School of Public Health

Factors Influencing the Body Composition of Adolescents and Young Adults with Down Syndrome

Katherine Elizabeth Bathgate

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Declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

Human Ethics The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), approval numbers HR 143/2011, HR 145/2011.

Signature: Rathenne Bathgate

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Publications and Presentations

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Abstract

Down syndrome is the most common biomedical cause of intellectual disability (Bourke, de Klerk, Smith, & Leonard, 2016) with a birth rate in Australia of 0.87 per 1000 live births (Maxwell, Bower, & O'Leary, 2015). With medical and social advancements the survival of children with Down syndrome is increasing (Glasson, Jacques, Wong, Bourke, & Leonard, 2016).

Multiple studies of adolescents and young adults have reported higher proportions of overweight and obesity in those with Down syndrome compared to controls (Bertapelli, Pitetti, Agiovlasitis, & Guerra-Junior, 2016; Havercamp et al., 2017; Parra, Costa, Real de Asua, Moldenhauer, & Suarez, 2017). Compared to adolescents and young adults without Down syndrome, those with Down syndrome are shorter in height (Bertapelli, Martin, Gonçalves, de Oliveira Barbeta, & Guerra-Júnior, 2014; Parra et al., 2017) and limb length (Zemel et al., 2015), and may have different lean and fat tissue distributions (González-Agüero, Ara, Moreno, Vicente-Rodriguez, & Casajus, 2011). These differences in anthropometry and body composition can inflate body mass index (BMI) values (Hatch-Stein et al., 2016) and thus classification using standard BMI cut-points may not be suitable for this population (Braunschweig et al., 2004; Zemel et al., 2015).

The aim of this thesis was to describe the body composition of adolescents and young adults with Down syndrome and relationships with physiological, behavioural and social factors including dietary intake, physical activity and sedentary behaviour.

The research was conducted as two studies; a cross-sectional analysis of questionnaire data from the 2004, 2009 and 2011 waves of the Down syndrome Needs Opinions Wishes (NOW) study, and a cross-sectional study of the body composition, dietary intake and physical activity behaviours of adolescents and young adults with Down syndrome, herein referred to as the Physical Activity, Nutrition and Down syndrome (PANDs) study.

In the Down syndrome NOW study family members/carers completed questionnaires in 2004, 2009 and 2011 on the impact of health, social and functional factors on children, adolescents and young adults with Down syndrome and their families. Proxy-reported height and weight data were reported in all three waves, the 2011 questionnaire also contained specific questions on food and physical activity behaviours which were analysed

for this study. The PANDs study involved directly measuring the height, weight and waist circumference of adolescents and young adults with Down syndrome plus optional dual energy x-ray absorptiometry (DEXA) to measure body fatness. Dietary intake data were collected over four days using a mobile food record (mFR) and physical activity data were collected over seven days using an accelerometer.

In the Down syndrome NOW and PANDs studies, analysis of both proxy-reported and directly measured height and weight identified high proportions of overweight and obesity in adolescents and young adults with Down syndrome when classified using standard BMI cut-points. Analysis of reported BMI from the 2004, 2009 and 2011 Down syndrome NOW studies showed that the relative risk of overweight and obesity increased as adolescents matured to young adulthood, especially in females, which supported transition as an important time for intervention.

For young adults in the PANDs study, sensitivity and positive predictive value estimates of the BMI cut-point for overweight were low, indicating that a Down syndrome specific BMI cut-point for overweight may be required. For participants in the PANDs study, waist-to-height ratio was a better indicator of abdominal obesity than waist circumference due to differences in the anthropometry and body composition of adolescents and young adults with Down syndrome and should be included in future research.

In the Down syndrome NOW 2011 study a higher BMI was associated with more frequent fast food consumption (females), living out of the family home, not eating with others at the dining table, greater adolescent and young adult food preparation skills, and higher family income with the strongest associations being with ability to prepare food and higher family income. These results indicated that interventions supporting young adults with food selection and preparation skills both in the family home and when living independently are needed.

The mFR was found to be a feasible method of collecting food intake data of adolescents and young adults with Down syndrome using images. Similar to adolescents and young adults without Down syndrome (Australian Bureau of Statistics, 2015), the number of vegetable serves reported by participants in the PANDs study did not meet Australian recommendations (NHMRC, 2013), however reported fruit serves did meet recommendations. For female young adults, a higher reported number of fruit serves was associated with lower BMI, waist circumference and waist-to-height ratio, and in both sexes a higher reported number of sugar-sweetened beverage (SSB) serves was associated with a higher percentage body fat. Targeted nutrition education encouraging increased fruit and vegetable serves and alternatives to SSB is recommended for adolescents and young adults with Down syndrome and their family members/carers.

Using standard physical activity cut-points most adolescents and half the young adults in the PANDs study were insufficiently active. Analysis of sedentary behaviour and physical activity patterns showed a greater percentage of time spent in prolonged bouts of sedentary behaviour compared to bouts of light, moderate and vigorous physical activity. Interestingly, in young women with Down syndrome, a higher BMI was associated with less time spent in sedentary behaviour and more time spent in physical activity. Although the reason for this is unknown, as parents/carers are key facilitators of physical activity opportunities for young adults with Down syndrome, the results of this study may be an indication that parents/carers were supporting young women with Down syndrome to be less sedentary and more active. Further research is required to test this hypothesis and any impact on health outcomes.

In conclusion, when using standard body composition cut-points a higher proportion of adolescents and young adults with Down syndrome had a BMI, percentage body fat and waist-to-height ratio indicating the presence of overweight and obesity and higher metabolic risk. The standard BMI cut-point for obesity and waist-to-height ratio cut-points performed well for adolescents and young adults with Down syndrome and should be included in future studies. Although it appears that family members/carers were supporting young women with a higher BMI to be less sedentary, adolescents and young adults with Down syndrome need to be supported to be more physically active and consume more vegetable serves. Higher BMI, percentage body fat and waist-to-height ratio measurements were associated with having higher food preparations skills and lower family income, as well as not eating at the dining table with others, living out of the family home, reporting less fruit serves and greater SSB serves. Interventions to improve the health of adolescents and young adults with Down syndrome should involve family members/carers and include practical food selection and preparation skills that facilitate healthier food choices whilst supporting developing independence.

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ADP	air displacement plethysmography
AMDR	accepted macronutrient distribution range
BIA	bioelectrical impedance analysis
BMI	body mass index
BMR	basal metabolic rate
CDC	Centers for Disease Control and Prevention
CHAT	Communicating Health and Technology
CI	confidence interval
col	column
cpm	count-per-minute
DEXA	dual energy x-ray absorptiometry
EAR	Estimated Average Requirement
EDNP	energy dense nutrient poor
EVA	exposure variation analysis
FFQ	food frequency questionnaire
ID	intellectual disability
IOTF	International Obesity Task Force
METS	metabolic equivalents
mFR	mobile food record
min	minutes
MVPA	moderate to vigorous physical activity
NHANES	National Health and Examination Survey
NHMRC	National Health and Medical Research Council
NNPAS	National Nutrition and Physical Activity Survey
NOW	Needs, Opinions, Wishes
PANDs	Physical Activity, Nutrition and Down syndrome
REE	resting energy expenditure
rho	Spearman's rank correlation coefficient
RMR	resting metabolic rate
SD	standard deviation
SSB	sugar sweetened beverages
T_4	thyroxine
TSH	thyroid stimulating hormone

UK	United Kingdom
USA	United States of America
WA	Western Australia
WHO	World Health Organization

Chapter 1 Introduction

1.1 Down syndrome

In 2015, 4.3 million Australians or 18.3% of the population reported having a disability (Australian Bureau of Statistics, 2016b). In Western Australia the prevalence of intellectual disability was 17.0/1000 live births with Down syndrome the most common biomedical cause, accounting for 6.2% of cases in Western Australia (Bourke, de Klerk, Smith, & Leonard, 2016).

From 1980-1996 the birth prevalence of Down syndrome in Western Australia was estimated at 1.11 per 1000 live births with more males (56.6%) than females, and 4.6% of these babies being born to Aboriginal mothers (S. Leonard, Bower, Petterson, & Leonard, 2000). Due to increasing maternal age the prevalence of Down syndrome conceptions (including live births, still births and terminations) has increased over time, however the live birth rate has fallen slightly to 0.87 per 1000 live births from 2004 onwards due to an increase in prenatal diagnosis and termination of Down syndrome pregnancies (Maxwell, Bower, & O'Leary, 2015).

Down syndrome is associated with varying levels of intellectual disability as well as medical conditions such as increased risk of cardiac, gastrointestinal (e.g. coeliac disease) and endocrine disorders (e.g. hypothyroidism), hearing and sight impairment, various orthopaedic conditions, dental disease and dementia (Roizen & Patterson, 2003). The presence of congenital heart disease (particularly in earlier birth cohorts), prematurity, low birth weight (with or without prematurity), caesarean delivery and Indigenous status have impacted negatively on survival rates (Glasson, Jacques, Wong, Bourke, & Leonard, 2016). However due to advancing medical knowledge and earlier cardiac surgery interventions, survival rates of Western Australian infants with Down syndrome are increasing (Glasson et al., 2016). Glasson et al. (2016) reported a 95% 10-year survival rate for Western Australian infants born 1990-1999, an increase from a 74% 10 year survival rate for infants born 1953-1959. As life expectancy for people with Down syndrome is now around 60 years (Glasson et al., 2016), this underscores the importance of health care for people with Down syndrome (Sobey et al., 2015).

1.2 Anthropometric and body composition assessment of adolescents and young adults with Down syndrome

The anthropometry and body composition of adolescents and young adults with Down syndrome is different from that of adolescents and young adults without Down syndrome. Young people with Down syndrome are shorter in height (Grammatikopoulou et al., 2008; Jobling, Cuskelly, & Rutherford, 2006; Parra, Costa, Real de Asua, Moldenhauer, & Suarez, 2017; Pitchford, Adkins, Hasson, Hornyak, & Ulrich, 2018; Real de Asua, Parra, Costa, Moldenhauer, & Suarez, 2014a) and have a slower growth velocity during certain stages of growth (Van Gameren-Oosterom, Van Dommelen, Oudesluys-Murphy, et al., 2012) compared to young people without Down syndrome. Studies have also identified that adolescents with Down syndrome have shorter limb length (Costa et al., 2013; Zemel et al., 2015) and possibly different lean and fat mass distribution (González-Agüero, Ara, Moreno, Vicente-Rodriguez, & Casajus, 2011; Pitchford et al., 2018) in comparison to adolescents without Down syndrome.

Down syndrome specific growth charts are available for North American (Zemel et al., 2015), Swedish (Myrelid, Gustafsson, Ollars, & Anneren, 2002), Egyptian (Afifi, Aglan, Zaki, Thomas, & Tosson, 2012), Chinese (Su et al., 2014), Turkish (Tuysuz, Goknar, & Ozturk, 2012), Dutch (Van Gameren-Oosterom, Van Dommelen, Oudesluys-Murphy, et al., 2012), United Arab Emirates (Aburawi, Nagelkerke, Deeb, Abdulla, & Abdulrazzaq, 2015), Saudi Arabian (Al Husain, 2003b), United Kingdom and Irish (McGowan et al., 2012) populations. To date, no Australian Down syndrome specific growth charts have been produced and the validity of international growth charts for Australian adolescents with Down syndrome has not been examined.

For Australian adolescents and young adults, overweight and obesity is assessed using the body mass index (BMI), calculated as weight (kg)/height $(m)^2$ (National Health and Medical Rearch Council [NHMRC] 2013b). For adolescents, the NHMRC (2013b) advises plotting BMI either on the Centres for Disease Control (CDC) (2001) or World Health Organization (WHO) (2007) BMI-for-age percentile growth charts, with the caveat that the same charts be used when comparing the prevalence of overweight and obesity in different population groups, as the percentile cut-points for overweight and obesity are different (NHMRC, 2013b). The CDC BMI-for-age percentile growth charts categorise overweight as a BMI between the 85^{th} and 95^{th} percentile with obesity being over the 95^{th} percentile, whereas the WHO BMI-for-age percentile growth charts have a higher cut-point for obesity at the 97th percentile (NHMRC, 2013b). International research into overweight and obesity in adolescents often applies the International Obesity Task Force (IOTF) cut-points which are a BMI-for-age rather than a growth chart percentile (Cole, Bellizzi, Flegal, & Dietz, 2000). These cut-points have recently been updated to be more aligned with the WHO BMI-for-age growth chart percentiles (Cole & Lobstein, 2012).

For Australian adults the NHMRC categorises overweight as a BMI greater or equal to 25 kg/m^2 but less than 30 kg/m^2, and obesity as a BMI equal to or over 30 kg/m^2 (NHMRC, 2013b). These BMI cut-points are also used by the CDC (2012), the WHO (2006) and applied in international studies of overweight and obesity (see Table 1.1). The NHMRC Clinical Practice Guidelines advises however, that different BMI cut-points may be required for some groups of adults due to differences in body composition and limb length (lower for Asian and Australian Aboriginal populations, higher for Pacific Islander populations) (NHMRC, 2013b); this may also be a consideration for adolescents and young adults with Down syndrome.

Due to differences in anthropometry (Soler Marin & Xandri Graupera, 2011) and possible differences in body composition (González-Agüero, Ara, et al., 2011; Pitchford et al., 2018) the BMI of young people with Down syndrome may be inflated (Hatch-Stein et al., 2016), raising the question of how applicable standard BMI cut-points for overweight and obesity are for the adolescent and young adult population with Down syndrome (Zemel et al., 2015). Whilst this question has been addressed for the BMI cut-points on both standard and Down syndrome specific BMI-for-age percentile growth charts (Bandini, Fleming, Scampini, Gleason, & Must, 2013; Hatch-Stein et al., 2016; Samur San-Matin, Goncalves, Bertapelli, Mendes, & Guerra-Junior, 2016), only one study, where adults with Down syndrome were included with those with intellectual disability, has evaluated the suitability of BMI to predict obesity for adults with Down syndrome (Temple, Walkley, & Greenway, 2010).

A small North American study of adolescents and young adults aged 13-21 years with Down syndrome (n=32) evaluated the performances of the 85th and 95th percentile cut-points on the CDC BMI-for-age growth chart using standard percentage body fat cut-points (Bandini et al., 2013). Whilst the 95th percentile cut-point to predict obesity had a high specificity (96%), sensitivity was lower (71%), particularly in females (50%), however only one female was obese (Bandini et al., 2013) and thus results may be impacted by the small sample size. The ability of the 85th percentile cut-point to predict overweight had a high sensitivity (100%) and lower specificity (60%), falsely identifying several adolescents and young adults with Down syndrome as overweight who did not have an excess of body fat (Bandini et al., 2013). Overall, efficiency of the 85th percentile cut-point for overweight was lower compared to the 95th percentile cut-point for obesity (Bandini et al., 2013). In a sample of North American adolescents aged 10-20 years (n=121) with Down syndrome, Hatch-Stein et al. (2016) found the 85th percentile cut-point on the CDC BMI-for-age growth chart to not only show high sensitivity (100%), but also higher specificity (78.3%), similar to the sensitivity and specificity of the cut-point observed for controls. Both of the above studies used dual energy X-ray absorptiometry (DEXA) to measure percentage body fat, however elevated adiposity was assessed using different scales; Bandini et al. (2013) used percentage body fat cut-points and Hatch-Stein et al. (2016) used a fat mass index. The greater sample size in the study by Hatch-Stein et al. (2016) may also have contributed to the higher specificity of the 85th percentile cut-point.

In addition to evaluating the performance of the CDC BMI-for-age growth chart 85th percentile, Hatch-Stein et al. (2016) also evaluated the sensitivity and specificity of the 85th percentile for predicting overweight using the United States of America (USA) Down syndrome specific BMI-for-age growth chart as developed by Zemel et al. (2015). Hatch-Stein et al. (2016) overlaid the BMI-for-age Down syndrome specific growth chart on the CDC BMI-for-age growth chart and found that the 50% percentile on the Down syndrome specific growth chart was closer to the 85th percentile on the CDC growth chart for both boys and girls. Although specificity of the Down syndrome specific BMI-for-age growth chart 85th percentile was high (100%), sensitivity was low (62.3%), and thus the authors recommended the CDC BMI growth chart as the preferred tool for assessing overweight in adolescents with Down syndrome (Hatch-Stein et al., 2016). Zemel et al. (2015) also advised against using Down syndrome specific growth charts to identify overweight and obesity as comparing individual BMI with the BMI of other children with Down syndrome may not be comparing against “an ideal healthy distribution of BMI” (Zemel et al., 2015, p. e1209).

The study involving adults with intellectual disability (n=46) including Down syndrome found the BMI cut-point for obesity (≥30 kg/m^2) had good specificity (100%) but lower sensitivity (57.1%) (Temple et al., 2010). This study was limited by the lack of presentation of the specific results for participants with Down syndrome, and as adults with Down syndrome are shorter (Parra et al., 2017; Real de Asua et al., 2014a) and may have a different body composition to participants without Down syndrome (González-Agüero, Ara, et al., 2011; Pitchford et al., 2018), there remains a need to evaluate the sensitivity and specificity of the adult BMI cut-points for overweight and obesity, specifically for young adults with Down syndrome.

Although BMI is easy to determine (Krebs et al., 2007) and feasible for people with intellectual disability (Verstraelen, Maaskant, van Knijff-Raeven, Curfs, & Van Schrojenstein Lantman-de Valk, 2009) it is unable to distinguish between fat and lean tissue (McCarthy, Cole, Fry, Jebb, & Prentice, 2006) and other measures of body composition have been used in research. Body fatness measured using air displacement plethysmography (ADP) (Fernhall et al., 2005; González-Agüero, Ara, et al., 2011; González-Agüero, Matute-Llorente, Gómez-Cabello, Vicente-Rodríguez, & Casajús, 2017; González-Agüero, Vicente-Rodríguez, Ara, Moreno, & Casajús, 2011; Rossato et al., 2017; Seron, Silva, & Greguol, 2014; Usera, Foley, & Yun, 2005), bioelectrical impedance analysis (BIA) (Jankowicz-Szymanska, Mikolajczyk, & Wojtanowski, 2013; Loveday, Thompson, & Mitchell, 2012; Rossato et al., 2017) and more commonly DEXA (Allison et al., 1995; Bandini et al., 2013; Baptista, Varela, & Sardinha, 2005; Esco, Nickerson, Bicard, Russell, & Bishop, 2016; González-Agüero, Ara, et al., 2011; González-Agüero, Matute-Llorente, Gomez-Cabello, Casajus, & Vicente-Rodriguez, 2013; Guijarro, Valero, Paule, Gonzalez-Macias, & Riancho, 2008; Hatch-Stein et al., 2016; Loveday et al., 2012; Myrelid, Frisk, Stridsberg, Anneren, & Gustafsson, 2010; Nascimento et al., 2016; Nickerson et al., 2015; Pitchford et al., 2018; Samur San-Matin et al., 2016), has been reported in several studies of adolescents and young adults with Down syndrome. Although DEXA provides data on fat and lean tissue (Albanese, Diessel, & Genant, 2003), it is limited by availability, expense and the requirement for participants to remain still during the procedure (Esco et al., 2016; Nascimento et al., 2016; Verstraelen et al., 2009), which may cause some anxiety particularly for participants with Down syndrome (González-Agüero et al., 2017).

Skinfold thickness measurement to determine body fatness has been used in several studies with adolescents and young adults with Down syndrome (Esposito, MacDonald, Hornyak, & Ulrich, 2012; Ferrara, Capozzi, & Russo, 2008; González-Agüero et al., 2017; González-Agüero, Vicente-Rodríguez, et al., 2011; Grammatikopoulou et al., 2008; Izquierdo-Gomez, Martínez-Gómez, Fernhall, Sanz, & Veiga, 2016; Izquierdo-Gomez et al., 2013; Izquierdo-Gomez, Martínez-Gómez, Villagra, Fernhall, & Veiga, 2015; Soler Marin &

Xandri Graupera, 2011), with the Slaughter equation found to be the most appropriate for a sample of Spanish children and adolescents with Down syndrome (n=28) as judged by comparison with percentage body fat results from ADP (González-Agüero, Vicente-Rodríguez, et al., 2011). A Down syndrome specific equation for predicting adolescent percentage body fat using skinfolds and ADP has been developed in a small Spanish study (n=28) (González-Agüero et al., 2017), but further research is required to validate the equation in this and other age groups.

