _____

Participant's signature _____

Or Mark X _____ **(witnessed by 2 researchers)**

Name of service/club_____

Name of Participant_____

Name of family carer/member

_____

Home Address

_____

Contact number for family carer/member

_____

Signature of researcher 1

_____Date_____

Signature of researcher 2

_____Date_____ (if required)

Special Olympics Programmes Health Impact Evaluation

FAMILY CARER/ MEMBER CONSENT FORM

I give consent for my family member to take part in the following areas of the research study

- ☐ Complete health, diet and physical activity questionnaire
- ☐ Have weight, height and waist circumference measured in private
- ☐ Complete a short fitness test with trained researchers
- ☐ Wear an activity monitor for one week
- ☐ Keep a food and drink diary for four days
- ☐ Take part in a focus group discussion led by two trained researchers

Family carer/member's name

_____

Family carer/member's signature

_____

Special Olympics Programmes Health Impact Evaluation

FAMILY CARER/ MEMBER CONSENT FORM

I consent to take part in the following areas of the research study

☐ Complete health, diet and physical activity questionnaires

☐ Take part in a focus group discussion led by two trained researchers

Name of service/club

_____

Name of family member/carer_____

Home Address

_____

Contact number for family carer/member_____

Signature of family carer/member _____

Date_____

Appendix B

Study Information Materials

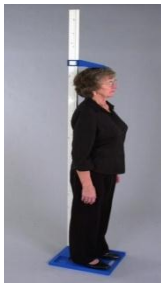
You are invited to come join us in our study.

We would like you to do:

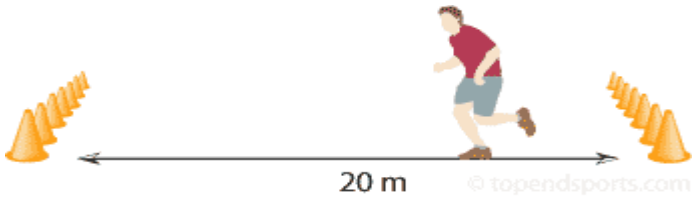
☐ **A health, diet and physical activity questionnaire**



☐ **Have weight, height, blood pressure and waist circumference measured in private**

☐ **A 6 minute walk test with a member of the team**



☐ **Keep a food and drink diary for four days**

A small number of you will also be asked to do the following 2 things:

☐ **Wear an activity monitor for one week**

☐ **Take part in a focus group discussion led by 2 trained researchers**

Frequently Asked Questions

You are being invited to take part in a study looking at the benefits of taking part in Special Olympics programmes, with a team of researchers from Dublin City University and Queens University Belfast. We are looking at whether those who take part in Special Olympics are healthier and happier than those who do not. We are also looking at the effect on family members of taking part in Special Olympics. If you want you can ask a family member or carer to read this information for you and help you understand what it is all about.

Why have I been chosen?

In this study we are inviting men and women over 16 years of age with an Intellectual Disability to take part.

Do I have to take part?

No you do not have to take part. It is up to you to decide whether or not you would like to take part. If you choose to take part **you can pull out at any time**.

What if I don't want to take part?

You won't miss out on anything if you do not take part.

What will happen to me if I take part?

There are 6 parts to the study.

1. We will ask you to fill in some questionnaires with the help of a family member. We will ask you questions about yourself such as if you are involved in sport such as Special Olympics, what foods you normally eat and how active you are.
2. We will then check your blood pressure and ask you to walk for 6 minutes (rests will be given if needed).
3. We will measure your weight, height and waist circumference.
4. We will ask you to fill in a diary for 4 days with all you have to eat and drink.
5. We will invite some people to take part in a group discussion on health, physical activity, nutrition and taking part in Special Olympics programmes.
6. A small number of participants will be asked to wear an activity monitor (accelerometer) around their waist for 1 week.

There are two other things that will happen.

1. A family member will be asked to fill in a questionnaire. We will ask questions about health and wellbeing, whether they volunteer with Special Olympics and the family income.
2. We will invite some family members/carers to take part in a group discussion on health, physical activity, nutrition and taking part in Special Olympics programmes.

Where can I get information about this study?

An information session will be held to tell you all about the study. You can come and hear more about the study to help you decide if you want to take part.

Will anyone help me if I have any questions?

The researchers will help and support you on the day. If you have any problems with the activity monitor or food diaries we will be around to help you.

What if I change my mind?

At any stage if you feel that you do not want to continue doing any of these things then you do not have to continue and you can stop.

Are there any risks of something bad happening to me if I take part?

We do not think anything bad will happen, however some small issues may arise such as:
You may not be fit enough for the 6 minute walk, you will be given a rest if needed
You may become upset or not like filling in the questionnaires, we can stop at any time
If you have to wear the activity monitor you may find it a little uncomfortable, we will do all we can to make sure you are wearing it properly
You may not feel comfortable having your weight, height and waist measured, we will ensure you have privacy for these
The research team will support and help you with any problems that do happen.

Are there any possible benefits of taking part?

You will get a copy of all the health measurements at the time and later in writing. By taking part you, your family and carers will be able to give important information about important issues that affect you to Special Olympics to help improve their programmes. They may get a better understanding of their role in the lives of people with an intellectual disability, what you want from them, how they can help to promote healthier lifestyles, how they can overcome barriers to people taking part and the cost benefits of their programmes.

What will be done with the answers I give?

All the answers you give will be private. You will be given a copy of your results. All the answers will be put together to make a report which may be published in a magazine, newspaper or book. Your name will not be written in the report.

If there is anything you don't understand feel free to ask any questions.

Thank you for reading this information, we look forward to meeting you.

If you would like to hear more about taking part in this project please contact Denise Walsh/ Edel Hoey (MSc Students) on 01-7005838/ 00353-1-7005838 or denise.walsh@dcu.ie edel.hoey4@mail.dcu.ie

Information SOPHIE Study

(Special Olympics Programmes Health Impact Evaluation) Study

We would like to welcome you to take part in a study looking at the impact of taking part in Special Olympics programmes, with a team of researchers from Dublin City University and Queens University Belfast. It will look at the health and wellness of people with intellectual disabilities who are involved and not involved in Special Olympics clubs.

People who agree to take part will be asked to tell us information about themselves such as their age, the service they go to, if they are involved in sport such as Special Olympics and what foods they normally eat. This information will be collected in a number of questionnaires which we and family or carers will help people to complete and a 4 day food and drink diary which you will take home. After this if they are happy to stay involved some measurements will be taken such as height, weight and blood pressure. For people who are able we will also ask them to do a 6 minute walk.

We are looking for members of a Special Olympics group, those not a member of a Special Olympics group or someone who has just joined a Special Olympics group. If you have just joined we will come back to do the same questions and measurements to see if there is any benefit to you in 9 months. If you are a member of a Special Olympics group (not a new member) or you are not taking part in any Special Olympics groups we will only need to come to get information from you once. We will then be comparing results of those who take part in Special Olympics programmes and those who do not take part.

We will be holding an information session on the day to answer any questions you may have.

If you would like to hear more about taking part in this project please contact Denise Walsh/ Edel Hoey (MSc Students) on 01-7005838/ 00353-1-7005838 or denise.walsh@dcu.ie

Appendix C Primary Participant Questionnaire

Unique ID_____

If Special Olympics club please indicate if this is 1st time-point ☐2 2nd time- point ☐3

This questionnaire is to be completed by the study participants supported/helped by family members and/or carers.

Basic information about the Study Participant

Q1.Where were you recruited for this study?

Special Olympics Club ☐1

Or

Service: St. Michael's House ☐2 Cope Foundation ☐3 Western Care ☐4

Praxis Care ☐5 Northern Health and Social Care Trust ☐6

Q2. Who is helping you to complete this questionnaire?
(This should be somebody who is very familiar with your normal daily routine)

Family member ☐1 If yes was it Mother ☐1 Father ☐2 Sibling ☐3 Other ☐4

Paid care staff ☐2 If yes was it Your Keyworker ☐1 Other staff member ☐2

If other please specify _____

Q3. Do you attend a service: Yes☐1 No☐2 **If no, skip to question 7**

If yes, is it St. Michael's House☐3 Cope Foundation ☐4 Western Care ☐5
Other ☐6 please state which one _____

Q3a. Are you a Day Attendee ☐1 Resident ☐2 **(Please tick both if apply)**

Q4. How many days a week do you get support from your service?

_____ days/week1

Q4a. For how many hours each day do on average you get support?

_____ hours/day1

Q5. How far do you live from your day service?

a) Less than 1km (1mile) ☐1
b) Between 2-5km (1-3miles) ☐2
c) Between 6-10km (4-6miles) ☐3
d) Between 11-15km (7-9miles) ☐4
e) Between 16-25km (10-16miles) ☐5
f) Greater than 25km (16miles) ☐6
g) Don't' know ☐7

h) Resident in service ☐[8]

Q6. How do you travel to your day service?

a) Walk ☐[1]
b) Public transport ☐[2]
c) Driven by family member ☐[3]
d) Transport provided by service ☐[4]
e) Other, please specify below ☐[5]
f) Resident in service ☐[6]

Q7. Do you take part in Special Olympics clubs?

Yes ☐[1] **If yes, continue to question 8**

No ☐[2]

Q7a. If no, which of the following applies to you?

No, but would like to ☐[1] **Continue to question 13**

No, and don't want to ☐[2] **Continue to question 13**

Used to ☐[3] **Continue to question 15**

Q8. If yes, how far do you live from your nearest Special Olympics club?

i) Less than 1km (1mile) ☐[1]
j) Between 2-5km (1-3miles) ☐[2]
k) Between 6-10km (4-6miles) ☐[3]
l) Between 11-15km (7-9miles) ☐[4]
m) Between 16-25km (10-16miles) ☐[5]
n) Greater than 25km (16miles) ☐[6]
o) Don't' know ☐[7]

Q9. How do you travel to your Special Olympics club?

a) Walk ☐[1]
b) Public transport ☐[2]
c) Driven by family member ☐[3]
d) Transport provided by service ☐[4]
e) Other, please specify below ☐[5]

Q10. Please list which club or clubs you attend below.

_____

_____

-

_____

_____

Q11. When did you first join a Special Olympics club?

m m / y y y y **Or if unknown please provide the year you first joined**_____

Q12. Do you take part in the Special Olympics Health Promotion Programme?

Yes ☐[1] No ☐[2] Don't Know ☐[3]

Q12a. If no, which of the following applies? No, but I would like to ☐[1]

No and I don't want to ☐[2] Never heard of it ☐[3]

Please skip to question 17

Q13. If you answered no to question 7 please choose why not from the list below:

a. Not interested in sport ☐[1]
b. No local club ☐[2]
c. Difficulties with transport ☐[3]
d. Cannot due to medical reasons ☐[4]
e. Negative media publicity ☐[5]
f. Was never asked/invited ☐[6]
g. Never heard about it ☐[7]
h. Tried but couldn't get in ☐[8]
i. No space in local club ☐[9]
j. Time does not suit ☐[10]
k. Venue does not suit ☐[11]
l. Don't have the family support I need to attend ☐[12]
m. Local club does not offer my preferred sport ☐[13]
n. Prevented joining due to my challenging behaviour ☐[14]
o. Other reasons, please specify below ☐[15]

Q14. Do you know how far you live from your nearest Special Olympics club?

p) Less than 1km (1mile) ☐[1]
q) Between 2-5km (1-3miles) ☐[2]
r) Between 6-10km (4-6miles) ☐[3]
s) Between 11-15km (7-9miles) ☐[4]
t) Between 16-25km (10-16miles) ☐[5]
u) Greater than 25km (16miles) ☐[6]
v) Don't' know ☐[7]

Please skip to question 17

Q15. . If you answered used to to question 7 please choose why not from the list below:

a. No longer interested ☐[1]
b. Local club closed ☐[2]
c. Difficulties with transport ☐[3]
d. Cannot due to medical reasons ☐[4]
e. Negative media publicity ☐[5]
f. No benefit of participation ☐[6]
g. I didn't like/don't enjoy it ☐[7]
h. My service provider no longer offers it ☐[9]
i. Time does not suit ☐[10]
j. Venue does not suit ☐[11]
k. Don't have the family support I need to attend ☐[12]
l. Local club does not offer my preferred sport ☐[13]
m. Had to leave due to my challenging behaviour ☐[14]
n. Other reasons, please specify below ☐[15]

Q16. How far do you live from your nearest Special Olympics club?

a) Less than 1km (1mile) ☐[1]
b) Between 2-5km (1-3miles) ☐[2]
c) Between 6-10km (4-6miles) ☐[3]
d) Between 11-15km (7-9miles) ☐[4]
e) Between 16-25km (10-16miles) ☐[5]

f) Greater than 25km (16miles) ☐[6]
g) Don't' know ☐[7]

Your General Health

Q17. Male ☐[1] **Female** ☐[2]

Q18. What age are you? _____ years

Date of birth: ____ / ____ / _____

Q19. Is your daily activity limited by a long term illness, health problem or disability?

Yes ☐[1] No ☐[2]

If you answered yes what is the long term illness, health problem or disability?

LIST _____

Q20. Would you describe your disability as mild ☐[1] **moderate** ☐[2] **severe** ☐[3]

Q20. Have you been diagnosed with any of the following?

Down's Syndrome	☐[1]	Cerebral Palsy	☐[2]
Autism	☐[3]	Non-specific Intellectual Disability	☐[4]
Fragile X	☐[5]	Other_____	☐[6]

Q21. Which of the following best describes your level of mobility?