Standard body fat reference curves and cut-points for percentage body fat have been developed for children, adolescents (Laurson, Eisenmann, & Welk, 2011; McCarthy et al., 2006; Ogden, Li, Freedman, Borrud, & Flegal, 2011) and adults (Pasco et al., 2014) without Down syndrome to address some of the limitations of BMI and give a better representation of body composition. Unaffected by height and body fat distribution, gender differences in body fat development during growth can be better represented by body fat reference curves (McCarthy et al., 2006). Developed using BIA results from 1985 United Kingdom (UK) children and adolescents, the curves by McCarthy et al. (2006) have been applied in one New Zealand study of adolescents with Down syndrome (n=70) (Loveday et al., 2012) where body fat was measured using BIA and DEXA. Curves developed using DEXA derived data from the USA National Health and Examination Survey (NHANES) (Ogden et al., 2011) were used in a recent Brazilian study of adolescents with Down syndrome (n=34) (Samur San-Matin et al., 2016). For adults, age and sex specific cut-points for percentage body fat corresponding to the standard BMI cut-points were developed by Pasco et al. (2014) from the DEXA results of 2491 Australian adults aged 20-96 years. To date, no study has applied these body fat cut-points to the percentage body fat data of a sample of young adults with Down syndrome.

Due to the increased health risks associated with central obesity, waist circumference measurement has been found to predict cardiovascular mortality more accurately than BMI (Welborn & Dhaliwal, 2007) with waist circumferences higher than 88 cm for women and 102 cm for men representing high risk of metabolic complications (NHMRC, 2013b). For Australian adolescents there are no waist circumference risk cut-points available however a waist circumference greater than half the height (waist-to-height ratio) can be used as an indicator of the need for further assessment (NHMRC, 2013b). Although different cut-points have been identified for some adult ethnic groups due to differences in body composition (NHMRC, 2013b), there are no specific cut-points for adults with Down syndrome, with waist circumference used as measure of central obesity in several studies with adolescents and young adults with Down syndrome (Goluch-Koniuszy & Kunowski, 2013; Grammatikopoulou et al., 2008; Parra et al., 2017; Real de Asua et al., 2014a; Soler Marin & Xandri Graupera, 2011).

As mentioned, waist-to-height ratio ≥0.5 has been used to indicate need for further assessment in the absence of waist circumference risk cut-points in adolescents. It has been validated for clinical use with Australian children and adolescents (Nambiar, Truby, Abbott, & Davies, 2009) and found to predict the metabolic syndrome in 109 obese Australian children and adolescents (Nambiar, Truby, Davies, & Baxter, 2013). Specific cut-points developed from the skinfold thickness data of 2773 Australian children and adolescents (Nambiar, Hughes, & Davies, 2010) have been proposed which correspond to the 85th and 95th percentile cut-points for overweight and obesity using the percentage body fat reference curves developed by McCarthy et al. (2006).

The usefulness of waist-to-height ratio in adults as a proxy for central obesity, and a better predictor of metabolic risk than waist circumference and BMI, was demonstrated by a systematic review and meta-analysis of 31 studies (Ashwell, Gunn, & Gibson, 2012). Also in adults without Down syndrome, a more recent study identified that of five anthropometric tests (including BMI and waist circumference), waist-to-height ratio was the best predictor of total percentage body fat and visceral fat mass as assessed using DEXA (Swainson, Batterham, Tsakirides, Rutherford, & Hind, 2017). Whilst a waist-to-height ratio ≥0.5 was proposed to indicate increased risk (Ashwell & Hsieh, 2005), a Spanish study of 81 adults has suggested higher cut-points to indicate obesity (0.53 in men, 0.54 in women) (Swainson et al., 2017).

Dhaliwal and Welborn (2009) compared measures of central obesity between cohorts of different body frame sizes (Australians and Asians) finding that unlike BMI and waist circumference, the waist-to-height ratio of both groups was equivalent, demonstrating the impact of adjusting waist circumference for height. As waist circumference may under-estimate risk for shorter individuals (Browning, Hsieh, & Ashwell, 2010) and adults with Down syndrome tend to be shorter than adults without Down syndrome (Parra et al., 2017; Real de Asua et al., 2014a), waist-to-height ratio may be more appropriate than waist circumference alone for adults with Down syndrome. In three studies involving adolescents and adults with and without Down syndrome no difference in waist circumference was reported between adults with Down syndrome and controls, however the mean waist-to-height ratio and BMI for participants with Down syndrome was significantly greater (Izquierdo-Gomez et al., 2016; Parra et al., 2017; Real de Asua et al., 2014a). Parra et al. (2017) suggested that the dissonance between BMI and waist circumference could be due to shorter height in young people with Down syndrome and standard cut-points would not be suitable.

In an analysis of the diagnostic abilities of waist circumference and waist-to-height ratio for Spanish adults with Down syndrome (n=49), Real de Asua, Parra, Costa, Moldenhauer, and Suarez (2014b) concluded that the waist-to-height ratio was more useful for assessing central obesity as standard waist circumference cut-points misclassified over 50% of adults with Down syndrome in comparison to waist-to-height ratio. Although bio-impedance was used to measure percentage body fat (Real de Asua et al., 2014b) there was no measure of visceral obesity and therefore the relationship between waist-to-height ratio and abdominal obesity in adolescents and young adults with Down syndrome is unknown. Additionally, longitudinal research is required to confirm the relationship between waist-to-height measurement and health outcomes for adolescents and young adults with Down syndrome.

1.3 Development of overweight and obesity in people with Down syndrome

There is evidence that the development of overweight and obesity in people with Down syndrome may have its genesis in early childhood, with some children between the ages of 1-5 years starting to display a higher BMI than their peers without Down syndrome (Hawn, Rice, Nichols, & McDermott, 2009; Van Gameren-Oosterom, Van Dommelen, Schönbeck, et al., 2012). Few studies have investigated the development of overweight and obesity in very young children with Down syndrome, however one large study comparing the BMI of Saudi children under the age of 5 years with (n=785) and without (n=989) Down syndrome found that although obesity was not detected in either group, overweight was only evident in the group with Down syndrome (Al Husain, 2003a). Similarly in a large Dutch study (n=1596), the higher prevalence of overweight and obesity in children over the age of 2 years (Van Gameren-Oosterom, Van Dommelen, Schönbeck, et al., 2012) was concerning, with more than 25% of children with Down syndrome over the age of 4 years being overweight, double the rate of children without Down syndrome of the same age.

A limitation of both these studies is that the BMI of the children with Down syndrome were classified as overweight and obese using IOTF cut-offs (Cole et al., 2000), thereby not accommodating for the different anthropometry of children with Down syndrome (Zemel et al., 2015). In another large retrospective UK study of the health and medication use of 6430 individuals (aged up to 30 years) with Down syndrome compared with age matched controls, the relative prevalence of obesity was higher in those with Down syndrome compared to controls for all age groups (Alexander et al., 2016). The authors of this study used the standard BMI cut-point for obesity for adults, and for children cut-points were developed at 2 standard deviations above the mean for the population without Down syndrome (Alexander et al., 2016). Thus the true rate of overweight and obesity in young children with Down syndrome may differ to the figures reported in these studies. A screening tool to detect overweight and obesity in children with Down syndrome is required (Zemel et al., 2015).

Several international studies have strongly supported the prevalence of overweight and obesity in primary school aged children with Down syndrome being higher than that of children without Down syndrome (Ferrara et al., 2008; Grammatikopoulou et al., 2008; Loveday et al., 2012; Magge, O'Neill, Shults, Stallings, & Stettler, 2008; Samarkandy, Mohamed, & Al-Hamdan, 2012; Tenenbaum et al., 2011; Van Gameren-Oosterom, Van Dommelen, Schönbeck, et al., 2012; Venegas et al., 2015; Whitt-Glover, O'Neill, & Stettler, 2006) and that prevalence of overweight and obesity increased with age (Grammatikopoulou et al., 2008; Hawn et al., 2009; Van Gameren-Oosterom, Van Dommelen, Schönbeck, et al., 2012). As with studies on younger children with Down syndrome most of the studies in primary school aged children were limited by the use of standard BMI-for-age growth charts and cut-points to determine the level of overweight and obesity with only Loveday et al. (2012) using percentage fat mass curves, hence the figures may be inaccurate. This trend in reported overweight and obesity prevalence continues through adolescence and into adulthood (Minihan, Fitch, & Must, 2007) with research consistently finding a high level of overweight and obesity in adults with Down syndrome using standard BMI classification cut-points (Bhaumik, Watson, Thorp, Tyrer, & McGrother, 2008; Braunschweig et al., 2004; Fujiura, Fitzsimons, Marks, & Chicoine, 1997; Henderson, Lynch, Wilkinson, & Hunter, 2007; Hsieh, Rimmer, & Heller, 2014; Jobling et al., 2006; Melville, Cooper, McGrother, Thorp, & Collacott, 2005; V. P. Prasher, 1995; Real de Asua et al., 2014a; Rubin, Rimmer, Chicoine, Braddock, & McGuire, 1998; Sohler, Lubetkin, Levy, Soghomonian, & Rimmerman, 2009; Soler Marin & Xandri Graupera, 2011). However due to the lower average height the standard BMI classification cut-points for overweight and obesity may need adjusting for adults with Down syndrome (Soler Marin & Xandri Graupera, 2011).

1.4 Overweight and obesity in adolescents and young adults with Down syndrome

The adolescent transition period between childhood and adulthood is marked by significant physical, behavioural and emotional growth and development which can impact on body composition (Patton et al., 2011), however there are differences for adolescents with Down syndrome. Physically, although the teenage growth spurt is evident, a large (n=1596) population based Dutch study found that the adolescent growth spurt for teenagers with Down syndrome was substantially reduced, with on average, young adult males 20.4 cm and females 18.9 cm shorter than their counterparts without Down syndrome at adulthood (Van Gameren-Oosterom, Van Dommelen, Oudesluys-Murphy, et al., 2012). Thus comparing BMI values between adolescents with and without Down syndrome or categorising BMI may have limitations and further investigation of anthropometry and body composition during adolescence of young people with Down syndrome is required.

For teenagers with (Hawn et al., 2009) and without Down syndrome (Bassett, Chapman, & Beagan, 2008) adolescence is a time when greater autonomy around food choices emerge and food patterns change. The recent 2011-12 Australian Health Survey found for adolescents without Down syndrome, 41% of daily energy came from discretionary foods, with adolescents being the greatest consumers of sweetened beverages (Australian Bureau of Statistics, 2014) and free sugars (Australian Bureau of Statistics, 2016a). The Australian Health Survey also identified that 71% of 14-18 year old males and 90% of 14-18 year old females were consuming less than the Estimated Average Requirement (EAR) for calcium (Australian Bureau of Statistics, 2015a), a requirement higher than earlier periods of growth (NHMRC and New Zealand Ministry of Health, 2006). Similarly young adulthood, for some with Down syndrome, is when independence, autonomy, relationships with family, friends and partners and participation in education, employment and the community become important for quality of life (M. Scott, Foley, Bourke, Leonard, & Girdler, 2013). For the majority of adolescents with Down syndrome however, a greater dependence on parents and carers for meal preparation and food purchasing (Van Gameren-Oosterom et al., 2013) could result in different food patterns and behaviours compared to adolescents without Down syndrome, and these food patterns and behaviours need to be explored.

The importance of this time of life in respect to the development of overweight and obesity was highlighted by Patton et al. (2011) in a large Australian cohort study of 1520 adolescents (Health of Young Victorians Study). Over a 10-year period from ages 14-24 years, the prevalence of overweight increased by 65% and obesity almost doubled as assessed using the IOTF BMI cut-points (Patton et al., 2011). Of those young adults who were overweight or obese, 80% had been in a lower weight category at some point during the preceding 10 years, indicating that adolescence and young adulthood is a key time for the development of behaviours and habits which impact on body composition and thus an important time for prevention of overweight and obesity (Patton et al., 2011).

For young people with Down syndrome, these findings are supported by an earlier retrospective Japanese study which reported changes in BMI of a small (n=34) cohort of young people with Down syndrome from early teenage years to adulthood (late twenties) (Miyazaki & Okumiya, 2004). The prevalence of obesity (BMI ≥25 kg/m^2) increased from the late teens (28% of males, 13% of females) to the late twenties (46% of males, 40% of females) highlighting adolescence and young adulthood as key times for obesity prevention (Miyazaki & Okumiya, 2004). As highlighted by the authors, the limitations of this study were using the same BMI classification of obesity (as determined by the Japan Society for the Study of Obesity) for both adolescents and young adults, and the impact of reduced height on BMI classifications of obesity for people with Down syndrome. There is no published research tracking changes in the body composition of a cohort of Australian young people with Down syndrome however, as indicated above, the evidence does suggest an increasing prevalence of overweight and obesity in adolescence through to young adulthood.

1.4.1 Rates of overweight and obesity in adolescents and young adults with Down syndrome

Table 1.1 summarises studies from 2006 to December 2017 which include statistics on overweight and/or obesity, as judged by BMI, in adolescents and young adults with Down syndrome. Studies were included if they identified some or all of the participants as having Down syndrome (rather than intellectual disability generally) and specific data were provided. The age range included 12-30 year olds and where the sample was not restricted to a particular BMI range.

1.4.1.1 Australian research

Four Australian studies investigating the level of overweight and obesity in adolescents and young adults with Down syndrome met the criteria for inclusion: three Queensland studies and a larger Western Australian study (refer to Table 1.1), with the prevalence of overweight and obesity reported in these studies varying over 50% and no study reporting any other measure of anthropometry apart from height and weight. The reported prevalence of overweight and obesity in these studies is higher than the prevalence of overweight and obesity in Australian young adults aged 18-24 years (38.9%) without Down syndrome and similar to the prevalence of overweight and obesity in young Australians aged 24-34 years (52.4%) without Down syndrome in 2014-15 (Australian Bureau of Statistics, 2015b). However as discussed in section 1.2 there are limitations to using BMI to classify overweight and obesity in the population with Down syndrome. In the study by Jobling and Cuskelly (2006) the level of overweight and obesity (50%) in adolescents with Down syndrome aged 11-18 years (n=38) was determined using a BMI of greater or equal to 25 kg/m^2 as overweight or obese. A second study published the same year on another small group of young adults aged 18-24 years with Down syndrome (n=18) found a comparable prevalence of overweight and obesity (55.6%) using a BMI of 27 kg/m^2 as the cut-point for obesity (Jobling et al., 2006). Although body composition was not the focus of either study, both have limitations with their small unrepresentative sample sizes and use of BMI alone to indicate level of fatness. A more recent Queensland study on obesity in 436 adolescents with intellectual disability (Krause, Ware, McPherson, Lennox, & O'Callaghan, 2016) presented figures specifically for adolescents with Down syndrome using the International Obesity Task Force (IOTF) cut-points and found that Down syndrome was “an independent risk factor for overweight and obesity among adolescents with ID [intellectual disability]” (Krause et al., 2016, p. 8). A relationship between Down syndrome and obesity has also been reported in other studies of adults with intellectual disability (Bhaumik et al., 2008; Hoey et al., 2017; Hsieh et al., 2014; Melville et al., 2008; Stancliffe et al., 2011).

In a large, population-based, representative (88.3% response fraction) Western Australian study (Pikora et al., 2014), a high percentage (57.4%) of adolescents and young adults with Down syndrome were perceived by their family members/carers to be overweight or obese with two thirds reporting that the excess weight condition was impacting on daily life for the young person. Parent perception has been shown to underestimate overweight and obesity prevalence in primary school aged children and adolescents without Down syndrome (Merema et al., 2016; Nambiar, Truby, Hughes, & Davies, 2013; Sand, Lask, Hysing, & Stormark, 2014; Shrewsbury et al., 2012; Wake, Salmon, Waters, Wright, & Hesketh, 2002) and in adolescents with intellectual disability (George, Shacter, & Johnson, 2011), however this has not been tested with parents and carers of adolescents and young adults with Down syndrome. Anthropometric data collected in the same study as reported in Pikora et al. (2014) will be analysed and reported in Chapter 3 of this thesis.

1.4.1.2 International research

Internationally, studies have reported high levels of overweight and obesity in adolescents and young adults with Down syndrome, however as the age range, sample size, methods of anthropometric and body composition measurement and criteria used to classify weight status varied from study to study, the figures cannot be directly compared (see Table 1.1). In addition, due to standard percentile cut-points and BMI classifications being applied, these figures may not accurately reflect the true prevalence.

Grammatikopoulou et al. (2008) (n=34) and Hatch-Stein et al. (2016) (n=121) analysed the BMI data of adolescents with Down syndrome using both CDC and Down syndrome specific growth charts. Both studies found the prevalence of overweight and obesity was higher using CDC BMI-for-age growth charts compared to the Down syndrome specific charts with Grammatikopoulou et al. (2008) proposing that the high level of stunting could be an explanation for the high BMI levels observed. Galli, Cimolin, Rigoldi, Condoluci, and Albertini (2015) and Samur San-Matin et al. (2016) used Down syndrome specific growth charts to classify BMI with Samur San-Matin et al. (2016) also using IOTF (Cole & Lobstein, 2012) and WHO (de Onis et al., 2007) references. Several studies of adolescents used the CDC BMI percentile growth chart cut-points (AbdAllah, Raffa, Alaidaroos, Obaid, & Abunznada, 2013; Bandini et al., 2013; Basil et al., 2016; Corder, Al Ahbabi, Al Dhaheri, & Chedid, 2017; Esposito et al., 2012; M. Polfuss, Simpson, Greenley, Zhang, & Sawin, 2017; Rimmer, Yamaki, Lowry, Wang, & Vogel, 2010; Seron et al., 2014; Tenenbaum et al., 2011; Xanthopoulos et al., 2017), Goluch-Koniuszy and Kunowski (2013) used Polish BMI-for-age growth charts and Niegawa et al. (2017) used Japanese BMI-for-age growth charts. As an alternative to BMI-for-age growth charts, four European studies and one United Arab

Emirates study (Aburawi et al., 2015; Begarie, Maiano, Leconte, & Ninot, 2013; Buonuomo et al., 2016; Jankowicz-Szymanska et al., 2013; Van Gameren-Oosterom, Van Dommelen, Schönbeck, et al., 2012) applied the International Obesity Taskforce (IOTF) cut-points (Cole et al., 2000) to classify BMI. Loveday et al. (2012) used percentage fat mass curves in their New Zealand study and Hawn et al. (2009) used an standard adult cut-point to classify the BMI of children as overweight and obese. As discussed earlier, these classifications, without taking differences in body composition into account, may not be estimating the true prevalence of overweight and obesity.

In studies which included young adults, BMI cut-points were the same as the NHMRC cut-points (Begarie et al., 2013; Bhaumik et al., 2008; Carfì et al., 2014; Havercamp et al., 2017; Hsieh et al., 2014; Parra et al., 2017; M. Polfuss et al., 2017; Pucci et al., 2016; Real de Asua et al., 2014a; Sohler et al., 2009; Soler Marin & Xandri Graupera, 2011; Stancliffe et al., 2011) with another study using a higher BMI figure of 35 to classify obesity (Henderson et al., 2007). Several studies of young adults included large age ranges and no data were specific to young adults, therefore the specific percentages of young adults who were classified as overweight or obese in these studies are unknown (Bhaumik et al., 2008; Henderson et al., 2007; Hsieh et al., 2014; Parra et al., 2017; Pucci et al., 2016; Real de Asua et al., 2014a; Sohler et al., 2009; Stancliffe et al., 2011). Havercamp et al. (2017) also included a wide age range, however results were presented for young adults aged 18-34 years. Over 80% of participants in this age group had a BMI that was classified as overweight or obese, significantly higher than rates in peers without disability (Havercamp et al., 2017).