Fully mobile	☐[1]
In need of mobility aids	☐[2]
Wheelchair user	☐[3]

Q22. During the past <u>30 days</u>, for about how many days did poor <u>physical</u> or <u>mental health</u> keep you from doing your usual activities, such as self-care (that is looking after yourself), work or recreation?

Number of days _____ None ☐[0]

Q23. Have you had any of the following in the last <u>12 months</u>? If yes, was this condition diagnosed by a doctor?

Please tick the relevant boxes in the table below.

Condition	Have you had any of the following in the past 12 months?		If yes, was this diagnosed by a doctor?	
	Yes[1]	No[2]	Yes[3]	No[4]
Asthma [a]				
Chronic bronchitis, chronic obstructive lung (pulmonary) disease, emphysema [b]				
Heart attack [c]				
Angina [d]				
Stroke [e]				
Rheumatoid arthritis (inflammation of the joints) [f]				
Osteoarthritis (arthrosis, joint degeneration)/ osteoporosis/ osteopenia [g]				
Lower back pain/ other chronic back condition [h]				
Diabetes [i]				
High blood pressure [j]				
High cholesterol [k]				
Cancer (malignant tumour, also including leukaemia & lymphoma) [l]				
Urinary incontinence, problems in controlling the bladder [m]				
ıxiety [n]				
epression [o]				
chizophrenia [p]				
ilepsy [q]				
her, please specify [r] _____				

Q24. In the last <u>12 months</u>, have you been screened or tested for any of the following?
Please tick the relevant boxes in the table below.

Condition	Have you been screened in the past 12 months?		If yes, where was this done?				
	Yes[1]	No[2]	GP/ Family Doctor[3]	Health Clinic[4]	Hospital[5]	Workplace[6]	Other[7]
Diabetes [a]							
Blood pressure [b]							
Cholesterol [c]							
(Women) Breast cancer – mammogram [d]							
(Women) Cervical cancer-smear [e]							
len) Prostate cancer [f]							
len)Testicular cancer [g]							
lon cancer or Bowel cancer [h]							
steoporosis/ DEXA scan [i]							

Q25. In the table below please indicate the number of contacts you have had with the following <u>health services practitioners</u> over the past <u>30 days.</u> Please indicate the average number of hours per visit and tick whether it was in a clinic/ outpatients or at home? Please also indicate the total number of visits over the past 12 months.

Type of care	Number of visits during last 30 days[1]	Average number of minutes per visit[2]	Clinic/ outpatients[3] √	Home visit[4] √	Number of visits during the past 12 months[5]	Total (office use only)
General Practitioner (GP)[a]						
Other Doctor/Consultant (e.g. orthopedic surgeon)[b] Please specify						
Physiotherapist[c]						
Occupational Therapist[d]						
Social Worker[e]						
Psychologist[f]						
Dietitian[g]						
Speech & Language Therapist[h]						
Nursing Staff- District/Public Health/Community Nurse[i]						
Home help/Healthcare assistant/ Home carer[j]						
Other[k] (e.g. chiropodist) Please specify						

Q26. Please list in the table below any medications prescribed by a doctor that you take regularly.

Name of Medication	Date Started	Dose*	Times per Day

Q27. When was the last time you visited a dentist, dental hygienist or orthodontist for your own benefit?

In the last 4 weeks ☐[1] | Between 1 and 12 months ago ☐[2] | 1-2 years ago ☐[3] | More than 2 years ago ☐[4] | Never ☐[5]

Q28. Which best describes the teeth you have?

I have all my own natural teeth – none missing ☐[1]
I have my own teeth, no dentures – but some missing ☐[2]
I have dentures as well as some of my own teeth ☐[3]
I have full dentures ☐[4]
I have no teeth or dentures ☐[5]

Q29. How many times do you brush your teeth each day?

Twice a day or more often ☐[1] | Once a day ☐[2] | Less than once a day ☐[3]

Q30. During the last <u>12 months</u>, have you had any day case procedures (not requiring an overnight stay)?

Yes ☐[1] No ☐[2]

If you have not have you had any day case procedures in the last <u>12 months</u> please continue to question 32.

Q31. For each day case procedure, please provide the reason for the procedure and the length of stay in the box below for the past 30 days and 12 months.

Day Procedure number	Reason for day procedure in the past 30 days[a]	Length of stay in hours[b]
I		
2		
3		
	Total (office use only)	
Day Procedure number	**Reason for day procedure in the past 12 months[a]**	**Length of stay in hours[b]**
4		
5		
6		
7		
8		
Any other procedures[9]		
	Total (office use only)	

Q32. During the last 12 months, did you receive care in a hospital Accident and Emergency department (without a hospital admission)?

Yes ☐[1] No ☐[2]

If you have not received care in a hospital Accident and Emergency department (without a hospital admission) in the last 12 months please continue to question 34.

Q33. If yes, for each time you received care in a hospital Accident and Emergency department (without a hospital admission) please provide the reason for receiving care and the length of stay in the box below <u>for the past 30 days and 12 months</u>.

A and E admission	Major diagnosis / reason for needing care <u>in the past 30 days</u>[a]	Length of stay in hours[b]
1		
2		
3		
4		
5		
Any other admissions[6]		
	Total (office use only)	

A and E admission	Major diagnosis / reason for needing care <u>in the past 12 months</u>[a]	Length of stay in hours[b]
7		
8		
9		
10		
11		
12		
13		
Any other admissions[14]		
	Total (office use only)	

Q34. During the last <u>12 months</u>, were you admitted to a hospital (for more than 24 hours)?

Yes ☐[1] No ☐[2]

If you have not been admitted to a hospital (for more than 24 hours) in the last 12 months please continue to question 36.

Q35. For each hospitalisation (during the last 30 days and 12 months), please provide the diagnosis or reason for hospitalisation and the length of stay in the box below.

Hospitalisation number	Major diagnosis / reason for hospitalisation in the past 30 days[a]	Length of stay in days (counting the no. overnight stays)[b]
1		
2		
3		
4		
Any other admissions[5]		
	Total (office use only)	
Hospitalisation number	**Major diagnosis / reason for hospitalisation in the past 12 months[a]**	**Length of stay in days (counting the no. overnight stays)[b]**
6		
7		
8		
9		
10		
11		
12		
Any other admissions[13]		
	Total (office use only)	

Q36. The next set of questions is about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the past 4 weeks …	All of the time[1]	Most of the time[2]	A good bit of the time[3]	Some of the time[4]	A little of the time[5]	None of the time[6]
Did you feel full of life? [a]						
Did you have a lot of energy? [b]						
Did you feel tired? [c]						
Did you feel worn out? [d]						

Q37. Have you often felt lonely in the last 4 weeks? Yes☐[1] No ☐[2]

Your Physical Activity levels

We are interested in finding out about the kinds of physical activities that people do as part of their everyday lives. This is any activity you do at work, in your care centre or in your Special Olympics club.

Q38. VIGOUROUS ACTIVITY

This is when you are working very hard and your heart beats fast.