The methods of collecting anthropometric data also varied between studies. Mostly participants were directly measured, however proxy-reported height and weight was used to calculate BMI in several studies (Havercamp et al., 2017; Hsieh et al., 2014; Ono et al., 2015; M. Polfuss et al., 2017; Rimmer et al., 2010; Stancliffe et al., 2011) and parent perception of overweight was reported in others (Bertoli et al., 2011; Carr, 2008; Pikora et al., 2014). Proxy-reported height and weight is more cost and time effective, especially in large studies (Brettschneider, Ellert, & Rosario, 2012), however underestimation of weight (and therefore BMI) is common in studies with adolescents (Akinbami & Ogden, 2009; Brettschneider et al., 2012) and adults (Reed & Price, 1998). In the first small study which investigated the relationship between proxy-reported and measured height and weight of adult Special Olympics participants (n=21), authors found good correlation between reported and measured height and weight, although similar to previous research, height was overestimated and weight was underestimated (Dobranowski, Lloyd, Côté, & Balogh, 2018).

Comparison of BMI with a control group of similarly aged participants without Down syndrome was applied in several studies to demonstrate a higher level of overweight and obesity in the group of adolescents or young adults with Down syndrome (AbdAllah et al., 2013; Basil et al., 2016; Carr, 2008; Havercamp et al., 2017; Hsieh et al., 2014; Jobling et al., 2006; Parra et al., 2017; Real de Asua et al., 2014a; Van Gameren-Oosterom, Van Dommelen, Schönbeck, et al., 2012). However as described earlier, the use of BMI to categorise weight status may have limitations for people with Down syndrome and thus comparisons with a control group without Down syndrome may be inaccurate.

1.4.2 Percentage and location of body fat

Studies comparing percentage body fat between adolescents and young adults without Down syndrome have reported varying results with some finding percentage body fat was significantly higher in participants with Down syndrome (Baptista et al., 2005; Fernhall et al., 2005; Izquierdo-Gomez et al., 2016; Izquierdo-Gomez, Martínez-Gómez, et al., 2015; Myrelid et al., 2010; Pitchford et al., 2018) and others finding no difference (Allison et al., 1995; González-Agüero, Ara, et al., 2011; Guijarro et al., 2008; Izquierdo-Gomez et al., 2013; Nascimento et al., 2016). In these contrasting studies, the measurement of percentage fat was conducted using DEXA, skinfold thickness and ADP, and sample sizes ranged from 10 participants with Down syndrome and controls (Myrelid et al., 2010) to 100 and over (Izquierdo-Gomez et al., 2016; Izquierdo-Gomez, Martínez-Gómez, et al., 2015). Gender differences in percentage body fat of adolescents and young adults with Down syndrome were similar to those observed in control groups with females having a greater percentage body fat than males (Bandini et al., 2013; Baptista et al., 2005; González-Agüero, Ara, et al., 2011; González-Agüero et al., 2017; Jankowicz-Szymanska et al., 2013; Loveday et al., 2012; Samur San-Matin et al., 2016; Soler Marin & Xandri Graupera, 2011),

Interestingly one of the studies that found no difference in percentage body fat and BMI between participants with Down syndrome and controls reported differences in body fat location (González-Agüero, Ara, et al., 2011) thereby suggesting that it may be more the location rather than percentage of body fat that could be the better indicator of the health risks associated with Down syndrome. González-Agüero, Ara, et al. (2011) used ADP and DEXA to compare the percentage and location of body fat and lean body mass of Spanish adolescents with Down syndrome (n=31) to that of controls (n=32) finding that females with Down syndrome had a higher fat and lean mass in the torso and lower fat and lean mass in the legs whereas males had a higher fat mass and lower lean mass in the whole body and lower lean mass in the legs. Despite females with Down syndrome having a higher torso fat mass than females without Down syndrome, there was no difference in waist circumference between adolescent females with Down syndrome and controls (González-Agüero, Ara, et al., 2011) which may be due to the significantly shorter height of female participants with Down syndrome. Differences in body composition are supported by a second USA study in which the body composition of adolescents with Down syndrome (n=22) were compared to matched controls (Pitchford et al., 2018). Using DEXA, adolescents with Down syndrome had higher trunk to total body percentage fat ratios, lower leg to total body percentage fat ratios, and lower arms and legs to total body percentage fat ratios, indicating a greater distribution of abdominal fat (Pitchford et al., 2018).

One small (n=38) Spanish study which used waist circumference as a measure of central obesity in young adults with Down syndrome (Soler Marin & Xandri Graupera, 2011) reported that 26.7% of women and 30.4% of men in the study were at high risk of metabolic complications, however this was not compared with data from young adults without Down syndrome, nor were the waist circumference cut-points for metabolic complications provided. A further Brazilian study of adolescents with Down syndrome (n=41) found that when using a standard percentile reference 25% of girls and 12% of boys had a waist circumference above the 90th percentile and 50% of girls and 44% of boys had a waist circumference between the 75th and 90th percentiles (Seron et al., 2014). Due to lower than average height and possible differences in body composition, lower waist circumference cut-points may be more appropriate for adolescents and young adults with Down syndrome and thus the high percentage of males and females with waist circumferences above the 50th percentile in the study by Seron et al. (2014) may have indicated an increased metabolic risk associated with increased central obesity.

The waist-to-height ratio has been used in several international studies comparing the anthropometry of adolescents and young adults with and without Down syndrome (Izquierdo-Gomez et al., 2016; Parra et al., 2017; Real de Asua et al., 2014a). In Izquierdo-

Gomez et al. (2016) and Parra et al. (2017) waist-to-height ratio was significantly greater in participants with Down syndrome compared to controls and Real de Asua et al. (2014a) reported a greater percentage of participants with Down syndrome with a waist-to-height ratio higher than the acceptable cut-point (86% versus 68%). Further research is needed to confirm this measure as a preferred indicator of metabolic risk for adolescents and young adults with Down syndrome.

1.5 Comorbidities associated with overweight and obesity in Down syndrome

In Australia, coronary heart disease, cerebrovascular diseases, cancer and type 2 diabetes are the leading causes of death (Australian Institute of Health and Welfare, 2014), with obesity a significant risk factor (NHMRC, 2013b). In the recent 2011-12 National Health Survey the prevalence of overweight and obesity, cardiovascular disease, high cholesterol, hypertension and type 2 diabetes was higher for Australians with disability under the age of 65 years compared to those without disability (Australian Institute of Health and Welfare, 2016). A higher prevalence of type 2 diabetes in Victorian adults with intellectual disability compared with adults without intellectual disability was found in the analysis of two state-wide surveys (Haider, Ansari, Vaughan, Matters, & Emerson, 2013) and in children and adults with Down syndrome (n=4081), the prevalence of diabetes was greater than that of matched controls included in a Victorian cohort study of hospitalisation records over 17 years (Sobey et al., 2015).

Large USA studies of obesity and secondary health conditions in adolescents with intellectual disability have reported that young people with disability who were overweight experienced a higher prevalence of asthma, depression, hypertension, diabetes and hypercholesterolemia compared to young people with a disability who were healthy weight (Rimmer et al., 2010; Yamaki, Rimmer, Lowry, & Vogel, 2011). Specifically, for adolescents and young adults with Down syndrome, being overweight or obese was associated flat feet (Jankowicz-Szymanska et al., 2013; Pau, Galli, Crivellini, & Albertini, 2013), sleep apnoea (Basil et al., 2016; Esbensen, 2016), altered walking gait (Galli et al., 2015) and reduced aerobic capacity (Wee et al., 2015). Whilst these are similar to the comorbidities experienced by overweight and obese young people without a disability (Lobstein, Baur, & Uauy, 2004; Wake et al., 2010), for young people with a disability, the potential increase in health care needs alongside those with their existing disability and possible impacts on their independence and participation in the community highlights the need for health promotion and intervention (Yamaki et al., 2011).

Aside from obesity, research into other chronic disease risk factors in populations with Down syndrome is limited and inconclusive. There is evidence that despite the higher level of overweight and obesity, levels of blood lipids, fasting insulin and glucose levels in adults with Down syndrome were no different to adults without Down syndrome (Braunschweig et al., 2004; Parra et al., 2017; Real de Asua et al., 2014a), or generally within normal ranges (Real de Asua, Quero, Moldenhauer, & Suarez, 2015; Soler Marin & Xandri Graupera, 2011). In several studies blood pressure has been lower in adults with Down syndrome compared to controls with and without disability (Draheim, McCubbin, & Williams, 2002; Nordstrøm, Paus, Retterstøl, & Kolset, 2016; Parra et al., 2017) including adults with abdominal obesity (Real de Asua et al., 2014b). Conversely in a small study with children with Down syndrome blood lipid levels were higher in children with Down syndrome compared to their siblings without Down syndrome (Adelekan, Magge, Shults, Stallings, & Stettler, 2012) and hyperlipidaemia was found in almost half the child and adolescent participants with Down syndrome (n=146) in a large retrospective Israeli study (Tenenbaum et al., 2011). In a large study of Italian children and adolescents with Down syndrome (n=357) mean triglyceride, total cholesterol and LDL-C levels were higher than the 95% percentile cut-off values for sex and age, indicating an increased risk of adult onset cardiovascular disease (Buonuomo et al., 2016). In a further study of 84 Italian children and adolescents with Down syndrome non-alcoholic fatty liver disease in was found in higher proportions than in children and adolescents without Down syndrome regardless of BMI status (Valentini et al., 2017). Increased insulin resistance has also been described in adults with abdominal obesity (Real de Asua et al., 2014b) further highlighting the need for longitudinal research on chronic disease risk factors and outcomes in adolescents and young adults with Down syndrome.

Although higher levels of cardiovascular disease have been reported in adults with Down syndrome (D. A. Hill et al., 2003) a study of atherosclerosis risk factors in adults with Down syndrome (n=52) compared to controls (n=52) found that despite higher levels of body fat and blood triglycerides, levels of atherosclerosis (as determined by intima-media thickness of the carotid artery) were lower in adults with Down syndrome (Draheim, Geijer, & Dengel, 2010) and low rates of hypertension have also been reported (Havercamp et al., 2017; Real de Asua et al., 2014a). In a study of mortality and causes of death between 1969-2003 of Swedish people with Down syndrome, Englund, Jonsson, Zander, Gustafsson, and Annerén (2013) reported that rates of atherosclerosis were lower than for the general population accounting for 6.9% of deaths. In an Australian population-based cohort study of children and adults with Down syndrome (n=4081) there was a lower risk of coronary events for males compared to matched controls (Sobey et al., 2015). Various physiological processes have been proposed as possible protective factors against cardiovascular disease in adults with Down syndrome (Corsi et al., 2009; Vis et al., 2009) however further research is required.

1.6 Gaps in the knowledge on body composition and Down syndrome

Very little is known about the body composition of Australian adolescents and young adults with Down syndrome and the performance of standard BMI, waist circumference and waist-to-height cut-points in this population. In addition, most of the international studies are of small sample size and varied methodology with limitations. There is also limited knowledge about the specific risk factors for the development of overweight and obesity in adolescence and young adulthood, which could be used to target interventions and strategies for young people with Down syndrome and their families. Although existing research consistently highlights the high levels of overweight and obesity in adolescents and young adults with Down syndrome, investigation is needed on the impacts of physiological, behavioural and social factors that influence overweight and obesity, in particular those that relate to food intake and physical activity in Australian youth with Down syndrome.

1.7 Study aims

Therefore the aims of this research were to:

1. Investigate the prevalence of overweight and obesity in adolescents and young adults with Down syndrome and describe the relationships between proxy-reported BMI, food and physical activity related behaviours, health, functional ability, family socioeconomic status, place of residence and social networks.
2. Describe the anthropometry and body composition of a sample of Australian adolescents and young adults with Down syndrome using standard BMI, percentage body fat, waist circumference and waist-to-height ratio cut-points.

3. Describe the performance of standard BMI, waist circumference and waist-to-height ratio cut-points for adolescents and young adults with Down syndrome including sensitivity and specificity of standard BMI cut-points.
4. Describe the reported dietary intake (fruit, vegetable and discretionary food groups), sedentary behaviour and physical activity patterns of adolescents and young adults with Down syndrome and the relationships with measured BMI, percentage body fat, waist circumference and waist-to-height ratio.

1.8 Thesis structure

Following a literature review which applies a socio-ecological model to factors influencing the body composition of adolescents and young adults with Down syndrome (Chapter 2), the thesis is divided into the following chapters.

Chapter 3 addresses objective 1 through a quantitative cross-sectional and cohort analysis of parent-reported weight and height and associated factors from the 2004, 2009 and 2011 waves of the Down syndrome Needs Opinions Wishes (NOW) study conducted at the Telethon Kids Institute (formerly the Telethon Institute for Child Health Research), situated in Perth, Western Australia.

Following on from the Down syndrome NOW study Chapter 4 is an overview of the second major study included in this thesis, the Physical Activity, Nutrition and Down syndrome (PANDs) study. The PANDs study had three major components (anthropometry and body composition, dietary intake, physical activity) and each of these are discussed in the following three chapters. Within each study the methods and results are discussed in relation to the literature.

Chapter 5 addresses objectives 2 and 3 and tests a number of hypothesis through a cross-sectional study of measured weight, height (for calculation of BMI), waist circumference, waist-to-height ratio and DEXA derived percentage body fat in a sample of adolescents and young adults with Down syndrome who participated in the PANDs study.

Chapter 6 includes the published article by the candidate (Bathgate et al., 2017) which partly addresses objective 4 and is a discussion of the feasibility of assessing diet with a mobile food record for adolescents and young adults with Down syndrome. A supplement to Chapter 6 provides an analysis of the reported food group intake of adolescents and young adults with Down syndrome.

Chapter 7 addresses the remainder of objective 4 and is a cross-sectional study of the physical activity and sedentary behaviour of adolescents and young adults with Down syndrome in the PANDs study.

An overall discussion of the data from both the Down syndrome NOW and PANDs studies, including conclusions and recommendations for future research and practice is in Chapter 8.

Table 1.1 Reported overweight and obesity in adolescents and young adults with Down syndrome

Author, year of publication	Study recruitment (Country)	Age range of participants with Down syndrome (years)	Number of participants with Down syndrome	Comparison to a control group	Anthropometric measurements	BMI proxy or directly measured	Classification of overweight & obesity	Overweight & obese (%)
Australian Studies								
Jobling and Cuskelly (2006)	Down Syndrome Research Program database (QLD)	11-18.5	38	No	Height Weight	Not specified	BMI ≥25 =overweight BMI ≥30 =obese	50% overweight and obese
Jobling et al. (2006)	Down Syndrome Research Program database (QLD)	17-23	18	Yes	Height Weight	Directly measured	BMI ≥27 =obese	55.6% obese
Pikora et al. (2014)	Western Australian Down syndrome NOW database (WA)	16-30	197	No	Nil	N/A	Parent perception	57.4% overweight and obese
Krause et al. (2016)	Ask Study (QLD)	13-18	42	No	Height Weight	Directly measured	IOTF cut-offs (Cole et al., 2000)	Males: 20.8% overweight 41.7% obese Females: 50.0% overweight 27.8% obese

Author, year of publication	Study recruitment (Country)	Age range of participants with Down syndrome (years)	Number of participants with Down syndrome	Comparison to a control group	Anthropometric measurements	BMI proxy or directly measured	Classification of overweight & obesity	Overweight & obese (%)
International Studies								
Henderson et al. (2007)	Primary health care records (UK)	18-61	64	No	Height Weight	Not specified	BMI ≥35 =obese	20% obese
Marques et al. (2007)	Schools for assistance to special children (Brazil)	10-19	30	Yes	Height Weight	Not specified	BMI for age percentiles (Must, Dallal, & Dietz, 1991)	26.7% overweight
Bhaumik et al. (2008)	Leicestershire Learning Disability Register (UK)	20+	125	No	Height Weight	Directly measured	BMI ≥25 =overweight BMI ≥30 =obese	50% obese
Carr (2008)	Population sample (UK)	30-40	38	Yes	Nil	N/A	Parent perception	30% slightly overweight 29% definitely overweight

Author, year of publication	**Study recruitment (Country)**	**Age range of participants with Down syndrome (years)**	**Number of participants with Down syndrome**	**Comparison to a control group**	**Anthropometric measurements**	**BMI proxy or directly measured**	**Classification of overweight & obesity**	**Overweight & obese (%)**
Grammatikopoulou et al. (2008)	Schools and Association of Parents of Children with Down Syndrome (Greece)	2-18	34 total 23 adolescents	No	Height Weight Skinfolds Waist and hip circumference	Directly measured	Down syndrome growth charts (Cronk et al., 1988)	Adolescents 30.4 % overweight 13.1% obese
							CDC BMI percentiles $\geq 85^{th}$ percentile overweight $\geq 95^{th}$ percentile obese	Adolescents60.9 % overweight 21.7% obese
Hawn et al. (2009)	Down Syndrome Clinic, Children's Hospital Outpatient Center/ Palmetto Health (USA)	0-18	80	No	Height Weight	Directly measured	BMI ≥25 overweight BMI ≥30 obese	Average BMI for girls 12+ years =32.6 Average BMI for boys 12+ years =25.0
Sohler et al. (2009)	Medical practice for people with intellectual disability (USA)	18+	41	No	Height Weight	Directly measured	BMI ≥25 overweight BMI ≥30 obese	34% overweight 51% obese
Rimmer et al. (2010)	Chicago youth with intellectual / developmental disability - online study (USA)	13-18	461 total 81 with Down syndrome	No	Height Weight	Proxy-reported	CDC BMI percentiles $\geq 85^{th}$ percentile overweight	55% overweight 31.2% obese

Author, year of publication	Study recruitment (Country)	Age range of participants with Down syndrome (years)	Number of participants with Down syndrome	Comparison to a control group	Anthropometric measurements	BMI proxy or directly measured	Classification of overweight & obesity	Overweight & obese (%)
							≥95th percentile obese	
Bertoli et al. (2011)	Associations for Down Syndrome (Italy)	0-64	518	No	Nil	N/A	Parent perception	30.8% overweight and obese
Soler Marin and Xandri Graupera (2011)	Attendees of two occupational centres (Spain)	16-38	38	No	Height Weight Skinfolds Waist and hip circumferences	Directly measured	BMI ≥25 overweight BMI ≥30 obese	36.8% overweight 36.8% obese
Stancliffe et al. (2011)	Adults using developmental disability services (USA)	20 +	706	No	Height Weight	Proxy-reported	BMI ≥25 overweight BMI ≥30 obese	72.7% overweight and obese 44.3% obese
Tenenbaum et al. (2011)	National Down Syndrome Medical Unit (Israel)	5-20	146	No	Height Weight	Directly measured	CDC BMI percentiles ≥85th percentile overweight ≥95th percentile obese	52.1% overweight 24.6% obese
Loveday et al. (2012)	New Zealand Down Syndrome Association and public hospitals (New Zealand)	5-18	70	No	Height Weight DEXA BIA	Directly measured	Body fat reference curves (McCarthy et al., 2006)	38% girls obese 23% boys obese