Q38a. First can I ask you to think about activity during a ***NORMAL WEEK?*** **(7**

Basketball
_____ times per wk

Digging[2]
_____times per wk

Heavy lifting[3]
_____times per wk

Hard long distance cycling[4]
_____ times per wk

Running[5]
_____ times per wk

Please circle or list the activities that you do and note the number of times you normally do

Soccer[6]
_____times per wk

Hard swimming[7]
_____times per wk

Other_____ Times_____

_____ _____

_____ _____

I am now going to ask you about the time you spent doing vigorous physical activities _____ ***IN THE LAST 7 DAYS (for at least 10 minutes at***

Q38b. During THE LAST 7 DAYS, on how many days did you do vigorous physical activity?

_____**days per week** **None** ☐0 **If no, skip to question 39**

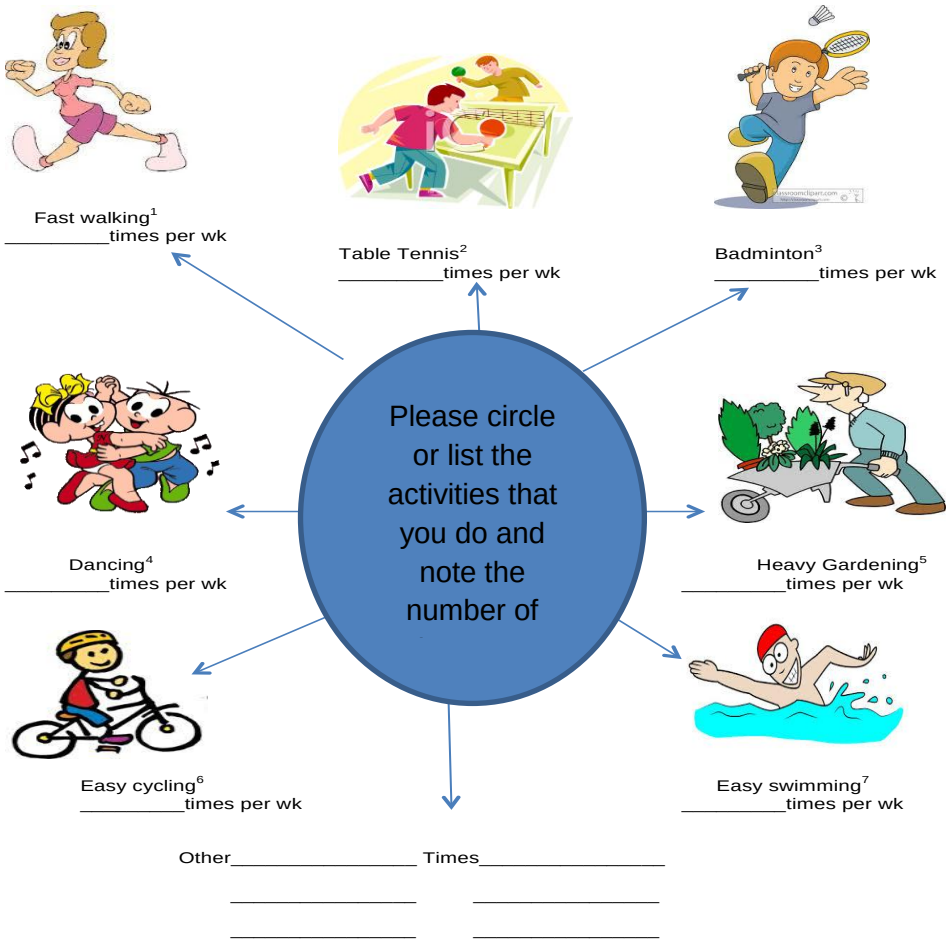
Q38c. How much time did you usually spend doing vigorous physical activities on one of those days?

_____/_____ hours and minutes per day Not sure/don't know ☐0

Q39. MODERATE ACTIVITY -
This is exercise that is not very hard, but it is not easy either.

Q39a. Can I ask you to think about moderate activity during a ***NORMALWEEK?*** **(7 days)**

Q39b. During THE LAST 7 DAYS, on how many days did you do moderate activity?



I am now going to ask you about the time you spent doing moderate physical activities ***IN THE LAST 7 DAYS (for at least 10 minutes at a time).***

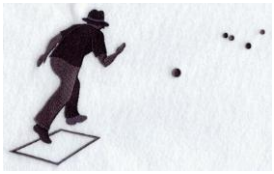
Q39c. How much time did you usually spend doing moderate physical activities on one of those days?

_____/_____ hours and minutes per day Not sure/don't know ☐0

MILD ACTIVITY  This is activity that is easy.

Q40a. Can I ask you to think about mild activity during a

Golf/pitch & putt[1]
_____times per wk

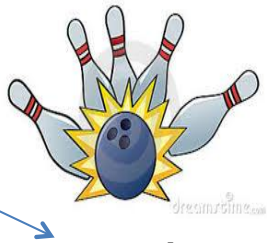


Bocce[2]
_____times per wk

Equestrian[3]
_____times per wk

Fishing[4]
_____times per wk

Please circle or list the activities that you do and note the number of times you normally do



Bowling[5]
_____times per wk

Easy Gardening[6]
_____times per wk

Easy Walking[7]
_____times per wk

Other_____ Times_____

_____ _____

_____ _____

I am now going to ask you about the time you spent doing mild physical activities ***IN THE LAST 7 DAYS (for at least 10 minutes at a time).***

Q40b. During THE LAST 7 DAYS, on how many days did you do mild physical activity?

_____**days per week** **None** ☐0 **If no, skip to question 41**

Q40c. How much time did you usually spend doing <u>mild physical activities</u> on one of those days?

_____/_____ hours and minutes per day Not sure/don't know ☐0

WALKING:

Q41. How many days, if any, in a *<u>NORMAL WEEK</u>* do you walk for more than 30 minutes or more?

_____days

Q42. Which of the following best describes your normal walking pace?

A slow pace A steady average pace A fairly brisk pace A fast pace- at least 4kmph

Q43. During <u>THE LAST 7 DAYS</u>, on how many days did you walk at a <u>brisk/fast pace</u> for at least 10 minutes at a time?

_____ days per week None ☐0 **If no, skip to question 45**

Q44. How much time did you usually spend walking on one of those days?

_____/_____ hours and minutes per day Not sure/don't know ☐0

Q45. If you are not as physically active as you would like to be, what would you say is the main reason why you are not (more) physically active at this time?

Not interested ☐1
Interested but not willing to spend the time ☐2
No time to do it ☐3
No facilities/places to exercise/be active ☐4
Injury/disability/medical condition ☐5
I feel I do enough physical activity ☐6
Other, specify _____ ☐7

If you <u>do not take part</u> in Special Olympics clubs please skip to question 47.

Q46. Please tick which of the following sports you take part in with your Special Olympics club. How many hours per week do you do each sport?

Swimming[1] ☐ _____hours
Alpine Skiing[2] ☐ _____hours
Aquatics [3] ☐ _____ hours
Athletics[4] ☐ _____ hours
Badminton[5] ☐ _____ hours
Badminton[6] ☐ _____ hours
Basketball[7] ☐ _____ hours
Bocce[8] ☐ _____ hours
Bowling[9] ☐ _____ hours
Equestrian [10] ☐ _____ hours
Floorball [11] ☐ _____ hours
Football [12] ☐ _____ hours
Golf [13] ☐ _____ hours
Gymnastics[14] ☐ _____ hours
Kayaking [15] ☐ _____ hours
Pitch & Putt[16] ☐ _____ hours
Table Tennis[17] ☐ _____ hours
Motor Activity
Training Program[18] ☐ _____ hours
Others [19] ☐ _____ hours

Total (office use only) _____ hours

Your Diet & Nutrition Status

Q47. Given your age and height, would you say that you are?

About the right weight	Too heavy	Too light	Not sure
☐[1]	☐[2]	☐[3]	☐[4]

Q48. Are you actively trying to manage your weight?

Yes ☐[1] No ☐[2] **If no, skip to question 51**

Q49. If yes, is it to lose, gain or maintain weight?

Lose weight ☐[1] Maintain weight ☐[2] Gain weight ☐[3]

Q50. Are you using any of the following to lose/maintain weight?

	Yes	No	
Eating fewer calories[a]	☐[1]	☐[2]	
Physical activity[b]	☐[1]	☐[2]	
Special diet[c]	☐[1]	☐[2]	Please state what this is

_____

Q51. In the past 12 months has a doctor, nurse or other health professional advised you to lose, maintain or gain weight?

Yes, lose weight ☐[1] Yes, maintain current weight ☐[2] Yes, gain weight ☐[3] No ☐[4]

Q52. How often do you eat fried food?

Daily ☐[1] 4-6 times a week ☐[2] 1-3 times a week ☐[3] Less than once a week ☐[4]

Q53. What type of milk do you use most often?

None ☐[1] **Skip to question 55** Whole milk/Full fat ☐[2]

Low fat ☐[3] Skimmed ☐[4]

Super/fortified ☐[5] Soya ☐[6]

Other, please specify_____ ☐[7]

Q54. How much milk do you drink each day?

None ☐[1] 250ml (half pint) ☐[2] 568 ml (one pint) ☐[3] One litre ☐[4] More than 1 litre ☐[5]

Q55. How often do you add salt to food while cooking?

Always ☐[1] Usually ☐[2] Sometimes ☐[3] Rarely ☐[4] Never ☐[5]

Q56. How often do you add salt to food while at the table?

Always ☐[1] Usually ☐[2] Sometimes ☐[3] Rarely ☐[4] Never ☐[5]

Q57. Do you make your own food choices?

Always ☐[1] Usually ☐[2] Sometimes ☐[3] Rarely ☐[4] Never ☐[5]

Q58. When you don't make your own food choices, who makes your food choices for you?

Family member ☐[1] Paid care worker ☐[2] Friend ☐[3] Neighbour ☐[4]

Other…….. ☐[5] Not applicable ☐[6]

Q59. Who usually prepares your meals?

Yourself- without support ☐[1]

Yourself- with support from family/friend/care staff ☐[2]

Family member ☐[3] Paid care worker ☐[4] Friend ☐[5] Neighbour ☐[6]

Other……..☐[7]

Q60. Who usually cooks your meals?

Yourself- without support ☐[1] Yourself- with support from family/friend/care staff ☐[2]

Family member ☐[3] Paid care worker ☐[4] Friend ☐[5] Neighbour ☐[6]
Other……..☐[7]

Q61. How would you describe your cooking skills?
Poor ☐[1] Fair ☐ Average☐[3] Good ☐[4] Very Good ☐[5]

Q62. Who usually does your food shopping?
Yourself- without support ☐[1] Yourself- with support from family/friend/care staff ☐[2]

Family member ☐[3] Paid care worker ☐[4] Friend ☐[5] Neighbour ☐[6]
Other……..☐[7]

Q63. Do you plan what foods are bought for you?
Always ☐[1] Usually ☐[2] Sometimes ☐[3] Rarely ☐[4] Never ☐[5]

Q64. Did you eat snacks between your meals yesterday?
Yes ☐[1] No ☐[2] **If no, skip to question 66**

Q64a. If yes, how many snacks did you have? _____

Q65. If yes, what types of snacks did you eat? (Please tick all that apply)

Biscuits/Cake	☐[1]	Scone	☐[2]
Crisps/Popcorn/Pretzels	☐[3]	Chocolate	☐[4]
Fruit	☐[5]	Dried fruit	☐[6]
Nuts	☐[7]	Yoghurt	☐[8]
Vegetables	☐[9]	Sweets	☐[10]
Other_____	☐[11]		

Q66. Who normally buys your snacks?
Yourself- without support ☐[1] Yourself- with support from family/friend/care staff ☐[2]

Family member ☐[3] Paid care worker ☐[4] Friend ☐[5] Neighbour ☐[6]
Other……..……...☐[7]

Q67. How often in a typical week do you drink fizzy drinks? (e.g. Coca cola, Fanta, Pepsi)

Daily	4-6 times a week	1-3 times a week	Less than once a week	Never
☐[1]	☐[2]	☐[3]	☐[4]	☐[5]

Q68. Do you regularly take any nutritional supplements?
Yes ☐[1] **No** ☐[2] **If no, skip to question 69**

Q68a. If yes, please tick all that apply below:

Multi vitamin supplements ☐[1]
Multi mineral supplements ☐[2]
Protein supplements (including shakes) ☐[3]
Weight loss aids ☐[4]
Oral nutritional supplements (e.g. Complan/Fortisip) ☐[5]
Other please specify_____ ☐[6]

The following 2 questions are about the meals you had yesterday.