Author, year of publication	Study recruitment (Country)	Age range of participants with Down syndrome (years)	Number of participants with Down syndrome	Comparison to a control group	Anthropometric measurements	BMI proxy or directly measured	Classification of overweight & obesity	Overweight & obese (%)
Esposito et al. (2012)	Down syndrome parent support groups (USA)	8-16	104	No	Height Weight Skinfolds	Directly measured	CDC BMI percentiles ≥85th percentile overweight ≥95th percentile obese	45.5% overweight and obese
Van Gameren-Oosterom, Van Dommelen, Schönbeck, et al. (2012)	Medical records from Down Syndrome Centres (The Netherlands)	2-18	1596	Yes	Height Weight	Directly measured	IOTF cut offs (Cole et al., 2000) Overweight figures include obesity	25.5% boys overweight 32.0% girls overweight 4.2% boys obese 5.1% girls obese
AbdAllah et al. (2013)	Help Centre (Jeddah, Saudi Arabia)	6-18	30	Yes	Height Weight	Directly measured	CDC BMI percentiles ≥85th percentile overweight ≥95th percentile obese	53% overweight and obese
Bandini et al. (2013)	Massachusetts community (USA)	13-21	32	No	Height Weight DEXA	Directly measured	CDC BMI percentiles ≥85th percentile overweight ≥95th percentile obese	34.4% overweight (35% boys, 33.3% girls) 18.8% obese (25% boys, 8.3% girls)
Begarie et al. (2013)	Special education Schools (France)	5-28	87	No	Height Weight	Directly measured	IOTF cut offs (Cole et al., 2000) for children	24.1% overweight 25.9% obese

Author, year of publication	Study recruitment (Country)	Age range of participants with Down syndrome (years)	Number of participants with Down syndrome	Comparison to a control group	Anthropometric measurements	BMI proxy or directly measured	Classification of overweight & obesity	Overweight & obese (%)
							BMI ≥25 overweight BMI ≥30 obese for adults	
Goluch-Koniuszy and Kunowski (2013)	Schools and education centres (Poland)	10-22	24	No	Height Weight Waist circumference	Directly measured	Polish BMI-for-age growth charts	45.8% obese (50% girls, 43.8% boys) 8.3% overweight (12.5% girls. 6.3% boys)
Jankowicz-Szymanska et al. (2013)	Special needs education centre (Poland)	16-22	80	No	Height Weight BIA	Directly measured	IOTF cut offs (Cole et al., 2000)	15% males overweight and obese 53.8% females overweight and obese
Carfì et al. (2014)	Day hospital clinic (Italy)	18-58	60	No	Height Weight	Directly measured	BMI ≥30 obese	Under 40 years of age: 12.1% obese
Hsieh et al. (2014)	Longitudinal Health and Intellectual Disabilities Study (USA)	18 +	337	Yes	Height Weight	Proxy-reported	BMI ≥25 overweight BMI ≥30 obese BMI ≥40 morbidly obese	30.9% overweight 53.4% obese 10.4% morbidly obese

Author, year of publication	Study recruitment (Country)	Age range of participants with Down syndrome (years)	Number of participants with Down syndrome	Comparison to a control group	Anthropometric measurements	BMI proxy or directly measured	Classification of overweight & obesity	Overweight & obese (%)
Real de Asua et al. (2014a)	Adult Down Syndrome Outpatient Clinic, Hospital Universitario de La Princesa (Spain)	25-47	51	Yes	Height Weight Waist circumference Waist-to-height ratio	Directly measured	BMI ≥25 overweight BMI ≥30 obese	37% overweight 37% obese
Seron et al. (2014)	Institutions assisting people with Down syndrome (Brazil)	12-18	41	No	Height Weight Waist circumference ADP	Directly measured	CDC BMI percentiles ≥85th percentile overweight ≥95th percentile obese	26.8% overweight (40.0% boys, 6.2% girls) 39.0% obese (24.0% boys, 62.5% girls)
Su et al. (2014)	Hong Kong Down Syndrome Association, special schools and hospitals (Hong Kong)	0-14	525	No	Height Weight Head circumference	Directly measured	Overweight: BMI ≥22.6 boys BMI ≥23.3 girls	At 14 years of age 26% boys and 12% girls were overweight
Aburawi et al. (2015)	National cross sectional study (United Arab Emirates)	0-16	182	No	Height Weight Head circumference	Directly measured	IOTF cut offs (Cole et al., 2000)	In children ≥10 years of age (n=29) 32% overweight 19% obese

Author, year of publication	Study recruitment (Country)	Age range of participants with Down syndrome (years)	Number of participants with Down syndrome	Comparison to a control group	Anthropometric measurements	BMI proxy or directly measured	Classification of overweight & obesity	Overweight & obese (%)
Galli et al. (2015)	Database of Gait Analysis Lab (Italy)	5-18	78	Yes	Height Weight	Not specified	≥95th percentile obese (Myrelid et al., 2002)	51.3% obese
Ono et al. (2015)	Japan Down Syndrome Society (Japan)	1-52	90	No	Height Weight	Proxy-reported	IOTF cut offs (Cole et al., 2000) for adolescents BMI ≥25 for adults	6-15 years 22% obese 16-52 years 48% obese
Basil et al. (2016)	Cincinnati Children's Hospital Medical Centre (USA)	2-18	303	Yes	Height Weight	Directly measured	CDC BMI percentiles ≥85th percentile overweight ≥95th percentile obese	22.4% overweight 47.8% obese
Buonuomo et al. (2016)	Bambino Gesu Children's Hospital (Italy)	2-19	357	No	Height Weight	Directly measured	IOTF cut offs (Cole et al., 2000)	18% overweight 8% obese

Author, year of publication	Study recruitment (Country)	Age range of participants with Down syndrome (years)	Number of participants with Down syndrome	Comparison to a control group	Anthropometric measurements	BMI proxy or directly measured	Classification of overweight & obesity	Overweight & obese (%)
Hatch-Stein et al. (2016)	The Children's Hospital of Philadelphia and Children's National Health System (USA)	10-20	121	Yes	Height Weight DEXA	Directly measured	CDC BMI percentiles ≥85th percentile overweight ≥95th percentile obese	61% overweight and obese
							Down syndrome BMI-for-age chart (Zemel et al., 2015)	31% overweight and obese
Pucci et al. (2016)	Education institutions (Brazil)	18-56	97	No	Height Weight	Directly measured	BMI ≥25 overweight BMI ≥30 obese	40.7% overweight 25.3% obese
Samur San-Matin et al. (2016)	Down syndrome treatment referral centres (Brazil)	10-17	34	No	Height Weight DEXA	Directly measured	IOTF cut offs (Cole et al., 2000) WHO cut-points (de Onis et al., 2007) Down syndrome specific cut-points (Myrelid et al., 2002; Styles, Cole,	IOTF 38.2% obese WHO 58.8% obese Styles 55.9% obese Myrelid 35.3% obese NHANES 41.2% obese

Author, year of publication	Study recruitment (Country)	Age range of participants with Down syndrome (years)	Number of participants with Down syndrome	Comparison to a control group	Anthropometric measurements	BMI proxy or directly measured	Classification of overweight & obesity	Overweight & obese (%)
							Dennis, & Preece, 2002) NHANES cut-points for percentage body fat (Ogden et al., 2011)	
Corder et al. (2017)	Gulf Down Syndrome Registry (UAE)	0-34	221	No	Height Weight	Not specified	CDC BMI percentiles ≥95th percentile obese	16.7% obese
González-Agüero et al. (2017)	Schools and institutions (Spain)	12-18	23	No	Height Weight Skinfolds ADP	Directly measured	IOTF cut offs (Cole et al., 2000)	74.0% healthy weight 26% overweight 0% obese
Havercamp et al. (2017)	Surveys of adults with and without Down syndrome and developmental disabilities (USA)	18+	291	Yes	Height Weight	Proxy-reported	BMI ≥25 overweight BMI ≥30 obese	For the 18-34 year age group: 22.8% healthy weight 39.9% overweight 43.3% obese

Author, year of publication	Study recruitment (Country)	Age range of participants with Down syndrome (years)	Number of participants with Down syndrome	Comparison to a control group	Anthropometric measurements	BMI proxy or directly measured	Classification of overweight & obesity	Overweight & obese (%)
Niegawa et al. (2017)	Clinic for Down Syndrome, Osaka Medical College Hospital (Japan)	5-15	102	No	Height Weight	Directly measured	BMI for age references for Japanese children	14.7% overweight 23.5% obese
Parra et al. (2017)	Adult Down syndrome outpatient clinic (Spain)	18-62	51	Yes	Height Weight Waist circumference Waist-to-height ratio	Directly measured	BMI ≥25 overweight BMI ≥30 obese	37.3% obese
M. Polfuss et al. (2017)	Eunice Shriver Kennedy National Institute for Child Health and Human Development DS-Connect® The Down Syndrome Registry (USA)	2-19	110	No	Height Weight	Proxy reported	Children: CDC BMI percentiles ≥85th percentile overweight ≥95th percentile obese Adults: BMI ≥25 overweight BMI ≥30 obese	30.1% overweight or obese

Author, year of publication	Study recruitment (Country)	Age range of participants with Down syndrome (years)	Number of participants with Down syndrome	Comparison to a control group	Anthropometric measurements	BMI proxy or directly measured	Classification of overweight & obesity	Overweight & obese (%)
Valentini et al. (2017)	Hospital outpatients (Italy)	5-18	280	No	Height Weight Waist circumference	Directly measured	WHO growth charts ≥85th percentile overweight ≥95th percentile obese	19.64% overweight 12.14% obese
Xanthopoulos et al. (2017)	Children's Hospital of Philadelphia (USA)	10-20	150	Yes	Height Weight	Directly measured	CDC BMI percentiles ≥85th percentile overweight ≥95th percentile obese	37% healthy weight 21% overweight 42% obese

DEXA=dual energy X-ray absorptiometry; BIA=bioelectrical impedance; ADP=air displacement plethysmography

Chapter 2 Literature Review

2.1 Socioecological frameworks

The multitude of interactive behaviours and factors influencing body composition have been illustrated using ecological frameworks (Must et al., 2014; Story, Kaphingst, Robinson-O'Brien, & Glanz, 2008). Devised to describe the influences of individual and environmental factors on eating behaviours, the domains and factors described in the framework by Story et al. (2008) can also be applied to other behaviours influencing body composition, as well as preventative and intervention strategies (Figure 2.1). The framework depicts four domains with the inner individual domain impacted by and interacting with the social, physical and macro-environmental domains (Story et al., 2008).

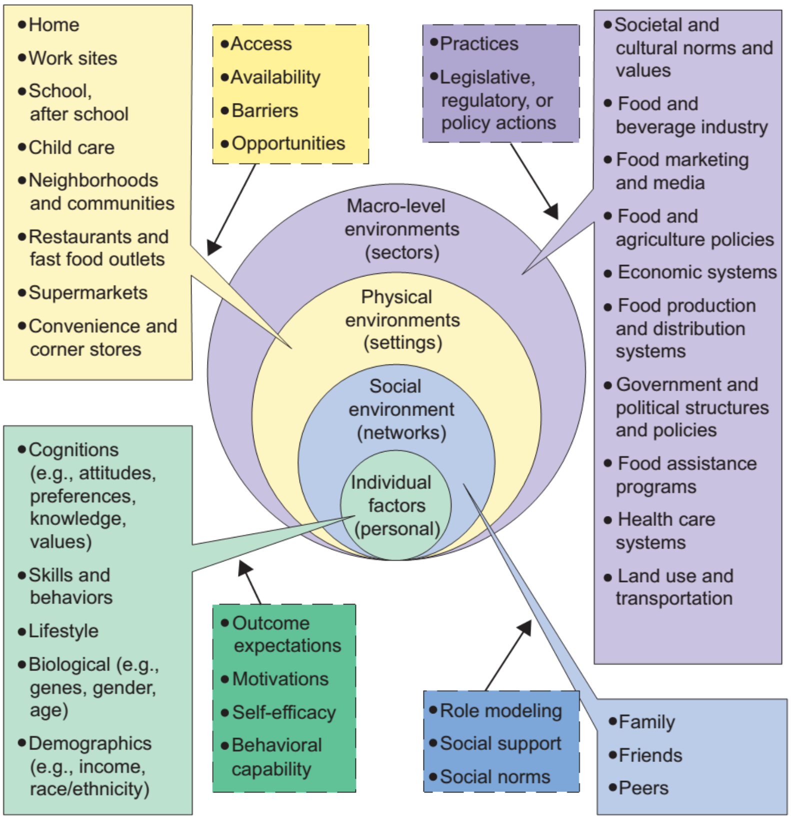


Figure 2.1 An ecological framework depicting the multiple influences on what people eat. Republished with permission of Annual Reviews Inc from “Creating Healthy Food and Eating Environments: Policy and Environmental Approaches” by M. Story, K. M. Kaphingst, R. Robinson-O’Brien and K. Glanz, 2008, *Annual Review of Public Health, 29*, p. C1; permission conveyed through Copyright Clearance Centre, Inc. Refer to Appendix A for copyright permission.

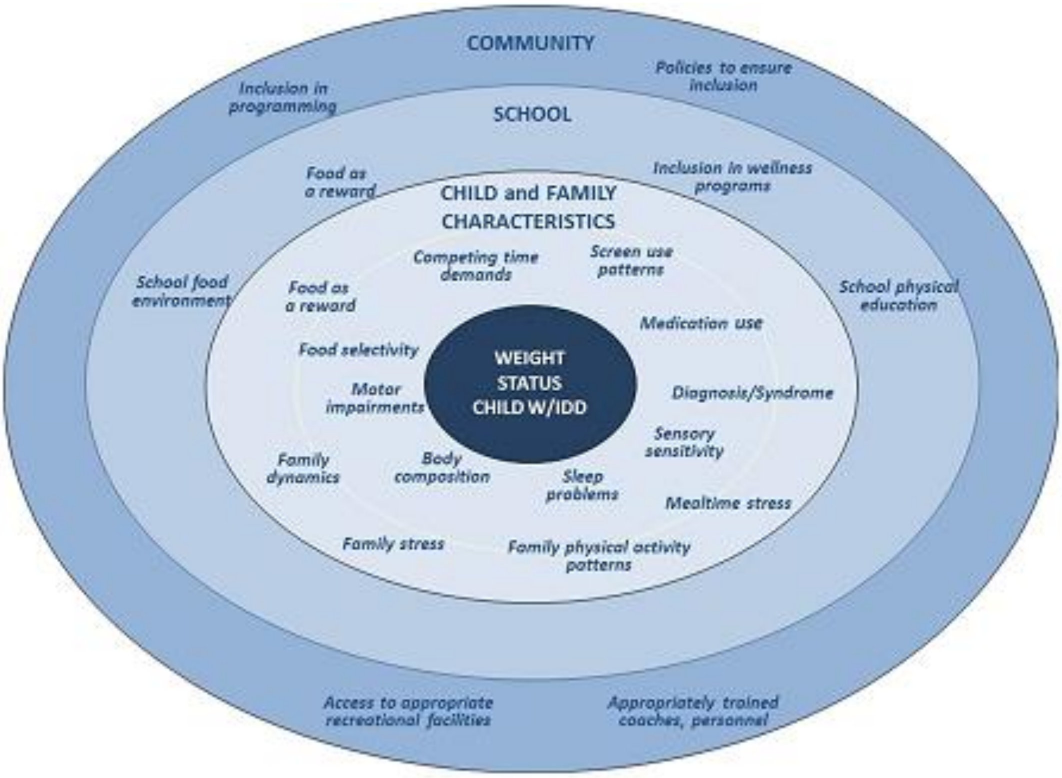


Figure 2.2 Socioecological framework related to risk factors for obesity in children with developmental disabilities. Reprinted with permission from Springer Nature "Obesity Prevention for Children with Developmental Disabilities," by A. Must, C. Curtin, K. Hubbard, L. Sikich, J. Bedford and L. Bandini, 2014, *Current Obesity Reports, 3*, p. 161. Copyright 2014 by Springer Nature. Refer to Appendix A for copyright permission.

Although for young people with intellectual disabilities the influences on body composition are similar to those for young people without a disability, the situation can be aggravated by the impact of their disability on their health and functioning (Grondhuis & Aman, 2014; Must et al., 2014). Examples could include lack of opportunities for young people with intellectual disabilities to participate in physical activity or lack of control over food intake (Grondhuis & Aman, 2014). In the socioecological framework by Must et al. (2014), specific risk factors for obesity in children with developmental disabilities are divided into three domains (child and family characteristics, school and community) which highlight the avenues for obesity prevention in this population (Figure 2.2).

This review will examine the factors described in the literature as having an influence on the body composition of adolescents and young adults with Down syndrome, using a socioecological framework approach as shown in Figure 2.3. The model is divided into three domains of influence, with physiological influences unique to the person with Down syndrome in the centre, surrounded by behavioural, social and community influences that the individual experiences both at home and in familiar environments, for example the school or workplace. The physiological factors discussed in this review are metabolic rate, thyroid levels and degree of disability. The influence of dietary intake and physical activity behaviours as well as the social and community factors of friendships and place of residence will also be discussed. Research published up to an including 2017 are included.

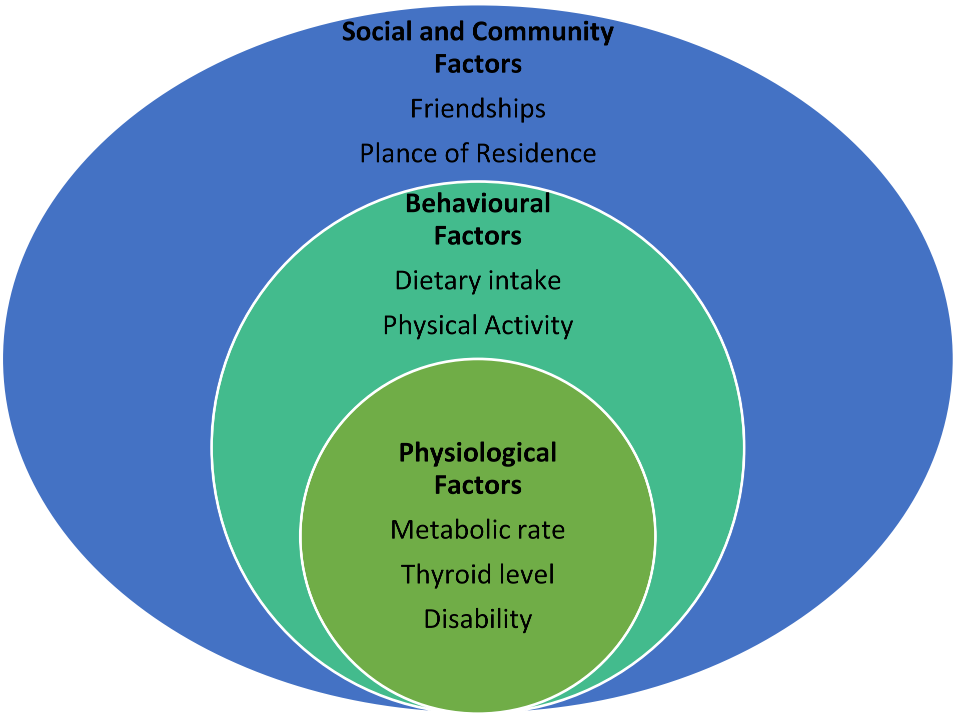


Figure 2.3 Sociological framework of factors affecting the body composition of adolescents and young adults with Down syndrome

Encompassed in this chapter are studies reporting the rates of overweight and obesity for adolescents and young adults with Down syndrome, as determined by standard classifications of BMI. In view of the doubt surrounding the validity of BMI for those with Down syndrome as highlighted in the Introduction to this thesis, the interpretation of many of the studies in the following review is difficult.

2.2 Physiological factors

Studies investigating the impact of physiological factors on body composition of adolescents and young adults with Down syndrome have highlighted metabolic rate (Allison et al., 1995; Fernhall et al., 2005), hypothyroidism (Iughetti et al., 2014; Pikora et al., 2014; V. Prasher, Ninan, & Haque, 2011) and degree of disability (Jankowicz-Szymanska et al., 2013) as possible influences, however research thus far is inconclusive. Before consideration of the impact of metabolic rate on body composition of adolescents and young adults with Down syndrome, the following sections provide background to resting or basal metabolic rate and the impact of thyroid status in children and adolescents with Down syndrome.