Q69. Where did you eat your breakfast, light meal and main/largest meal yesterday?
(Please tick all that apply)

	Break-fast[1]	**Light meal (e.g. light lunch, supper, tea)[2]**	**Main/ Largest Meal (e.g. dinner or heavy lunch)[3]**	**Snacks (e.g. sweets, chocolate, crisps, fruit, yoghurt)[4]**
Didn't have a…[a]				
At home[b]				
While travelling, taken from home[c]				
While travelling, take away[d]				
At work/school/college/day services packed at home[e]				
At work/school/college/day services take away[f]				
At a work/school/college/day services canteen[g]				
At a coffee shop/café[h]				
At a restaurant[i]				
Take away from a deli[j]				
Take away from a fast food restaurant[k]				
Somewhere else, (please specify)[l]				

Q70. What did you eat for your breakfast, light meal, and main meal yesterday?
(Please tick all that apply for each meal)

	Break- fast[1]	Light meal (e.g. light lunch, supper, tea)[2]	Large Meal (e.g. Dinner or heavy lunch)[3]
Didn't have a…[a]			
BREAKFAST FOODS			
Bread/toast/roll/bap/pitta bread (not as a sandwich)[b]			
High fibre breakfast cereal (including porridge)[c]			
Other breakfast cereal (including cereal bars)[d]			
Fruit[e]			
Cooked breakfast (including full Irish; eggs-boiled, fried, poached, scrambled)[f]			
Filled breakfast roll[g]			
Yoghurt[h]			
Croissant/Pastry/Scone[i]			
LUNCH/DINNER FOODS			
Meat/Fish/Vegetarian sandwich/bap/wrap/pitta[j]			
Soup[k]			
Pizza[l]			
Green salad/vegetables[m]			
Coleslaw/potato salad/egg salad[n]			
Cheese[o]			
Pasta/Rice[p]			
Potato-boiled/mashed/roast[q]			
Chips/wedges[r]			
Red meat/Chicken Fish[s]			
Other vegetables (e.g. carrots, cauliflower, corn)[t]			
Fast food take away (e.g. burger meal)[u]			
Sauce: Tomato/curry/vegetable based[v]			
Sauce: creamy[w]			
Other[x]			

Smoking Status

Q71. How many cigarettes do you smoke per day?

None ☐[1] **If none, skip to question 73**
10 or less ☐[2]
11-20 ☐[3]
21-30 ☐[4]
31 or more ☐[5]

Q72. If you smoke are you currently?

Trying to quit ☐[1]
Actively planning to quit ☐[2]
Thinking about quitting but not planning to ☐[3]
Not thinking about quitting ☐[4]

Q73. Has being involved in Special Olympics made you quit or try to quit smoking?

Yes ☐[1] No ☐[2] Not Applicable ☐[3]

If yes, please state why

_____

Alcohol Intake

Q74. How often do you have a drink containing alcohol?

Never ☐[1]
Monthly or less ☐[2]
2-4 times a month ☐[3]
2-3 times a week ☐[4]
4 or more times a week ☐[5]

Q75. Has being involved in Special Olympics made you stop or reduce the amount of alcohol you drink?

Yes ☐[1] No ☐[2] Not Applicable ☐[3]

If yes, please state why

_____

Your Family, Social Networks & Neighbours

Q76. Do you regularly join in the activities of any of the following types of organisation?

(Please do not include Special Olympics Club involvement here)
(Please tick all that apply)

	Yes[1]	No[2]
Sports clubs (Parish, GAA, Golf, Other), gym, exercise classes [a]		
Political parties, trade unions, environmental groups [b]		
Parent-teacher associations, tenants groups, residents groups, neighbourhood watch, youth groups, other community action groups [c]		
Church or other religious/parish groups, charitable or voluntary organisations (e.g. collecting for charity, helping the sick, elderly) [d]		
Evening classes, arts or music groups, education activities [e]		
Social clubs (e.g. mother & toddler group, rotary club, women's groups, elderly group) [f]		
Theatre, drama groups, gigs/concert, pub [g]		
Other, please specify:_____ [h]		

Q77. How many people are so close to you that you can count on them if you have serious personal problems?

None ☐[1] 1 or 2 ☐[2] 3 to 5 ☐[3] More than 5 ☐[4]

Q78. How much interest do people show in what you are doing?

A lot ☐[1] Some ☐[2] Uncertain ☐[3] Little ☐[4] No concern ☐[5]

Your General Household Information

The information being collected in the next section is of a personal nature. Some people may find the questions sensitive. Please be assured that all answers will be treated in the strictest confidence and will not be shared or divulged to any persons outside the study team.

Q79. What is the highest level of education you have completed to date?

Special education school	☐1
None/ primary not complete	☐2
Primary or equivalent	☐3
Intermediate/Junior/ Group Certificate/GCSE or equivalent	☐4
Leaving Certificate/A Levels or equivalent	☐5
FETAC levels 1-5	☐6
Diploma/ Certificate	☐7
Primary degree	☐8
Postgraduate/ Higher degree	☐9

Q80. What is your <u>current</u> marital status?

Single (never married)	☐1	Separated	☐4
Cohabiting	☐2	Divorced	☐5
Married	☐3	Widowed	☐6

Q81. How many individuals live in your household in each of the following age categories?

Adults (18-65)	_____
Adults (65+)	_____
Children (14-17)	_____
Children (5-13)	_____
Children (<5)	_____
Total	_____

Q82. How many individuals in your household are currently working?

_____

Q83. WHICH of these descriptions BEST describes your usual situation in regard to work? (Please tick one only)

Employee (incl. apprenticeship or Community Employment)	☐1
Self-employed outside farming	☐2
Farmer	☐3
Student full-time	☐4
On State training scheme (FÁS, Failte Ireland etc.)	☐5
Unemployed, actively looking for a job	☐6
Long-term sickness or disability	☐7
Home duties / looking after the home or family	☐8
Retired	☐9
Other (specify) _____	☐10

Q84. Please indicate which of the below that best describes where you live.

- Living at home ☐1
- 5-day community group home ☐2
- 7-day (48-week) community group home ☐3
- 7-day (52-week) community group home ☐4
- 5-day residential centre ☐5
- 7-day (48-week) residential centre ☐6
- 7-day (52-week) residential centre ☐7
- Nursing home ☐8
- Mental health community residence ☐9
- Psychiatric hospital ☐10
- Intensive placement (challenging behaviour) ☐11
- Intensive placement (profound or multiple disability) ☐12
- Other/unspecified intellectual disability service ☐13
- Designated residential support placement ☐14
- Other, Please Specify_____ ☐15

Q84a. If ticked option 'Living at home' is it

Owned with mortgage	☐1	Rented from Local Authority	☐2
Rented privately	☐3	Owned outright	☐4
Other	☐5		

Please specify other _____

Q85. Who do you live with?

- Alone ☐1
- Spouse/Partner ☐2
- Parent(s) ☐3
- Sibling ☐4
- Other individuals with an intellectual disability ☐5
- Care Staff ☐6
- Other, Please specify: _____ ☐7

Q86a. ROI Residents Only. Please tick any of the following you receive due to your disability?

- Disability Allowance ☐1
- Household Benefits Package ☐2
- Fuel Allowance ☐3
- Free Travel ☐4
- Respite Care Grant ☐5
- Other, Please Specify_____ ☐6

Q86b. NI Residents Only. Please tick any of the following you receive due to your disability?

- Disability Living Allowance ☐1
- Personal Independence Payment ☐2
- Working Tax Credit ☐3
- Employment and Support Allowance ☐4
- Incapacity Benefit ☐5
- Severe Disablement Allowance ☐6
- Respite Care Grant ☐7
- Other, Please Specify_____ ☐8

Q87. Do you have the use of a car (including vans, minibuses, etc.)?

Yes ☐[1] No ☐[2]

Q88. Do you regularly use a computer, tablet or smart phone?