2.2.1 Resting or basal metabolic rate

Accounting for 60-80% of energy expenditure, basal or resting metabolic rate comprises the energy used by muscle tissue and organ systems at rest (Pontzer, 2015; Psota & Chen, 2013). The remaining components of energy expenditure in non-pregnant or lactating adolescents and young people are physical activity (19-32% of energy expenditure), growth, digestion, thermoregulation and immune function (Pontzer, 2015). Influenced by body composition, age, sex, nutritional status (Vermorel et al., 2005) and certain hormones (Pontzer, 2015), metabolically active fat free mass is the greatest determinant of resting energy expenditure (REE), with those with a higher fat free mass generally having a higher metabolic rate (Westerterp, 2017). The impact of fat free mass is reflected in males generally having a higher basal or resting metabolic rate compared to females (Buchholz, Rafii, & Pencharz, 2007) and younger people having a higher metabolic rate compared to older people (St-Onge & Gallagher, 2010).

In clinical testing, resting metabolic rates (RMR) are up to 10% higher than basal metabolic rates (BMR) due to stricter clinical conditions under which BMR is measured (for example, requiring an overnight stay) which are not required for the measurement of RMR (Pontzer, 2015; Psota & Chen, 2013). Although the doubly labelled water method is considered the gold standard for the measurement of total energy expenditure (Pontzer, 2015), in a clinical setting RMR is usually measured using indirect calorimetry and expressed as kcal per unit of time (Psota & Chen, 2013). A systematic review of best practice for RMR research using indirect calorimetry recommended that prior to measurement, healthy subjects fast for at least 5 hours (to ensure the thermic effect of food is not included in the measurement), along with overnight abstinence from caffeine, and 2-hour abstinence from nicotine, alcohol and moderate physical activity (Compher, Frankenfield, Keim, & Roth-Yousey, 2006). Additionally, participants are recommended to rest for 10-30 minutes and be measured in a supine position in a comfortable temperature environment (Compher et al., 2006).

A lower BMR has been suggested to increase the risk of obesity compared to a higher BMR in particular populations (Anthanont & Jensen, 2016). However a retrospective review of the medical records of 163 healthy euthyroid USA adults without Down syndrome found no difference in weight change over time for those with a low BMR compared to those with a high BMR (Anthanont & Jensen, 2016). In this study, BMR values (corrected for age, sex, fat free mass and fat mass) were measured using indirect calorimetry immediately following an overnight stay in the research facility. Changes in body weight over time were analysed, with no difference found for weight gained between those in the top and bottom 15th percentile for BMR. The authors therefore suggested that lifestyle factors were more likely responsible for changes in body composition in healthy adults (Anthanont & Jensen, 2016).

2.2.1.1 Thyroid status

Thyroid hormones regulate energy expenditure through various metabolic pathways associated with BMR, with hypothyroidism associated with weight gain and decreased thermogenesis (Reinehr, 2010). The reported prevalence of hypothyroidism in children and adults with Down syndrome is higher than in those without Down syndrome (Alexander et al., 2016; Allison et al., 1995; Glasson, Dye, & Bittles, 2014; Iughetti et al., 2014; Parra et al., 2017). Subclinical hypothyroidism (normal thyroxine [T_4], elevated thyroid stimulating hormone [TSH]) is the most commonly diagnosed thyroid disorder in people with and without Down syndrome, with smaller reported prevalences of clinical hypothyroidism (low T_4, high TSH) and hyperthyroidism (high T_4, low TSH) (Claret, Corretger, & Goday, 2013; Dayal et al., 2014; Iughetti et al., 2014; Meyerovitch, Antebi, Greenberg-Dotan, Bar-Tal, & Hochberg, 2012; Parra et al., 2017; Pierce, LaFranchi, & Pinter, 2017; Walsh, 2016).

2.2.1.1.1 Children

There have been several studies of thyroid dysfunction in children with Down syndrome, with recent large cohort longitudinal studies showing wide variation in the rates of diagnosed hypothyroidism (7.2-48%) (Alexander et al., 2016; Claret et al., 2013; Iughetti et al., 2014; Pierce et al., 2017). Subclinical hypothyroidism was the most commonly diagnosed form and for some participants was transient (Claret et al., 2013; Iughetti et al., 2014; Pierce et al., 2017).

A retrospective review of the medical records of 1903 Spanish children with Down syndrome found 7.8% (n=149) were diagnosed with a thyroid disorder; 137 of these with hypothyroidism (Claret et al., 2013). Of those who had been diagnosed with hypothyroidism before the age of 5 years, almost all (53 out of 54 children) were diagnosed with subclinical hypothyroidism (Claret et al., 2013) which in most cases (n=39) spontaneously resolved in childhood irrespective of treatment. Although this study did not involve a control group and the number of cases was small, it highlights the importance of distinguishing between the two forms of hypothyroidism and the age groups involved when reporting prevalence statistics.

An Italian longitudinal study measured plasma TSH, free T_4, thyroglobulin antibody and thyroid peroxidase antibody levels of 145 children with Down syndrome annually from birth to 10 years of age and compared these to standard reference ranges to determine the probability of developing a thyroid condition over this time period (Iughetti et al., 2014). The authors found the probability of any thyroid dysfunction increased from 30% in the first year of life to 49% at the 10th year; 41% of those affected received treatment at some point during the 10 years for either clinical or subclinical hypothyroidism. Despite the finding that the probability of subclinical hypothyroidism remained stable over the 10-year period (22% to 24%), there was considerable movement of participants in and out of this group (Iughetti et al., 2014). The authors observed that over the 10-year period 22 out of 104 euthyroid participants developed subclinical hypothyroidism, one third of participants with subclinical hypothyroidism developed clinical hypothyroidism and one third with subclinical hypothyroidism became euthyroid without treatment (Iughetti et al., 2014), as also observed in the earlier Spanish study (Claret et al., 2013). The probability of clinical hypothyroidism increased from 7% to 24% and one child developed hyperthyroidism (Iughetti et al., 2014). Although there was no matched cohort, Iughetti et al. (2014)

reported that these probabilities were higher than in the population without Down syndrome by comparing their findings to a large retrospective Israeli study (Lazar et al., 2009) where 0.4% of the cohort aged 0-16 years had an initial diagnosis of hypothyroidism that required treatment.

Similarly a recently published retrospective cohort study in the United Kingdom also found a higher rate of hypothyroidism in children and adults with Down syndrome compared to those without Down syndrome (Alexander et al., 2016). Comparison of the linked medical records of 6430 children and adults with Down syndrome to controls (matched on location, gender and year of birth) found an elevated incidence rate ratio for hypothyroidism of 13.1 (95% CI 11.2; 15.2), particularly in children less than 3 years of age with an incidence rate ratio of 96.3 (95% CI 23.5; 394.7) (Alexander et al., 2016). This study did not indicate if these elevated figures in children included subclinical hypothyroidism.

A recent retrospective study of the medical records of 508 USA children and young adults with Down syndrome aged 0-26 years (mean age 7 years) attending a Down syndrome clinic found 24% were diagnosed with a thyroid condition; 10% with subclinical hypothyroidism (Pierce et al., 2017). The authors predicted that by age 7.5 years, 25% of children with Down syndrome would experience a thyroid disease, increasing to 50% by adulthood (Pierce et al., 2017). Additionally, 10 of the 76 cases of earlier diagnosed subclinical hypothyroidism presented with normal thyroid levels at a later clinic visit, supporting earlier studies that this can be a transient condition (Pierce et al., 2017).

2.2.1.1.2 Adults

In adults with Down syndrome, the prevalence of hypothyroidism has varied from 43.6% of a sample of 40 Norwegian adults (Nordstrøm, Paus, Andersen, & Kolset, 2015) to 34% of 291 North American adults (Havercamp et al., 2017), 26.4% of 197 young Australian adults (Pikora et al., 2014) and 21.5% of 200 United Kingdom adults at the beginning of a 15-year longitudinal study (V. Prasher & Gomez, 2007). Whilst V. Prasher and Gomez (2007) conducted biochemical testing and thus were able to distinguish between the types of thyroid disorders (11% with subclinical hypothyroidism and 10.5% with clinical hypothyroidism), in other cross-sectional studies parental reported diagnoses were used and thus it is unknown if the data included both subclinical and clinical hypothyroidism (Havercamp et al., 2017; Nordstrøm et al., 2015; Pikora et al., 2014). This is an important consideration as 4 out of 19 cases of subclinical hypothyroidism identified at the beginning of the UK 15-year prospective longitudinal study with adults with Down syndrome (n=112) had converted to euthyroidism by the 5th year, thus the disorder was not an automatic precursor to clinical hypothyroidism (V. Prasher & Gomez, 2007). Transient hypothyroidism observed in children with Down syndrome has been previously discussed (2.2.1.1.1).

As with other research comparing the rates of hypothyroidism in adults with Down syndrome to adults without Down syndrome (Alexander et al., 2016) the figures reported in the Australian study with young adults with Down syndrome (Pikora et al., 2014) are much higher than figures for hypothyroidism in the Australian population: 5% prevalence of subclinical hypothyroidism and a 0.5% prevalence of clinical or overt hypothyroidism (Walsh, 2016). V. Prasher and Haque (2005) raised the interesting question as to whether these high rates reflected the true prevalence of thyroid conditions in people with Down syndrome or whether (similar to BMI values as discussed in Chapter 1), comparison to standard cut-points has given false positives leading to incorrect diagnoses and treatment. In their study of the free T_4 and TSH levels of 110 healthy adults with Down syndrome (excluding those with pre-existing thyroid disorders and other comorbidities), subclinical hypothyroidism was found in 13% and low free T_4 with normal TSH levels in 15% of participants (V. Prasher & Haque, 2005). Overall there was a lower median free T_4 and higher median TSH level compared to adults without Down syndrome (V. Prasher & Haque, 2005). As these participants were healthy with no clinical symptoms, the authors recommended that Down syndrome-specific reference ranges be developed to reduce the risk of false positive diagnoses (V. Prasher & Haque, 2005).

This view is supported by a more recent retrospective study of the free T_4 and TSH levels of 428 Israeli children and adults with Down syndrome who had not been diagnosed with a thyroid condition or prescribed thyroid medication (Meyerovitch et al., 2012). Although levels of T_4 and TSH in children and adults with Down syndrome were normally distributed similar to controls, there was a shift towards higher levels of TSH in children and adults with Down syndrome (Meyerovitch et al., 2012). This trend was also observed in two smaller Egyptian studies that measured the T_4 and TSH levels of children with Down syndrome compared to controls (El Gebali, Zaky, Agwa, & Mohamed, 2014; Yahia et al., 2012) where the mean T_4 and TSH levels were higher in children with Down syndrome, but still within normal levels. Meyerovitch et al. (2012) suggested the phenomenon of higher TSH levels could be an inherent part of Down syndrome rather than representing a higher level of subclinical hypothyroidism.

2.2.1.1.3 Thyroid status and body composition

The impact of thyroid status on body composition is mediated by the effect of hypothyroidism on REE (Reinehr, 2010). Although higher rates of hypothyroidism have been consistently reported in children and adults with Down syndrome (Glasson et al., 2014; Iughetti et al., 2014), some studies have questioned whether a higher TSH level is inherent in Down syndrome and thus the rates of hypothyroidism may not be as high as reported (Meyerovitch et al., 2012; V. Prasher & Haque, 2005).

The relationship between hypothyroidism and BMI in children with Down syndrome is inconclusive with Iughetti et al. (2014) finding no correlation between an elevation in TSH levels and BMI z- scores, and Pierce et al. (2017) also finding no correlation between thyroid dysfunction and BMI, weight or height percentile. Additionally, Van Gameren-Oosterom, Van Dommelen, Schönbeck, et al. (2012), in their retrospective study of the medical records of 1596 Dutch children with Down syndrome, found that although there was a higher rate of overweight in children with hypothyroidism compared to children without hypothyroidism, the difference was not statistically significant. In light of the discussion of the validity of BMI as a measure of body composition in Chapter 1 further research is needed.

In adults, a recent population based cross-sectional Western Australian study (n=197) of young adults with Down syndrome aged 15-30 years found that those who were reported as being overweight or obese by family members/carers were 2.9 times more likely to have also been reported as hypothyroid, than those young adults who were not reported to be overweight or obese (Pikora et al., 2014). Apart from not using a measure of body composition, the fact that weight and thyroid conditions were reported rather than measured or obtained from medical records was a limitation, however alternatives (anthropometric measurement, biochemical testing or medical records) were not feasible in this large cross-sectional study conducted over a state a quarter the size of Europe. This study did not indicate if the hypothyroidism was being treated however it did find that this condition was reported to be having an impact on daily life of over half the relevant young adults, indicating that better management was required (Pikora et al., 2014). To determine if hypothyroidism is a causative factor for overweight and obesity, further longitudinal research is needed into the prevalence of thyroid conditions in children and young adults with Down syndrome, including biochemical testing, and examination of clinical symptoms, comparison with the population without Down syndrome and investigation of any relationships with RMR and body composition using methods such as DEXA. The validity of standard reference ranges for T_4 and TSH in children and adults with Down syndrome should also be further explored.

2.2.1.2 Studies of resting metabolic rate in people with Down syndrome

There have been two studies investigating metabolic rate as a factor in the development of overweight and obesity in euthyroid children with Down syndrome (D. L. Hill et al., 2013; Luke, Roizen, Sutton, & Schoeller, 1994). Both studies found that although REE/RMR was lower in these children compared to those without Down syndrome, it was not predictive of changes in fat mass over time (D. L. Hill et al., 2013; Luke et al., 1994).

Interestingly, this trend of lower RMR in children with Down syndrome was not observed in adults once hypothyroidism has been taken into account (Allison et al., 1995; Fernhall et al., 2005). Allison et al. (1995) compared the RMR (kcal/day) of 13 adults with Down syndrome and 77 unmatched controls. Although controls were significantly older (mean age 36.6 ± 10.4 versus 29.7 ± 10.2 years), there was no significant difference in fat free mass, fat mass and percentage body fat (Allison et al., 1995). RMR was measured for 20 minutes using indirect calorimetry after a 12-hour fast and 30-minute rest in a comfortable temperature environment (Allison et al., 1995) however there was no mention of other standard conditions identified as best practice by Compher et al. (2006). Due to the impact of thyroid hormones on RMR, T_4 levels of all participants with Down syndrome were tested and compared with T_4 levels of controls for whom data were available (15/77 controls) (Allison et al., 1995). Although no participants were excluded due to hypothyroidism, TSH levels were not tested (Allison et al., 1995) and therefore subclinical hypothyroidism could not be ruled out. Mean T_4 levels in those with Down syndrome were significantly lower than those of controls (Allison et al., 1995) as was also observed in 110 healthy adults with Down syndrome a decade later (V. Prasher & Haque, 2005). After controlling for sex, fat free mass, fat mass, age and height, RMR was significantly lower in participants with Down syndrome compared to controls however when T_4 levels were considered in the analysis, the difference in RMR was no longer significant. The authors tentatively suggested that lower T_4 levels may have a role in the lower RMR observed in participants with Down syndrome (Allison et al., 1995).

Fernhall et al. (2005) measured the RMR of 22 healthy euthyroid USA adults with Down syndrome and 20 unmatched controls aged from 17-39 years using indirect calorimetry which complied with best practice as described by Compher et al. (2006). The authors found no difference in RMR between groups after adjusting for body weight, fat free mass and body surface area, with body surface area the best predictor of RMR. The authors concluded that in euthyroid adults, lower RMR was not a factor contributing to higher levels of obesity observed in those with Down syndrome.

Thus in summary of the limited studies available, although it appears that RMR was lower in euthyroid children with Down syndrome, RMR was similar in adults with or without Down syndrome when only those with normal thyroid levels (using standard reference ranges) were included (Fernhall et al, 2005) or when T_4 levels were controlled for in the analysis (Allison et al., 1995). Longitudinal studies from childhood with larger groups are required to determine the relationship, if any, between RMR and changes in body composition in adolescents and young adults with Down syndrome.

2.2.2 Level of functioning

Wong, Dwyer, and Holland (2014) proposed a relationship between the degree of intellectual disability and overweight and obesity in adults with Down syndrome due to the level of functional ability and independence. The authors proposed that adults with a higher functional ability may be more likely to be overweight or obese due to less parental and caregiver vigilance over dietary intake and physical activity, however research is limited. Oates, Bebbington, Bourke, Girdler, and Leonard (2011) in their population based study of Western Australian children and adolescents with Down syndrome (n=363) found that those with a higher level of functioning were more likely to participate in sport and hobbies. Similarly, Taiwanese adolescents with Down syndrome (n=997) with higher level of functioning participated more and had greater enjoyment from participation in a range of recreational, social and physical activities (Wuang & Su, 2012).

In adolescent females with Down syndrome, a significant correlation between the degree of disability and total body fat percentage (as determined using BIA) has been reported, however this was not observed in males (Jankowicz-Szymanska et al., 2013). In Polish adolescent females (n=13) with Down syndrome those with moderate intellectual disability had a higher mean BMI and body fat percentage compared to those with mild intellectual disability (Jankowicz-Szymanska et al., 2013). These findings were limited by no indication of how the degree of disability (mild, moderate) was determined and participants not being free-living and thus further research is required.

2.3 Behavioural factors

Energy balance is the balance between energy intake and energy expenditure, with overweight and obesity a result of positive energy balance (J. O. Hill, 2006; Romieu et al., 2017). The diet related behaviours that reportedly affect energy balance in adolescents and young adults with Down syndrome include not just energy and macronutrient intake, but also factors relating to eating patterns and food literacy. Physical activity and sedentary behaviours, their measurement as well as barriers and facilitators will also be discussed in the context of adolescents and young adult with Down syndrome.

2.3.1 Dietary intake

Total energy and macronutrient intake (J. O. Hill, 2006; Romieu et al., 2017), portion sizes (Young & Nestle, 2012), eating frequency (Mattes, 2014), eating timing (Garaulet & Gómez-Abellán, 2014) and dietary patterns (Hu et al., 2016; Romieu et al., 2017) have all been associated with body composition in people without Down syndrome, however limitations associated with dietary intake data collection and analysis can impact on the interpretation of results. Dietary intake is measured using 24-hour recalls, food frequency questionnaires (FFQ), food records or brief dietary screening tools (Labonté et al., 2016) however each is subject to biases and potential error and no method has been validated for people with intellectual disability (Hoey et al., 2017). Problems with memory and portion estimation impacts on the accuracy of self-reported 24-hour recalls and food records (which are often completed at the end of the day) and food frequency questionnaires and brief screening tools are limited by the range of foods and beverages included (Subar et al., 2015). The process of completing food records can lead to underreporting as participants change their usual eating patterns, particularly those who are overweight (Burrows, Martin, & Collins, 2010; Fisher, Johnson, Lindquist, Birch, & Goran, 2000; Subar et al., 2015; Subar et al., 2003). Measurement of dietary intake can also be impacted by the desire to report dietary habits that are considered more favourable or healthy (Börnhorst et al., 2013; Hébert, 2016). Known as social desirability bias, this should also be considered in the interpretation of dietary intake (Hébert, 2016).

Acceptable food intake data collection methods for people with intellectual disabilities present additional challenges due to difficulties with memory, cognition, literacy and communication and thus proxy reported data are often used (Emerson, Felce, & Stancliffe, 2013; Havercamp et al., 2017; Humphries, Traci, & Seekins, 2008, 2009). Proxy reported dietary data are widely collected from parents of young children (Börnhorst et al., 2013) and family members/carers of older people (Dias Medici Saldiva et al., 2017) for similar reasons to those impacting on data collection for individuals with intellectual disability. Similarly to self-reported intake, social desirability bias can impact on proxy reporting of dietary intake, as well as perception of the participant's weight status (Börnhorst et al., 2013). These biases, while tested in studies with parents of children (Börnhorst et al., 2013), have not been tested with the family members/carers of participants with intellectual disability. For adolescents and young adults with intellectual disability, growing independence outside the home can further limit the acceptability of proxy reported dietary intake (Humphries et al., 2008, 2009). Validated instruments for recording both self and proxy reported dietary intake are needed for this population.

The following sections describe studies where the dietary behaviours of adolescents and young adults with Down syndrome have been assessed using either a nutrient, food group or eating frequency approach. Successful independent living also requires skills associated with food literacy (Jobling & Cuskelly, 2006). Along with other dietary factors that influence body composition there is limited research into the food literacy skills of adolescents and young adults with Down syndrome, and further studies are required.

2.3.1.1 Energy and macronutrient intake

In general, a high energy intake has been linked more strongly with a positive energy balance than low physical activity (Mattes, 2014). Although research investigating the relationship between energy intake and body composition in adolescents and young adults with Down syndrome has not suggested a significant relationship (Ferrara et al., 2008; Fujiura et al., 1997; Jobling et al., 2006), studies have been limited by the use of dietary intake instruments and reference energy requirements not yet validated for adolescents and young adults with Down syndrome. Using a parent completed 2-week dietary record, Ferrara et al. (2008) compared the energy intake of Italian children and adolescents with Down syndrome (n=77) and age matched controls (n=40) to the recommended energy requirements for height, finding that both adolescents with Down syndrome and controls consumed less energy than required. The authors used recommended energy requirements based on height (rather than weight or age) due to children and adolescents with Down syndrome being comparatively short for their age (Ferrara et al., 2008).

In Australia the NHMRC published tables of estimated energy requirements for children and adolescents as part of the Nutrient Reference Values (NHMRC and New Zealand Ministry of Health, 2006). For each year of age, a reference weight and height is given along with the estimated energy requirement at different physical activity levels. The NHMRC advised that for some ethnic groups should the reference weight or height for a given age vary significantly from actual weight or height, then the reference weight would be a better guide to estimating actual energy requirements than age provided BMI is in the healthy range (NHMRC and New Zealand Ministry of Health, 2006). As the largest component of energy requirement is BMR (Pontzer, 2015) and lean body mass is the greatest determinant (Westerterp, 2017), it can be seen that the reference weight would be the preferred guide for estimating energy requirements. Reference weights however are based on an acceptable BMI range and in some ethnic groups there may be differences in what is considered an acceptable BMI (NHMRC and New Zealand Ministry of Health, 2006). This may also be the same for children and adolescents with Down syndrome where a lower than average height may have impacted on BMI (Grammatikopoulou et al., 2008; Van Gameren-Oosterom, Van Dommelen, Schönbeck, et al., 2012) and there may be differences in lean body mass (González-Agüero, Ara, et al., 2011). As described in Chapter 1, the use of standard BMI classifications for overweight and obesity in adolescents with Down syndrome may be misclassifying some healthy weight adolescents as overweight (Bandini et al., 2013). Therefore further research is required into what constitutes a healthy BMI for adolescents with Down syndrome, and which of reference height and weight is the better guide to use when estimating energy requirements.

Jobling et al. (2006) (n=17), Grammatikopoulou et al. (2008) (n=34), Goluch-Koniuszy and Kunowski (2013) (n=24) and Magenis et al. (2017) (n=19) compared energy intake collected using 3-day proxy reported food records to reference values. The first three studies reported less energy consumption compared to estimated energy requirements (Goluch-Koniuszy & Kunowski, 2013; Grammatikopoulou et al., 2008; Jobling et al., 2006), however there was limited detail on how energy requirements were estimated. Goluch-Koniuszy and Kunowski (2013) used recommended daily allowance values, and Grammatikopoulou et al. (2008) used reference values from the UK Department of Health in their studies with adolescents. In the Australian study with young adults, Jobling et al. (2006) did report that energy requirements were estimated using age, sex, weight, height and activity level but it was not mentioned if any allowances were made for differences in anthropometry and body composition of young adults with Down syndrome. The differences between energy intake and requirements could also be due to the limitations of using proxy reported food records to collect dietary intake data such as underreporting (Humphries et al., 2008, 2009; Subar et al., 2015).

In their analysis of the energy, macro- and micro-nutrient intake of children and adolescents with (n=19) and without Down syndrome, Magenis et al. (2017) reported a higher energy intake amongst children and adolescents with Down syndrome, exceeding the USA Dietary Reference Intakes recommendations for energy in 68.4% of participants. Although intakes of protein, carbohydrate and fat were also above the accepted macronutrient distribution range (AMDR) in most participants with and without Down syndrome (Magenis et al., 2017), relationships with body composition were not investigated.

The few studies investigating the relationship between macronutrient intake and body composition in adolescents and young adults with Down syndrome (Fujiura et al., 1997; Grammatikopoulou et al., 2008) have been inconclusive. Fujiura et al. (1997) found no correlation between the intake of energy or fat from a FFQ and BMI in a sample of 49 adults with Down syndrome, whereas a positive association between carbohydrate intake assessed by a 3-day food record and percentage body fat measured using skinfold thicknesses was found in a Greek study of 23 adolescents with Down syndrome (Grammatikopoulou et al., 2008). Jobling et al. (2006) found no difference in energy and fat intake between adolescents and young adults with Down syndrome and their younger siblings, with the authors suggesting that due to differences in physical activity and height the energy requirement of the young people with Down syndrome should have been less than their younger siblings. However as the siblings without Down syndrome were on average 2 years and 5 months younger than the siblings with Down syndrome, and not all sibling pairs were the same gender a lower energy requirement may not have been correct for every sibling pair. In addition, as dietary recording was occurring concurrently for the two siblings the burden of recording may have impacted on food habits as it would have been easier for both siblings to consume the same type and amount of food. Further studies with larger cohorts and validated dietary tools are needed to determine the significance of macronutrient intake as a factor in the body composition of adolescents and young adults with Down syndrome.

2.3.1.2 Food group intake

There is growing recognition of assessing dietary intake as food groups rather than nutrients due to the impact of food patterns on health, including that of adolescents and young adults (Hu et al., 2016; McNaughton, Ball, Mishra, & Crawford, 2008; Richter et al., 2017). A diet pattern higher in fruit, vegetables, seeds and low fat dairy and lower in discretionary foods, red meat and high fat dairy has been associated with reduced excess weight gain in a large USA 10-year cohort study of adolescents (n=2656) transitioning to young adulthood (Hu et al., 2016), whilst a similar dietary pattern of fruit, salad, cereals and fish has been associated with lower blood pressure in older adolescents (n=1086) in a population-based Australian study (McNaughton et al., 2008). Whilst these studies suggest a benefit to the health of adolescents and young adults from a higher plant and lower discretionary food diet there is limited research in groups with Down syndrome.

In comparison to adult control groups without Down syndrome, use of a validated brief dietary assessment tool in two Spanish studies found a greater mean intake of fruit and vegetables in adult groups with Down syndrome (both n=51) (Parra et al., 2017; Real de Asua et al., 2014a). Although participants were reported to live in community settings (Parra et al., 2017), the authors were not specific about who was responsible for participants' food intake and the possible influence of caregivers on dietary behaviours. Norwegian research (Nordstrøm et al., 2015) comparing the intake of food groups of young adults with Down syndrome (n=40) with that of two other disabilities, found that most adolescents and young adults with Down syndrome in the study did not consume fruit, fruit juice and vegetables daily. Many of the young adults with Down syndrome were low consumers of fruit and vegetables, 40% consumed fruit three or less times per week and 25% consumed vegetables three or less times per week (Nordstrøm et al., 2015). Those who were a healthy weight or overweight were more likely to consume fruit and vegetables four or more times per week compared to adults who were obese as judged by the standard WHO BMI categories (Nordstrøm et al., 2015). This relationship between fruit and vegetable intake and BMI was supported by a higher BMI being associated with reduced plasma carotenoids (Nordstrøm et al., 2015) which are biomarkers for fruit and vegetable intake (Baldrick, Woodside, Elborn, Young, & McKinley, 2011). Further research into fruit and vegetable intake and health outcomes in young people with Down syndrome is required.

Few studies have investigated the reported consumption of discretionary food and beverage serves in people with intellectual disability and any relationship with BMI. Discretionary foods and beverages are generally high in saturated fat, added sugars and salt and are not required to meet nutritional intakes (NHMRC, 2013a). Beverages containing added sugars should be limited in the Australian diet due to the impact on tooth decay and energy intake (NHMRC, 2013a). A positive correlation between BMI and reported fast food consumption frequency in adolescents with intellectual disability and their parents (n=207) was reported in a study of USA parents where they were surveyed about the nutrition and physical activity behaviours of themselves and their children, however BMI of both parents and children were self-reported and thus may be impacted by bias (George et al., 2011).

Using food frequency questionnaires completed by participants with the support of a caregiver, the Norwegian study of food group intake by participants with three different disability types found that 21% of participants with Down syndrome consumed soft drink once or more a day (Nordstrøm et al., 2015). A recent USA survey of adults with intellectual disability (n=1450), completed by caregivers, found that almost 60% of participants consumed one or more cans of sugar sweetened soft drink per day (Hsieh et al., 2014). Although the Norwegian study did not determine if soft drinks were sugar or artificially sweetened (Nordstrøm et al., 2015) and neither study was able to provide average daily intakes (Hsieh et al., 2014; Nordstrøm et al., 2015), these findings highlight the need for health promotion interventions as well as validated instruments for recording dietary intake data.

2.3.1.3 Eating frequency

The number or frequency of eating occasions as well as the amount consumed at each occasion determines the energy intake of an individual (Mattes, 2014). Although a recent review of the evidence for both eating frequency and portion size found increasing eating frequency to be more closely related to increases in total energy intake as compared to increasing portion size, the relationship with body composition is inconclusive (Mattes, 2014). Few studies have included eating frequency in studies of diet and body composition in adolescents and young adults with Down syndrome. Grammatikopoulou et al. (2008, p. 262) included this question with their 3-day food record “how many meal episodes do you have every day on average”. Almost 70% of the adolescents reported 5 or 6 meal episodes per day, similar to the findings by Goluch-Koniuszy and Kunowski (2013) in their 3-day food record study with adolescents with Down syndrome (n=24). A meta-analysis of 21 sub-studies found that a higher eating frequency was associated with lower rates of overweight and obesity in children and adolescents, particularly in boys (Kaisari, Yannakoulia, & Panagiotakos, 2013). The authors suggested that a metabolic or endocrine response to eating or the confounding factor of increased physical activity may have had a role in this observation, however the exact cause is unknown (Kaisari et al., 2013). The relationship between energy intake and body composition was not tested in either study of adolescents with Down syndrome, requiring further research.

2.3.1.4 Feeding behaviours

Early research using the Child Feeding Questionnaire developed by Birch et al. (2001) reported that parents displayed more controlling feeding behaviours for their children with Down syndrome (n=36) compared to siblings (n=36), with parents reporting greater feeling of responsibility for feeding (O'Neill, Shults, Stallings, & Stettler, 2005). Parents were also more concerned about the weight status of their child with Down syndrome and reported greater restriction and lower pressure for their children to eat compared to siblings without Down syndrome (O'Neill et al., 2005). In a further recent study of the feeding behaviours of parents of children with disability, for the parents of those with Down syndrome higher levels of monitoring and restriction were reported by parents of children with a BMI classified as obese as compared children with a BMI classified as healthy (M. Polfuss et al., 2017). No research has been conducted to observe if the controlling behaviours reported by parents of children with Down syndrome extends to adolescence and early adulthood. These behaviours may continue due to recent evidence that overweight and obese children and adolescents with Down syndrome (n=17) display signs of hyperphagia more commonly observed in children and adolescents with Prader-Willi syndrome (Foerste, Sabin, Reid, & Reddihough, 2016) and should be investigated.

2.3.1.5 Food literacy

The components of food literacy have been defined as the "…knowledge, skills, and behaviours required to plan, manage, select, prepare and eat food to meet needs and determine intake" (Vidgen & Gallegos, 2014, p. 54). Although the ability to make and maintain healthy choices is important for independent living for people with Down syndrome (Jobling & Cuskelly, 2006), and evidence suggests that food literacy is related to a healthier diet in both adolescents (Vaitkeviciute, Ball, & Harris, 2015) and adults (Spronk, Kullen, Burdon, & O'Connor, 2014) without Down syndrome, there is limited research on the food literacy skills, knowledge and behaviour of young people with Down syndrome.

Using semi-structured interviews with 38 Australian adolescents aged 11-18 years with Down syndrome and their families, Jobling and Cuskelly (2006) concluded that knowledge of healthy food choices among adolescents was poor, one of the reasons being that parents were performing most of the food selection and preparation tasks. Less than 50% of participants could name a healthy food from the healthy eating pyramid and most particpants experienced difficulty placing food picture cards on the right part of the healthy eating pyramid. Softdrinks (unknown if sugar or artifically sweetened) were identified as healthy by 37% of participants compared to 21% of participants who identified milk to be healthy. When asked to identify foods from a range of pictures for a healthy lunch, the most popular choices were Coke, hamburger, chips and sausage roll (Jobling & Cuskelly, 2006) which may be more a reflection of preference than knowledge. These results also suggest that participant's responses were not impacted by a social desireability bias (Hébert, 2016). Despite the large age range in this study (Jobling & Cuskelly, 2006) and no comparison with adolescents without Down syndrome, the results highlighted the need for appropriate nutrition education and skill development both at home and school.

The ability to prepare a simple meal was included in two large population-based surveys of families with young people with Down syndrome. In a Dutch study of independent living skills, 55.5% of older adolescents with Down syndrome (n=322) were reported to be able to prepare and eat breakfast independently, however only 6.6% were able to prepare a simple hot meal without assistance (Van Gameren-Oosterom et al., 2013). This study did not specify however which foods constituted breakfast and if any cooking (e.g. using a toaster) was involved. In an Italian study of children, adolescents and adults with Down syndrome living in Rome (n=518), 40% of adolescents and 34-44% of young adults experienced little or no difficulty with preparing simple meals with the remainder experiencing a greater level of difficulty (Bertoli et al., 2011). Although both studies were proxy-reported there was no indication of the role of parents and caregivers in meal preparation which could have partly explained the data as parents and caregivers may have assumed this role. Additionally, despite no comparison to meal prepration skills of young people without Down syndrome these results do further support the need for food literacy skill development in young people with Down syndrome.

2.3.2 Physical activity and sedentary behaviour

The impact of physical activity on energy expenditure and body composition is dependent on the mode (aerobic or resistance) and frequency of exercise (Li, O'Connor, Zhou, & Campbell, 2014). In their review of the relationship between physical activity and energy balance, Li et al. (2014) concluded that although aerobic exercise led to greater energy expenditure and weight loss compared to resistance training, the latter resulted in increased fat free mass. The authors also identified that frequency of exercise (up to 3 times per week) was positively related to changes in body composition (Li et al., 2014). Australia's Physical Activity Guidelines recommend that children and adolescents participate in at least 60 minutes per day of moderate to vigorous physical activity (MVPA) and adults participate in 2.5 to 5 hours of moderate or 1.25 to 2.5 hours of vigorous physical activity (or combination) weekly (Australian Government Department of Health, 2014). Results from the 2011-12 and 2014-15 self-reported Australian Health Surveys showed that 60% of children and adolescents, 61.5% of young adult males (18-24 years) and 57% of young adult females (18-24 years) were meeting these physical activity guidelines (Australian Bureau of Statistics, 2013a, 2015b). Studies have reported that fewer Australian adolescents with Down syndrome are achieving these physical activity guidelines (Oates et al., 2011; Shields, Dodd, & Abblitt, 2009), however the methods of data collection may be impacting on results. Studies of the impact of frequency or absolute amount of physical activity on body composition in adolescents with Down syndrome are inconclusive and further research is required.

2.3.2.1 Physical activity measurement

Studies of physical activity in adolescents and young adults with Down syndrome have used questionnaires (Ferrara et al., 2008; Foerste et al., 2016; Fujiura et al., 1997; Havercamp et al., 2017; Oates et al., 2011; Stancliffe & Anderson, 2017), interviews (Jobling et al., 2006), and accelerometers to measure physical activity levels (Esposito et al., 2012; Izquierdo-Gomez et al., 2014; Matute-Llorente, González-Agüero, Gómez-Cabello, Vicente-Rodríguez, & Casajús, 2013; Nordstrøm, Hansen, Paus, & Kolset, 2013; Phillips & Holland, 2011; Shields et al., 2009), with both methods of data collection having limitations and advantages.

2.3.2.1.1 Subjective physical activity measurement

Questionnaires and interviews conducted with adolescents and young adults with Down syndrome and their familiy members/carers have consistently reported physical activity participation levels lower than physical activity guidelines, and lower than young people without Down syndrome (Ferrara et al., 2008; Foerste et al., 2016; Fujiura et al., 1997; Havercamp et al., 2017; Jobling et al., 2006; Oates et al., 2011; Stancliffe & Anderson, 2017). An Australian population-based survey of families of children and adolescents with Down syndrome (n=208) found that 29.5% of children and adolescents were participating in strenuous physical activity for at least 7 hours per week (Oates et al., 2011) whilst two additional Australian studies (Foerste et al., 2016; Jobling et al., 2006) along with an Italian study (Ferrara et al., 2008) (n=77) reported adolescents and young adults with Down syndrome participated in less physical activity than controls. Fujiura et al. (1997) (n=49) reported that 46% of North American young men and 33% of young women with Down syndrome engaged in moderate or strenuous activity once or more per week, however there was no definition of these terms, nor an estimation of the amount of time spent at each intensity or comparison to a control group. A recent large USA study of the physical activity levels of adults with intellectual disability, found of those with Down syndrome (n=7659), 12.9% met the 1995 guidelines of five or more weekly sessions of at least 30 minutes of light/moderate physical activity (Stancliffe & Anderson, 2017). These data was lower than that of the USA population of whom 30.8% met the guidelines (Stancliffe & Anderson, 2017). Another recent USA study of adults with Down syndrome (n=291) found that whilst 62.9% were reported to participate in moderate physical activity, 44% were engaged for 30 minutes or more and 6.2% were physically active five or more times per week (Havercamp et al., 2017). Whilst these data was higher than that of adults with developmental disability (excluding Down syndrome), comparable data for adults without disability was not available (Havercamp et al., 2017).

Self-reporting by individuals with intellectual disability can be limited by difficulties with recall and communication (Peiris et al., 2017) and thus physical activity questionnaires are usually proxy-completed (Pitetti, Baynard, & Agiovlasitis, 2013). As adolescents and young adults participate in physical activities both in and out of the home environment accurate reporting by a proxy can be difficult (Foerste et al., 2016). Physical activity questionaire repsonses can also be impacted by social desireability bias (Brenner & DeLamater, 2014) which has not been tested with participants with Down syndrome or their families/carers. Long questionnaires as used by Oates et al. (2011) or small sample sizes of people with Down syndrome such as in the studies by Jobling et al. (2006) (n=18) and Foerste et al. (2016) (n=17) can also be a limitation in research.

2.3.2.1.2 Objective physical activity measurement

Research using accelerometers to measure the physical activity level of adolescents and young adults with Down syndrome has found varying levels of participation and a large variation in the percentage of those reported to have met physical activity guidelines (see Table 2.1 for a summary of studies published since 2007). For adolescents, the physical activity guideline of ≥60 minutes per day of MVPA was consistent across all studies (Esposito et al., 2012; Izquierdo-Gomez et al., 2014; Izquierdo-Gomez et al., 2017; Matute-Llorente et al., 2013; Nordstrøm et al., 2013; Phillips & Holland, 2011; Pitchford et al., 2018; Shields et al., 2009) with the guidelines referred to by Esposito et al. (2012) including other intensities of physical activity provided most of the minutes were spent in moderate or vigorous physical activity. The physical activity guidelines for adults (Nordstrøm et al., 2013; Phillips & Holland, 2011) differed between countries. The percentage of adolescent participants achieving the guideline varied from no participants (Matute-Llorente et al., 2013; Phillips & Holland, 2011) to over 40% (Iughetti et al., 2014; Shields et al., 2009). This variation could in part be due to differences in accelerometer protocols and data reduction in the different studies as well as difference in the definition of ≥60 minutes per day of MVPA in the physical activity guidelines of different countries. In some studies any minutes spent in MVPA contributed towards the goal (Esposito et al., 2012; Izquierdo-Gomez et al., 2014; Izquierdo-Gomez et al., 2017; Matute-Llorente et al., 2013; Pitchford et al., 2018; Shields et al., 2009) whereas in other studies only the amount of time spent in 10 minute bouts was included (Nordstrøm et al., 2013; Phillips & Holland, 2011).