Yes ☐[1] No ☐[2]

Q89. Do you regularly use the internet?

Yes ☐[1] No ☐[2]

Q90. How frequently do you use the Internet to seek health information such as injury, physical activity, nutrition or performance in sport?

Daily ☐[1] Weekly ☐[2] Monthly ☐[3] Sometimes ☐[4] Never ☐[5]

Q91. ROI Only. Are you covered by a medical card?

Yes – full medical card ☐[1] Yes – GP only medical card ☐[2] No ☐[3]

Q92. Do you have private health insurance that covers the cost of private medical treatment (e.g. VHI, BUPA, VIVAS)?

Yes ☐[1] No ☐[2]

Q93. Would you describe the place where your household is situated as being…..?

In open country ☐[1] In a city (other than Dublin) ☐[4]
In a village ☐[2] In Dublin/Belfast City ☐[5]
In a town (1,500+) ☐[3]

Q94. In what country were you born?

Republic of Ireland ☐[1]
Northern Ireland ☐[2]
Other UK ☐[3]
Other, specify_____ ☐[4]

Q95. What is your ethnic or cultural background?

(a) White
Irish ☐[1] Irish Traveller ☐[2] British ☐[3] Any other white background ☐[4]

(b) Black or Black Irish
African ☐[5] Any other black background ☐[6]

(c) Asian or Asian Irish
Chinese ☐[7] Any other Asian background ☐[8]

(d) Other including mixed background ☐[9]

Insert own description _____

Q96. What is your religion?

a) Roman Catholic ☐[1]
b) Presbyterian Church in Ireland ☐[2]
c) Church of Ireland ☐[3]
d) Methodist Church in Ireland ☐[4]
e) Other Christian ☐[5]
f) Islam ☐[6]
g) Jewish ☐[7]
h) Other_____ ☐[8]
i) No religion ☐[9]

Thank you for taking the time to complete this questionnaire.

NB** RESEARCHER PLEASE COMPLETE THE NEXT PAGE**

To be completed by research team

Q97. How long did the interview take

less than 30 mins ☐1
30-60 mins ☐2
60-90 mins ☐3
90-120 mins ☐4
over 120 mins ☐5

Q98. How much support did the study participant require to complete this questionnaire?

None- completed without support ☐1
Minimal support provided by family member/carer/researcher ☐2
Significant support provided by family member/carer/researcher ☐3
All questions answered by family member/carer ☐4

Q99. Researcher's comments on the interview

_____
_____
_____
_____
_____

Interviewer Check list **Completed:**

Q100. Self EQ-5D-3L Yes ☐1 No – refused ☐2 No – unable ☐3

Q101. Carer's EQ-5D-3L on their behalf Yes ☐1 No – refused ☐2 No – unable ☐3

Q102. Height/Ulna Length Yes ☐1 No – refused ☐2 No – unable ☐3

Q103. Weight/Mid Upper Arm Circ. Yes ☐1 No – refused ☐2 No – unable ☐3

Q104. Waist Circumference Yes ☐1 No – refused ☐2 No – unable ☐3

Q105. Blood Pressure Measurements Yes ☐1 No – refused ☐2 No – unable ☐3

Q106. Resting Heart Rate Yes ☐1 No – refused ☐2 No – unable ☐3

Q107. Post PA Test Heart Rate Yes ☐1 No – refused ☐2 No – unable ☐3

Q108. 6 Minute Walk Yes ☐1 No – refused ☐2 No – unable ☐3

Q109. Primary Participant Questionnaire Yes ☐1 No – refused ☐2 No – unable ☐3

Q110. Food diary Yes ☐$_1$ No – refused ☐$_2$ No – unable ☐$_3$

Q111. Accelerometer Yes ☐$_1$ No – refused ☐$_2$ No – unable ☐$_3$ Not required ☐$_4$

Date survey pack administered: _____ / _____ / _____

Date survey pack returned: _____ / _____ / _____

Completeness checked by researcher _____ **(signature)**

Appendix D Food Diary

SOPHIE (Special Olympics Programmes Health Impact Evaluation) Study Food Diary

In this study we are looking at what you eat and drink. We would really appreciate it if you would keep a record in this diary of everything you eat and drink for 4 days; 2 days will be week days and 2 will be weekend days.

How to fill in your diary **(Video also available to help with this)**

It is very important that you do not change what you normally eat or drink just because you are keeping a diary. Try to write down what you are eating or drinking as soon as you can and not leave it until the end of the day.

Don't forget to include all drinks including water.

Whenever you have something to eat or drink write down;

When:
Each day is divided into time slots from first thing in the morning until late at night until the following morning. Find the right time slot and in the next column record the exact time when you eat or drink something.

Where:
Please record where you had each drink, snack or meal.
For example this could be;

- At home
- At work/service canteen
- Watching television
- In the car

With Whom:
Please record who you had each drink, snack or meal with.
For example this could be;

- Alone
- With family
- With friends

What:
Please describe your food and drink giving as much detail as you can.
Include any extras like sugar and milk in your tea or cereal, butter or other spreads on your bread and sauces such as ketchup and mayonnaise.
If you know it include: **cooking method** (e.g. roast, baked, boiled, fried)
brand name (e.g. Kelloggs, Chef, Galtee)

Portion size:
Please describe portion sizes as best you can.
You can write S (small), M (medium) or L (large) or specify glass, cup, mug, packet (crisps), number (biscuits), slice (cake, pizza).
For example if you have sausages, mashed potato and beans for dinner, list how many sausages, how many scoops of mashed potato and how much of the tin of beans you had.

Where got from/made by:
Please specify if you made this food yourself or if was made by family member/ carer/ bought readymade.

For example this could be;

- Home (food and drink, brought into the house and stored there until eaten)
- Shop (food and drink bought by you to eat/drink outside the home)
- Restaurant/cafe (describe what type)
- Cinema kiosk/vending machine

There in an example of how to fill in a food diary on the next page.

THIS IN AN EXAMPLE ONLY OF HOW TO FILL IN YOUR FOOD DIARY

Day **EXAMPLE**	**Day** Thursday	**Date** March 31st

Time slot	**When**	**Where**	**With Whom**	What
6am **to** **9am**	7.30 8.30	Kitchen, home Street	Alone With friends	Squeeze pure orange juice Tea with milk and 1 sugar Cornflakes, with milk and sugar Toast, with butter and jam Mars Bar
9am **to** **12 noon**	11 12	Service dining room Street	With friends Alone	Coke Crisps (Tayto) Water
12 noon **to** **2pm**	12.45 1.50	Service canteen Service corridor	With friends Alone	Ham and cheese sandwich with bread Crisps (tayto) Apple Ribena Kitkat Water

Day Example		**Day** Thursday		**Date** March 31st
Time slot	**When**	**Where**	**With Whom**	**What**
2pm **to** **5pm**	3.45 4.30	Bus Home, watching television	Alone With family	Fruit gums Tea (as above) Biscuits (jaffa cakes)
5pm **to** **8pm**	6.30	Home, at table	With family	Pork sausages, grilled, Galtee Baked beans, Heinz Mashed potato, with a little but Broccoli Strawberry yoghourt, Yoplait Water
8pm **to** **10pm**	8 9.30	Watching TV Kitchen	Alone Alone	Orange Cream crackers (Jacobs) Cornflakes with milk and sugar
10pm **to**	10.30	Watching TV Bedroom	With sister	Cadbury's hot chocolate (made

6am				

Day 1		Day		Date		
Time slot	**When**	**Where**	**With Whom**	**What**	**Portion size**	**Where got from/made by**
6am to 9am						
9am to 12 noon						
12 noon to 2pm						

Day 1		Day		Date	ID No.	
Time slot	**When**	**Where**	**With Whom**	**What**	**Portion size**	**Where got from/made by**
2pm to 5pm						
5pm to 8pm						
8pm to 10pm						
10pm to 6am						

Day 2	Day	Date

Time slot	When	Where	With Whom	What	Portion size	Where got from/made by
6am to 9am						
9am to 12 noon						
12 noon to 2pm						

Day 2		**Day**		**Date**	**ID No.**	
Time slot	**When**	**Where**	**With Whom**	**What**	**Portion size**	**Where got from/made by**
2pm to 5pm						
5pm to 8pm						

8pm to 10pm						
10pm to 6am						

Day 3	**Day**	**Date**

Time slot	**When**	**Where**	**With Whom**	**What**	**Portion size**	**Where got from/made by**
6am to 9am						

9am to 12 noon						
12 noon to 2pm						
Day 3		**Day**		**Date**	**ID No.**	
Time slot	**When**	**Where**	**With Whom**	**What**	**Portion size**	**Where got from/made by**
2pm to 5pm						

5pm to 8pm						
8pm to 10pm						
10pm to 6am						

Day 4	**Day**	**Date**

Time slot	**When**	**Where**	**With Whom**	**What**	**Portion size**	**Where got from/made by**

6am to 9am						
9am to 12 noon						
12 noon to 2pm						
Day 4		**Day**		**Date**	**ID No.**	
Time slot	**When**	**Where**	**With Whom**	**What**	**Portion size**	**Where got from/made by**

2pm to 5pm						
5pm to 8pm						
8pm to 10pm						
10pm to 6am						

When you have completed your diary, think back and consider whether these 4 days were typical or was there something unusual such as a party, visitors, or perhaps you were not feeling well.

Was there anything unusual about these 4 days? Yes ☐$_1$
No ☐$_2$
If YES, please can you tell us what was different from usual.
……

……

……

Would you like to add any more comments about what you have to eat and drink?
……

……

……

If you have any questions about filling in this food diary please call Edel Hoey (MSc student) on 01-7005838 (003531-7005838) or email edel.hoey4@mail.dcu.ie

This food diary was adapted with permission from Dr Alison Lennox (ROOTS Adolescent Food Diary, Medical Research Council, Human Nutrition Research, Cambridge, UK).

Appendix E Protocol for Weight, Height and Waist circumference Measurements

SOPHIE Study Protocol for Measuring Weight, Height and Waist Circumference

Adapted from WHO STEPS Surveillance (Part 3: Training and Practical Guides 3-3-1, Section 3: Guide to Physical Measurements (Step 2))

Measuring Height

1. Set up stadiometer as per instructions
2. Ask the participant to remove their:
   - foot wear (shoes, slippers, sandals, etc.)
   - head wear (hat, cap, hair bows, comb, ribbons, etc.)
3. Ask the participant to stand facing you with:
   - feet together
   - heels against the back board of the stadiometer
   - knees straight
4. Ask the participant to look straight ahead and not tilt their head up
5. Make sure eyes are the same level as the ears
6. Move the measure arm gently down onto the head of the participant and ask the participant to breathe in and stand tall
7. Read the height to 0.01m at the exact point
8. Ask the participant to step away from the stadiometer
9. Record the height measurement in centimetres in the participant's record
10. Repeat steps 1-9
11. Calculate and record mean height

Measuring Weight

1. Set up calibrated weighing scales as per manufacturer's instructions on a firm, flat surface
2. Ask the participant to remove their footwear (shoes, slippers, sandals, etc.)
3. Ask the participant to step onto scale with one foot on each side of the scale
4. Ask the participant to:
   - stand still
   - face forward
   - place arms at their sides
   - wait until asked to step off
5. Record the weight to 0.1kg on the participant's record
6. Repeat steps 1-5
7. Calculate and record mean weight

Measuring Waist Circumference

1. Ask the participant to stand behind privacy screens
2. Ask the participant to pull up clothing covering the waist
3. If this is not possible, the measurement may be taken over light clothing but not thick or bulky clothing
4. Standing to the side of the participant locate the last palpable rib and the top of the hip bone, you may ask the participant to assist you in locating these points on their body
5. Wrap the measuring tape around the participant (or ask them to do it themselves)
6. Position the tape against the skin at the midpoint of the last palpable rib and the top of the hip bone, making sure to wrap the tape over the same spot on the opposite side
7. Check that the tape is horizontal across the back and front of the participant and as parallel with the floor as possible
8. Ask the participant to:
9. stand with their feet together with weight evenly distributed across both feet
10. hold the arms in a relaxed position at the sides
11. breathe normally for a few breaths, then make a normal expiration
12. Measure waist circumference and read the measurement at the level of the tape to the nearest 0.1 cm, making sure to keep the measuring tape snug but not tight enough to cause compression of the skin
13. Record the measurement on the participant's record
14. Repeat steps 1-13
15. Calculate and record mean waist circumference

Appendix F Physical Measurement Data Collection Sheet

Data Collection Sheet **Time point 1** ☐ **or Time point 2** ☐

Unique ID code		Date:	
Resting BP	Heart Rate/min pre:		Heart Rate/min post:
Height 1 (m):	Height 2 (m):		Mean:
Weight 1 (kg):	Weight 2 (kg):		Mean:
B.M.I. (kg/m$^{2)}$:			
Waist Circ.1 (cm):	Waist Circ. 2 (cm):		Mean:
If unable to measure height Ulna Length 1 (cm):	Ulna Length 2 (cm):		Mean:
If unable to weigh Mid Upper Arm Circ.1(cm):	Mid Upper Arm Circ.2 (cm):		Mean:

6 Minute Walk Test:

20m		320m		620m	
40m		340m		640m	
60m		360m		660m	
80m		380m		680m	
100m		400m		700m	
120m		420m		720m	
140m		440m		740m	
160m		460m		760m	
180m		480m		780m	
200m		500m		800m	
220m		520m		820m	
240m		540m		840m	
260m		560m		860m	
280m		580m		880m	
300m		600m		900m	

Distance in last lap:	Direction travelled on last lap:
Total distance covered:	towards ☐ away from finish line ☐