Although all studies required participants to wear an accelerometer for 7 days, inclusion in the analysis of each study required different minimum wear times, from 8 hours over 3 days (Iughetti et al., 2014; Izquierdo-Gomez et al., 2017) to 10 hours over 7 consecutive days (Phillips & Holland, 2011) (see Table 2.1). Stricter minimum wear protocols can reduce the number of participants and thus the quantity of valid data (M. Smith et al., 2017). Inclusion in analysis may have been influenced by non-compliance in wearing the accelerometer for the full 7 days due to discomfort or inconvenience (Shields et al., 2009; Whitt-Glover et al., 2006); and future technology may make accelerometers less obtrusive to wear.

Accelerometers are unable to record counts during cycling or swimming (Matute-Llorente et al., 2013) and thus the amount of energy expended in physical activity can be underestimated (Izquierdo-Gomez et al., 2014; Nordstrøm et al., 2013). As swimming is one of the more popular forms of physical activity for Australian adolescents and young adults with Down syndrome (Jobling & Cuskelly, 2006; Jobling et al., 2006; Oates et al., 2011), recording time spent swimming has been advised in future studies (Matute-Llorente et al., 2013).

In studies using accelerometers, count-per-minute (cpm) cut-points indicate the level of physical activity intensity (light, moderate, vigorous) with the amount of time spent at moderate and vigorous intensity the basis of physical activity guidelines. In most studies with adolescents with Down syndrome, different accelerometers and cut-point references for moderate and vigorous activity were used, with only the two studies of adults using the same cut-point references (Nordstrøm et al., 2013; Phillips & Holland, 2011) (see Table 2.1). Using different MVPA cut-points will give different results as to the percentage of participants meeting MVPA guidelines (Matute-Llorente et al., 2013), with Izquierdo-Gomez et al. (2014) finding lower compliance with the guidelines when applying the higher cut-points used earlier by Matute-Llorente et al. (2013).

One of the main limitations of studies investigating the physical activity levels of adolescents and young adults with Down syndrome is the use of standard MVPA cut-points. Children and adolescents with Down syndrome display joint laxity and muscle hypotonia which can affect walking gait (Galli, Rigoldi, Brunner, Virji-Babul, & Giorgio, 2008). A study of the gait patterns of adolescents with Down syndrome with a BMI classified as obese (n=15) reported significantly shorter walking distance, slower walking speed and shorter step cycle and step length as compared to obese adolescents without Down syndrome (Elshemy, 2013). It has been proposed that the differences in gait characteristics also observed in adults with Down syndrome resulted in higher net metabolic rate when walking compared to adults without Down syndrome (Agiovlasitis, McCubbin, Yun, Widrick, & Pavol, 2015). Agiovlasitis et al. (2011, p. 1324) measured the METS (metabolic equivalents) of adults with and without Down syndrome (both n=18) during walking of different intensities finding that in adults with Down syndrome "METs increased at a faster rate with increasing activity count rate compared with participants without Down syndrome". As a result of these physiological differences Down syndrome specific MVPA cut-points have been developed for use in future research (Agiovlasitis et al., 2011; Peiris et al., 2017).

Step-rates (steps per minute) have also been used as a measure of physical activity intensity in studies using acceleromters, with an average of 100 steps per minute the threshold for moderate – vigorous physical activity (Agiovlasitis, Beets, Motl, & Fernhall, 2012). This threshold, developed for people without disabilities may not be suitable for people with Down syndrome due to a lower than average height and higher energy expenditure during walking (Agiovlasitis et al., 2012). Lower step-rate thresholds for young men and women with Down syndrome and of differing heights were suggested in a study comparing the energy expenditure and step-rates of healthy, active young adults with (n=18) and without Down syndrome (Agiovlasitis et al., 2012) and these could also apply to adolescents (Pitetti et al., 2013). Further studies with greater sample sizes are needed to confirm these proposed thresholds.

Table 2.1 Objectively measured physical activity levels in adolescents and young adults with Down syndrome

Author, year of publication, Country	Age of participants (years)	Number of participants with Down syndrome	Matched control group	Measurement instrument and minimum length of wear	Definition of MVPA	Physical Activity Guidelines	% meeting Physical Activity Guidelines
Shields et al. (2009) Australia	7-17	23	No	RT3 accelerometer Minimum wear time 6 out of 7 days	Moderate ≥970 cpm Vigorous ≥ 2333 cpm (Rowlands, Thomas, Eston, & Topping, 2004)	≥60 minutes MVPA daily	42.1%
Phillips and Holland (2011) UK	12-70	152 with intellectual disability 79 with Down syndrome	No	Actigraph CT1M Minimum wear time 10 hours per day for 7 continuous days	Children 12-15 years: ≥2802 cpm Adults >16 years: ≥2020 cpm (Troiano et al., 2008)	Children: ≥ 60 minutes MVPA daily Adults: ≥150 mins MVPA per week in ≥ 10 minute bouts	No adolescent or adult participant met the physical activity guidelines
Esposito et al. (2012) USA	8-16	104	No	Actical accelerometer Minimum wear time 10 hours per day for at least 4 days out a 7 day period	Sedentary: <25 counts per 15 second epoch Light: 25-375 counts per 15 second epoch Moderate: 376-1625 counts per 15 second epoch Vigorous: >1626 counts per 15 second epoch (Puyau, Adolph, Vohra, Zakeri, & Butte, 2004)	≥60 minutes MVPA daily	20.6%

Author, year of publication, Country	Age of participants (years)	Number of participants with Down syndrome	Matched control group	Measurement instrument and minimum length of wear	Definition of MVPA	Physical Activity Guidelines	% meeting Physical Activity Guidelines
Matute-Llorente et al. (2013) Spain	12-16	19	Yes	Actitrainer uniaxial accelerometer Minimum wear time 10 hours per day for at least 4 days out of a 7 day period	Sedentary: <25 counts per 15 second epoch Light: 25-574 counts per 15 second epoch Moderate: 574-1003 counts per 15 second epoch Vigorous: >1003 counts per 15 second epoch (Evenson, Catellier, Gill, Ondrak, & McMurray, 2008)	≥60 minutes MVPA daily	No adolescent participant met the physical activity guidelines
Nordstrøm et al. (2013) Norway	16-45	87 with intellectual disability 40 with Down syndrome	No	Actigraph GT3X+ accelerometer Minimum wear time 10 hours per day for at least 4 out of 7 days	≥2020 cpm (Troiano et al., 2008)	≥30 minutes daily in bouts of 8-10 minutes	7.1% males 8.3% females
Izquierdo-Gomez et al. (2014) Spain	11-20	100	No	Actigraph GT1M, GT3X, GT3X+ accelerometers Minimum wear time 8 hours per day for at least 3 out of 7 days	Moderate: 2000-2999 cpm Vigorous: >3000 cpm (F. P. Freedson, Pober, & Janz, 2005)	≥60 minutes MVPA daily	43%
Izquierdo-Gomez et al. (2017) Spain	11-20	99	No	Actigraph GT1M, GT3X, GT3X+ accelerometers Minimum wear time 8 hours per day for at least 3 out of 7 days	Moderate: ≥ 2000 cpm Vigorous: ≥ 4000 cpm (Andersen et al., 2006)	≥60 minutes MVPA daily	22% (baseline)

Author, year of publication, Country	Age of participants (years)	Number of participants with Down syndrome	Matched control group	Measurement instrument and minimum length of wear	Definition of MVPA	Physical Activity Guidelines	% meeting Physical Activity Guidelines
Pitchford et al. (2018) USA	12-18	22	Yes	Actigraph GT3X accelerometer Minimum wear time 10 hours per day for at least 4 out of 7 days	Moderate: 2296-4011 cpm Vigorous: ≥4012 cpm (Evenson et al., 2008)	≥60 minutes MVPA daily	4.5%

MVPA=moderate vigorous physical activity; cpm=counts-per-minute

2.3.2.2 Physical activity and body composition

In Australian adolescents and adults without Down syndrome, higher physical activity levels are associated with a lower BMI (Allender et al., 2011; Australian Bureau of Statistics, 2013a). Although studies investigating the impact of physical activity on body composition of adolescents and young adults with Down syndrome have found positive associations between physical activity, muscular fitness (Izquierdo-Gomez, Martínez-Gómez, et al., 2015) and bone density (Guijarro et al., 2008; Matute-Llorente et al., 2013), there is inconsistent evidence of a relationship with body fatness. Using structured interviews with both participants and their parents, Jobling et al. (2006) found a positive relationship between physical activity and BMI in a sample (n=18) of young adults with Down syndrome which was not observed in siblings without Down syndrome. The authors suggested this could be due to the influence of parents supporting their overweight young adult to be more physically active (Jobling et al., 2006), however it may also be due to social desireability bias (Brenner & DeLamater, 2014) impacting on responses or the limitations of using BMI as a measure of body fatness in this population (Temple et al., 2010). In a recent USA study of adolescents with Down syndrome (n=22) and matched controls, although there were no relationships found between BMI, sedentary behaviour and physical activity, there were strong negative relationships found between total body, leg and trunk percentage body fat (as determined by DEXA) and vigorous physical activity (Pitchford et al., 2018). The authors also reported that MVPA was a significant predictor of total percentage body fat (Pitchford et al., 2018).

In other studies strong relationships between physical activity and BMI, body fatness and waist circumference were not identified (Esposito et al., 2012; Izquierdo-Gomez, Martínez-Gómez, et al., 2015; Shields et al., 2009; Shields, Hussey, Murphy, Gormley, & Hoey, 2017), however as studies have been limited by small sample sizes, cross-sectional design, and the measurement of body fatness, the relationship between physical activity and body composition in adolescents and young adults with Down syndrome needs further investigation.

As almost all studies investigating the relationship between physical activity, anthropometry and body compostion have been cross-sectional in design (Esposito et al., 2012; Izquierdo-Gomez, Martínez-Gómez, et al., 2015; Jobling et al., 2006; Pitchford et al., 2018; Shields et al., 2009; Shields et al., 2017), the direction of an association is undetermined – is physical activity impacting on body composition and/or is body composition impacting on physical activity? One recent longitudinal study of physical activity in adolescents with Down syndrome (n=99) did not investigate any relationship between physical activity levels and BMI, however changes in physical activity from baseline to 2-year follow up were not significant (Izquierdo-Gomez et al., 2017). In all previous studies BMI has been used as in indicator of body fatness, however this may not be an apporpriate measure of body composition for young people with Down syndrome (Pitchford et al., 2018). Skinfolds (Esposito et al., 2012; Izquierdo-Gomez, Martínez-Gómez, et al., 2015), waist circumference (Shields et al., 2017) and DEXA (Pitchford et al., 2018) have been used in adolescents with Down syndrome, however further research using DEXA and waist-to-height ratio both with adolescents and young adults with Down syndrome is needed. Therefore, although it has been suggested that physical activity is not a factor in higher levels of body fatness as assessed using BMI, skinfolds and waist circumference in young people with Down syndrome (Izquierdo-Gomez, Martínez-Gómez, et al., 2015), there may be a relationship with body fatness as measured using DEXA and further research is required to address the limitations discussed above.

2.3.2.3 Sedentary behaviour

The amount of time adolescents with and without Down syndrome spend in sedentary behaviour activities increases with age (Cooper et al., 2015; Esposito et al., 2012; Izquierdo-Gomez et al., 2014; Phillips & Holland, 2011). As measured using accelerometers Australian children and adolescents aged 7-17 years with Down syndrome (n=19) have been reported as spending almost 11 hours per day engaged in sedentary behaviour (Shields et al., 2009), similar to the amount of time reported in a UK study of adolescents and adults with Down syndrome (n=79) (Phillips & Holland, 2011). Studies of participation in recreational, physical, social, skill based and self-improvement activities in children and adolescents with Down syndrome from Taiwan (n=997) (Wuang & Su, 2012) and the USA (n=62) (MacDonald, Leichtman, Esposito, Cook, & Ulrich, 2016) found the highest participation rates for sedentary activities (watching television, playing computer and video games).

Australia's Sedentary Behaviour Guidelines for Young People (13-17 years) advises that no more than 2 hours per day should be spent on electronic media for entertainment (e.g. television, computers) and long periods of sitting should be broken up as often as possible

(Australian Government Department of Health, 2014). A Western Australian questionnaire based study (n=200) reported that in 2004, 76% of adolescents with Down syndrome watched 14 hours or less of television per week with few using hand-held computers or devices (Oates et al., 2011). In the 2011-12 Australian Health survey 29% of children and adolescents aged 5-17 years met the electronic media guideline on the previous 7 days with 59% meeting the guideline on the previous 5 days (Australian Bureau of Statistics, 2013a). Although electronic media use appears less for adolescents with Down syndrome, the increasing availability and accessibility of hand-held mobile devices and applications as sources of entertainment for people with intellectual disability (Stephenson & Limbrick, 2015) justifies further research.

Foerste et al. (2016) also used proxy-reported questionnaires in an Australian study to compare the physical activity and sedentary behaviours of overweight adolescents with Down syndrome (n=17) compared to overweight adolescents with Prader-Willi syndrome (n=16) and overweight adolescents without disability (n=19). Adolescents with Down syndrome spent 35 hours per week in sedentary behaviour and the most time of the three groups watching television (mean of 13 hours per week) (Foerste et al., 2016). This amount of time watching television was similar to that reported for adolescents without Down syndrome in the 2011-12 Australian Health Survey (84 minutes per day). Proxy-reported questionnaires as used by Oates et al. (2011) and Foerste et al. (2016) are limited by the reliance on respondent’s awareness of the daily activities of the adolescent with Down syndrome. As adolescents spent time in school and other environments outside the home proxy-reported data may not always be accurately reported (Foerste et al., 2016).

The Australian Health Survey 2011-12 reported that adults engaged in 39 hours per week of sedentary behaviour, of which 13 hours was spent watching television (Australian Bureau of Statistics, 2013a). A small Australian study found that young adults aged 18-24 years with Down syndrome (n=18) watched 3.5 hours of television per day, a significantly greater amount of time compared to their younger siblings without Down syndrome at less than 2 hours per day (Jobling et al., 2006). As research into sedentary behaviour participation of young adults with Down syndrome is limited, further research is required.

2.4 Social and community factors

Where adolescents and young adults with Down syndrome live and who they interact with can have an impact on body composition, possibly through the amount of autonomy to make dietary choices (Hsieh, Heller, Bershadsky, & Taub, 2015) and participation in physical activity (S. J. Downs, Boddy, Knowles, Fairclough, & Stratton, 2013). However as current evidence is inconclusive, these relationships are an area for future research.

2.4.1 Friendships and social interactions

Although friendships and social interactions are associated with better self-rated health and wellbeing in adults with intellectual disability (Emerson, Hatton, Robertson, & Baines, 2014), the frequency of friendship activity experienced by young people with intellectual disability can be low (Emerson & McVilly, 2004). Several studies have reported that many young adults with Down syndrome have none or few friendships (Carr, 2008; Oates et al., 2011) and are more likely to participate in leisure activities alone (Jobling et al., 2006). A positive association between friendship/social support and a healthier BMI was found using a parent completed survey of young adults with Down syndrome (n=49), (Fujiura et al., 1997), however the authors indicated that this may be indicative of the impact of several interelated factors. A further parent completed survey of children and adolescents with Down syndrome (n=208) found no association between BMI and the number of friends (Oates et al., 2011), however there are limitations with the intepretation of BMI values for young people with Down syndrome. Friendships and social interaction has been identified as a facilitator of physical activity for children, adolescents and young adults with Down syndrome (Barr & Shields, 2011; S. J. Downs et al., 2013; Menear, 2007; Shields & Synnot, 2016) which may be the mechanism for any positive impact on body composition.

2.4.2 Place of residence

For young adults with intellectual disability including Down syndrome who live in independent or less supervised environments, the opportunities for choice and decision making about food and physical activity can be increased, however this can also lead to higher levels of obesity (Hsieh et al., 2015; Stancliffe et al., 2011). In a small study of young adults with Down syndrome (n=40), young adults living outside the family home were more likely to be higher consumers of soft drinks and precooked meals, and more involved with food decisions compared to young adults living with family (Nordstrøm et al., 2015).

Additionally a large study of adults with intellectual disability (n=1450) also found those who lived in less supervised urban settings consumed more fast foods, salty snacks and sugar sweetened beverages and less fruit and vegetables (Hsieh et al., 2014). A relationship between accommodation and BMI was observed in a Scottish study of adults with intellectual disability (n=945), where women who lived independently were 2.4 times as likely to be obese as compared to women living with family, however food and physical activity behaviours were not included in the study (Melville et al., 2008).

In focus groups where the topic of well-being was discussed with Australian young adults with Down syndrome (n=12), autonomy and independence in decision making was highly valued with all participants expressing the desire to live independently of their parents (M. Scott et al., 2013). This time of transition is therefore an ideal opportunity for health education and skill development (Hsieh et al., 2015; Nordstrøm et al., 2015), however there is a need for effective health promotion programs that meet both the specific health and learning needs of people with intellectual disability (H. M. Scott & Havercamp, 2016).

2.5 Conclusion

The physiological, behavioural and social factors influencing the body composition of adolescents and young adults with Down syndrome requires further research and may prove to be interrelated. High levels of hypothyroidism, especially subclinical hypothyroidism and the impact this may have on RMR have been reported in many studies of adolescents and young adults with Down syndrome, however questions have been raised about the possibility of elevated TSH being an inherent condition of Down syndrome and the suitability of standard cut-points to diagnose hypothyroidism for this group. Further research is therefore needed to confirm the higher levels of hypothyroidism and the impact on RMR and body composition. Although studies have not clearly identified energy or macronutrient intake, physical or sedentary behaviours as significant factors influencing the higher rates of overweight and obesity reported in adolescents and young adults with Down syndrome, further research using validated dietary intake data collection instruments and Down syndrome specific MVPA cut-points is needed. The possible interaction between level of functioning, place of residence and the impact on dietary and physical behaviours highlights the need for education, skill development and support for adolescents and young adults with Down syndrome to make healthy lifestyle choices.

Preface to Chapter 3

Chapter 3 is a cross-sectional and cohort analysis of the 2004, 2009 and 2011 waves of the Down syndrome NOW study conducted by the Telethon Kids Institute (formerly the Telethon Institute for Child Health Research). Included are questionnaire data reported as part of the Physical Activity, Nutrition and Down syndrome (PANDs) study which is outlined in Chapter 4.

The candidate was not involved in the design, data collection or analysis of data from the 2004 and 2009 Down syndrome NOW waves. The candidate was involved in the design of the questionnaire used in the 2011 wave and in the analysis of data as discussed in Chapter 3.

Chapter 3 Factors associated with the anthropometry of adolescents and young adults with Down syndrome

3.1 Introduction

Cross-sectional studies of the anthropometry of adolescents and young adults with Down syndrome have identified higher rates of overweight and obesity (Bertapelli, Pitetti, Agiovlasitis, & Guerra-Junior, 2016; Havercamp et al., 2017) however only a few studies have reported on changes in anthropometry over time. At the start of a 5-year retrospective study (n=80), the BMI of 12 children with Down syndrome (average age 10.3 years) was categorised as overweight/obese, with 11 children maintaining this category at the conclusion of the study (Hawn et al., 2009). In a retrospective Japanese study the percentage of males and females (n=34) with a BMI classified as overweight and obese increased as adolescents matured to young adulthood (Miyazaki & Okumiya, 2004). In a later review of the medical records of 303 North American children and adolescents aged 2-18 years with Down syndrome, Basil et al. (2016) reported for adolescents over the age of 12 years a steady increase in BMI z-score with age accompanied by a decrease in height z-score with age. Whilst two of these studies indicated that the BMI of adolescents with Down syndrome were more likely to be categorised as overweight or obese as they matured, the use of standard cut-points may have misclassified the BMI of these adolescents and young adults and therefore BMI cut-points need to be interpreted with caution.

As highlighted in 2.2.2, 2.3 and 2.4, the relationships between the anthropometry of adolescents and young adults with Down syndrome and level of functioning, dietary and physical activity behaviours, place of residence and social networks warrant further investigation. For Australian adolescents (Australian Bureau of Statistics, 2013b) and adult females without Down syndrome (Australian Institute of Health and Welfare, 2015), lower socioeconomic status is associated with an increased risk of overweight and obesity. A recent large cross-sectional study found no association between family socioeconomic status and BMI in Brazilian adolescents with Down syndrome (n=1249) (Izquierdo-Gomez & Marques, 2017), however the authors proposed that differences may not have been detected due to the overall higher BMI of participants. Further research is required to investigate any relationship between socioeconomic status and anthropometry in adolescents and young adults with Down syndrome.

3.1.1 Aim, objectives and hypotheses

The aim of this study was to:

Investigate the prevalence of overweight and obesity in adolescents and young adults with Down syndrome and describe the relationships between proxy-reported BMI, food and physical activity related behaviours, health, functional ability, family socioeconomic status, place of residence and social networks.

To address this aim the objectives of this study were to:

1. Describe the anthropometry and prevalence of overweight and obesity of adolescents and young adults with Down syndrome.
2. Investigate changes in height, weight and BMI over time for adolescents and young adults with Down syndrome.
3. Investigate the relationship between perceived overweight/obesity and proxy-reported BMI for adolescents and young adults with Down syndrome.
4. Describe the feeding behaviours of family members/carers of adolescents and young adults with Down syndrome.
5. Describe the food and physical activity behaviours of adolescents and young adults with Down syndrome.
6. Investigate the relationship between proxy-reported BMI, food and physical activity related behaviours, health, functional ability, family socioeconomic status, place of residence and social networks of adolescents and young adults with Down syndrome.

From the literature review the following hypotheses were proposed:

1. A high proportion of adolescents and young adults with Down syndrome will be overweight and obese when applying standard BMI cut-points.
2. The BMI of adolescents and young adults with Down syndrome will increase over time.
3. The perception of overweight and obesity will be an underestimation in comparison to proxy-reported height and weight.

4. Family members/carers of adolescents and young adults with Down syndrome will report high levels of controlling feeding behaviours.
5. Overweight and obesity as defined by standard cut-points will be associated with lower functional ability, lower family socioeconomic status, living independently, less physical activity and fewer friendships.

3.2 Methodology

This study was a cross-sectional analysis of data collected by the Telethon Kids Institute (formerly the Telethon Institute for Child Health Research) as part of the Down syndrome Needs Opinions Wishes (Down syndrome NOW) study with additional questionnaire data from the Physical Activity, Nutrition and Down syndrome (PANDs) study which was conducted with the same cohort. The aim of the Down syndrome NOW study was to investigate the impact of the medical, social, educational and functional aspects of Down syndrome on the individual, family and community. The study was conducted in three waves (2004, 2009 and 2011) as two-part questionnaires which were available to be completed on paper and online. The age range for the 2004 wave was 0-25 years, for the 2009 wave 15-30 years and for the 2011 wave 16-31 years. Questions in part one of the questionnaires focussed on the health and needs of the person with Down syndrome and part two on the health and needs of the family. In 2009 additional questions on sexuality, everyday functioning, post-school transition and family quality of life were added to the original 2004 questionnaire. In 2011 additional questions on nutrition, physical activity, infant feeding, daily occupation and activities, young adult quality of life, social participation and environmental influences were added to the questionnaire (see Appendix B).

The age range for the PANDs study was 12-30 years and the study involved collecting data on the anthropometry, dietary intake and physical activity behaviours of adolescents and young adults with Down syndrome (as discussed further in Chapters 4.0, 5.0, 6.0 and 7.0). As participants for the PANDs study were recruited from the same database as the Down syndrome NOW study, most participants had participated in the earlier 2011 Down syndrome NOW wave, however for those who had not participated in the 2011 wave or were ineligible to participate due to young age, an abridged version of the 2011 questionnaire (Table 3.1) was included as part of their participation in the PANDs study.

Their questionnaire data are included in this chapter. All questionnaires were completed by family members/carers of participants with Down syndrome.

Table 3.1 Sections included in the Down syndrome NOW 2011 and PANDs study questionnaires

Section	Down syndrome NOW 2011 questionnaire	PANDs study questionnaire
Part 1 – Your son/daughter		
Parent information	√	√
Medical conditions	√	√
Medical care, services and illnesses	√	√
Nutrition	√	√
Everyday functioning	√	√
Daily occupations and activities	√	
Young adult's quality of life	√	
Resources and income	√	√
Environmental influences	√	
Accommodation needs	√	
Social relationships	√	√
Respite	√	
Participation: Life-H	√	
Personality and behaviour	√	
Part 2 – Your family		
Family quality of life	√	
Family communication	√	
Self-assessment of mood	√	
Self-assessment of personal health	√	√
Informal assistance needs	√	
Availability of time	√	
Agreement with your partner	√	
Family and community support	√	
Questionnaire feedback	√	√

3.2.1 Ethics approvals

Ethics approval for the Down syndrome NOW study waves was granted by the Princess Margaret Hospital for Children Ethics Committee. Ethics approval to use the data from the

2004, 2009 and 2011 waves was granted by the School of Public Health and the Curtin University Human Research Ethics Committee (SPH-03-2011, HR 143/2011, HR 145/2011) (see Appendices C, D and E).

3.2.2 Community participation

Consumer and community participation in research is important to ensure that research is relevant to the needs of the target group and therefore more likely to lead to changes in health outcomes (NHMRC, 2016). The involvement of families of children with disability is vital when planning and conducting research (Morris, Shilling, McHugh, & Wyatt, 2011). A consumer reference group of parents of young adults with Down syndrome, including representatives from the Down Syndrome WA, was established by the Telethon Kids Institute to advise on all stages of the planning, implementation and translation of the Down syndrome NOW study waves. The questions relating specifically to this thesis were presented and discussed with the group prior to inclusion in the Down syndrome NOW 2011 questionnaire. The candidate is also a parent of a young adult with Down syndrome but was not a member of the consumer reference group for the Down syndrome NOW study.

Outcomes of the Down syndrome NOW study waves were communicated to families in Western Australia through regular newsletters and a booklet *Understanding Down syndrome: Capturing family experiences through research* which was sent to families and available from the Telethon Kids Institute website. Outcomes have also been communicated with families nationally through the Down Syndrome Australia journal *Voice*.

3.2.3 Recruitment

A database of Western Australian children diagnosed with Down syndrome was established in 1997 at the Telethon Institute for Child Health Research (now Telethon Kids Institute) as part of a study on medical conditions in children with Down syndrome (S. Leonard, Bower, Petterson, & Leonard, 1999). Participants for 2004, 2009 and 2011 Down syndrome NOW studies (Foley et al., 2016) and the PANDS study were identified from this Down syndrome NOW database. In the 2004, 2009 and 2011 Down syndrome NOW studies, families living in Western Australia were posted a questionnaire with consent implied if they returned it in the reply paid envelope or completed the questionnaire online. Where contact details were unavailable on the Down syndrome NOW database, questionnaires were posted by the Disability Services Commission (WA). Families were followed up by phone to ensure they had received the questionnaire and to check for any questions or problems with completing the questionnaire. Some families completed the questionnaire over the phone or in a face to face interview if preferred. Details on how participants for the PANDs study were recruited are in 4.3.

3.2.4 Data collection

Questionnaire variables collected as part of the 2004, 2009 and 2011 Down syndrome NOW studies and the PANDs study and analysed in this chapter are itemised in Table 3.2. Although data on income, health and medical conditions, everyday function, accommodation and number of friends were also collected in earlier waves of the Down syndrome NOW study, data only from the 2011 questionnaire will be reported in this thesis. Previous publications have reported on these data from the Down syndrome NOW study waves (Foley et al., 2015; Foley et al., 2014; Foley et al., 2013; Oates et al., 2011; Pikora et al., 2014; Thomas et al., 2011).

Table 3.2 Data used from each wave of the Down syndrome NOW questionnaire and the PANDs study

Data	2004	2009	2011	PANDs
Proxy-reported height and weight	√	√	√	
Reported weight condition			√	
Qualitative responses on weight status	√			
Child Feeding Questionnaire (Birch et al., 2001)			√	√
Food and physical behaviour questions (Martin et al., 2008)			√	√
Medical conditions			√	
Index of Social Competence (McConkey & Walsh, 1982)			√	√
Family income			√	
Accommodation type			√	
Number of friendships			√	

As part of the 2004, 2009 and 2011 questionnaires, family members/carers reported the height and weight of participants. BMI was calculated (hereafter described as reported

BMI) and categorised using standard cut-points (CDC, 2018; NHMRC, 2013b) (see Table 3.3). In this study, the height, weight, BMI and BMI percentile of adolescents and young adults in the 2004, 2009 and 2011 Down syndrome studies as reported by family members/carers are presented, along with an analysis of the changes in height, weight and BMI of those who participated in both the 2004 and 2009 waves and both the 2004 and 2011 waves. For adolescents in the 2004 and 2009 Down syndrome studies the CDC BMI percentile calculator for child and teen (CDC, 2018) was used to calculate the BMI percentile. Height and weight questions were included in the PANDs study questionnaire however these data were not used in this analysis as family member/carer responses may have been impacted by participation in the PANDs study which involved direct weighting and measuring of participants.

Table 3.3 Cut-points used for assessing BMI

Parameter	**Reference**	**Cut-point**	**Cut-point**
		Overweight	**Obesity**
Adolescent (≥12 y & <18 y)	CDC BMI percentile calculator for child and teen (CDC, 2018)	85^{th}-95^{th} percentile	>95^{th} percentile
Young adult (≥18 y)	NHMRC definition (NHMRC, 2013b)	≥25 – 29.9 kg/m2	≥30 kg/m2

In the 2011 questionnaire family members/carers indicated if their adolescent/young adult was overweight/obese or underweight, and if so, to what extent did the condition impact on daily life and its management. These data from the Down syndrome NOW 2011 questionnaire were included in a publication on the impact of health conditions of adolescents and young adults with Down syndrome (Pikora et al., 2014). In this current analysis the relationship between these data on family member/carer perception of overweight/obesity and BMI (as calculated from proxy-reported height and weight) was analysed.

In the Down syndrome NOW 2004 questionnaire, a qualitative question asked family members/carers to comment on any difficulties experienced by their child in maintaining a healthy weight. Responses to this question have been grouped into themes and presented with sample responses.

An adapted form of the Child Feeding Questionnaire (Birch et al., 2001) was included in the Down syndrome NOW 2011 questionnaire to identify the level of parental responsibility and monitoring of food intake and the relationship with BMI. Validity of the Child Feeding Questionnaire has been tested using confirmatory factor analysis in large studies of parents of children and adolescents without Down syndrome (Anderson, Hughes, Fisher, & Nicklas, 2005; Birch et al., 2001; Boles et al., 2010; Canals-Sans et al., 2016; Kaur et al., 2006; M. L. Polfuss & Frenn, 2012) and in two studies involving parents of children with Down syndrome (O'Neill et al., 2005; M. Polfuss et al., 2017). The Child Feeding Questionnaire included questions under the factors of ‘perceived responsibility’, ‘perceived parent weight’, ‘perceived child weight’, ‘concern about child weight’, ‘pressure to eat’, ‘restriction’ and ‘monitoring’ (Birch et al., 2001). Modifications were made to the wording of some of the questions of the Child Feeding Questionnaire (Birch et al., 2001) to make them more applicable to Australian adolescents and young adults. For example, the word ‘child’ was replaced with ‘your son/daughter’ in all questions. The name of sweet and savoury snack foods given as examples were also changed from North American to Australian terminology: candy was replaced with lollies, pastries replaced with biscuits, Doritos and cheese puffs replaced with corn chips. Additional questions were also added as the questionnaire was being applied to an adolescent and young adult cohort who may also consume sweetened beverages and alcohol (see Table 3.4). These modifications and additions were similar to those included by Kaur et al. (2006) in their study of the validity of the Child Feeding Questionnaire for adolescents. One question was inadvertently left out of the ‘restriction’ factor ‘If I did not guide or regulate my child's eating, she would eat too many junk foods’, and thus this factor includes six questions rather than seven. Responses were scored using a Likert scale (score range 1-5) as detailed in Birch et al. (2001) with a higher score indicative of greater parental control of eating.

As the Child Feeding Questionnaire was modified for this population, internal consistency of each factor was analysed, along with the means for each factor. The ‘monitoring’ factor was analysed twice, once including the question on alcohol and once without the question on alcohol as not all adolescents and young adults would consume alcohol. Responses to the Child Feeding Questionnaire on perceived child and parent weight were not analysed as part of this study. To test for any relationship between Child Feeding Questionnaire factors and body fatness, the correlation between the mean of each factor and reported BMI as both a continuous and categorical variable was analysed.

Table 3.4 Modifications and additions to the Child Feeding Questionnaire

Factor	Original question	Modified question	Additional questions
Responsibility	When your child is at home, how often are you responsible for feeding her?	When your son/daughter is at home, how often are you responsible for preparing his/her meals?	
Perceived child weight	Your child kindergarten through 2nd grade Your child from 3rd through 5th grade Your child from 6th through 8th grade	What was your son's/daughter's weight in primary school?	What was your son's/daughter's weight in secondary school? What was your son's/daughter's weight post-secondary school?
Monitoring			How often do you keep track of the high-sugar beverages (e.g. lemonade, Cola) that your son/daughter drinks? Does your son/daughter drink alcohol? Yes/No If yes, how often do you keep track of alcoholic beverages that your son/daughter drinks?

Questions on food behaviours and physical behaviours in the Down syndrome NOW 2011 questionnaire and PANDs study questionnaire were adapted from The Child and Adolescent Physical Activity and Nutrition Survey (Martin et al., 2008). These included categorical questions on where the participant consumed their main meal, how often they consumed fast food, how many days they were active for 60 minutes or more and the types of physical activities in which they participated. Additionally, a categorical question on food preparation skills was analysed separately from the Index of Social Competency (McConkey & Walsh, 1982). The frequencies of responses to these questions were tabulated by age group (adolescent/young adult) and sex. Responses to the question on the types of physical activities in which participated were also graphed (total and by sex). Responses given as ‘other’ were included in the listed responses if they were similar e.g. walking to work was included with ‘walking/riding bike to and from school’.

The relationships between reported BMI as both a continuous and categorical variable and food and physical activity behaviours (except for types of physical activities) were only analysed for participants in the Down syndrome NOW 2011 study. Although responses from participants in the PANDs study were included with the descriptive statistics on food and physical activity behaviours, these were excluded from the analysis with BMI for reasons described previously.

Other data collected in the Down syndrome NOW 2011 questionnaire and analysed for their relationship with BMI (as calculated from proxy-reported height and weight) were the impact of illness, the level of every day functioning, accommodation type, number of friendships, family financial stress and family income. The cumulative impact of illness on the daily life of the participant with Down syndrome was used as the indicator of health status. In the questionnaire family members/carers indicated if the participant currently had any of the 28 medical conditions listed (with space to indicate other medical conditions not listed) and if so, the level of impact on the participant’s daily life (none, minor, moderate and major). Each individual medical condition impact (excluding menstrual conditions for females) was scored, the scores for each participant combined and the total impact of illness score analysed for any relationship with BMI.

Functional status was assessed using the communication, self-care and community skills domains of the Index of Social Competence (McConkey & Walsh, 1982). These data have previously been analysed in relation to behaviour in young adults with Down syndrome (Foley et al., 2015). The relationships between individual domains, total scores and BMI (as calculated from proxy-reported height and weight) for participants in the Down syndrome NOW 2011 wave were analysed.

In the Down syndrome NOW 2011 questionnaire categorical questions on accommodation type, number of friendships, family financial stress and income were included. When analysing the relationship between these factors, the categorical food and physical activity factors described earlier and BMI, responses were grouped into binary variables to maximise sample size for analysis as shown in Table 3.5.

Table 3.5 Categorical responses and binary variables

Factor	Categorical responses	Binary variables
Fast food consumption	4-6 times per week	More than once a week
	2-3 times per week	
	Once or less than once per week	Once or less than once a week
	Twice a month	
	Once or less than once a month	
Main meal setting	Eating with others at the dining table	At the dining table with others
	Eating alone at the dining table	Not at the dining table with others
	Eating alone on the couch	
	Eating with others on the couch	
	Other	
Food preparation skills	Adequate variety without supervision	Prepares food without supervision
	Simple hot foods without supervision	
	Simple cold foods without supervision	
	Simple foods with supervision	Requires supervision/support
	Needs all food prepared	
Days physically active for ≥60 minutes	0 days	0-2 days in the week
	1-2 days	
	3-4 days	3-7 days in the week
	5-6 days	
	7 days	
Accommodation	Family home	In the family home
	Group home	Not in the family home
	Hostel/ Hospital/nursing home	
	Unit or house, living with relatives/friends	
	Unit or house, living alone	
Friendships	No friends	0-2 friends
	1 or 2 close friends	
	Between 3 to 6 close friends	3-6+ friends
	More than 6 close friends	
Family financial stress	We are spending money we haven't got	Under financial stress
	We have just enough money to get us through to next pay day	
	There's some money left over each week but we just spend it	
	We save a bit every now and then	Not under financial stress
	We can save a lot	
Family income	Less than $20,799	<$52,000 per annum
	Between $20,800 and $31,199	
	Between $31,200 and $41,599	
	Between $41,600 and $51,999	
	Between $52,000 and $64,999	≥$52,000 per annum
	Between $65,000 and $77,999	
	Between $78,000 and $103,999	
	$104,000 and above	

3.2.5 Statistical analysis

Descriptive statistics, reported as means with standard deviation (SD) or proportions where appropriate, were used to summarise participant characteristics, anthropometry, perceived and reported BMI categories, Child Feeding Questionnaire factor scores, food and physical activity behaviours and types of physical activity in which the young people participated. In each of the 2004, 2009 and 2011 waves and by age group (adolescent, young adult), independent samples t-tests with unequal variances were used to compare the mean age, height, weight and reported BMI and BMI percentile between the sexes, and Pearson's chi-squared test of independence was used to examine the relationship between reported BMI categories (i.e. not overweight or obese, overweight or obese) and sex. For changes in reported BMI for those who participated in both the 2004 and 2009 waves and both the 2004 and 2011 waves of the questionnaire, paired samples t-tests were employed to compare the mean values. Independent samples t-tests assuming unequal variances were then used to investigate the difference in these changes between male and female participants. For changes in reported BMI categories over time, relative risk for overweight/obesity was calculated for males and females, and their difference, represented as ratio of relative risk, was derived using the method of Altman (Altman & Bland, 2003). The relationship between perceived and reported BMI status was examined using exact McNemar's test.

Cronbach's alpha was used to assess the internal consistency of the Children's Feeding Questionnaire factors with the mean scores for each factor compared by age group, reported BMI category and sex using independent samples t-tests with unequal variances. Spearman's rank correlation was used to explore the relationship between Children's Feeding Questionnaire, impact of illness scores and Index of Social Competence scores and reported BMI as a continuous variable. Correlation strength was determined using the guidelines of 0.00-0.25 = little or no relationship, 0.25 to 0.50 = fair relationship, 0.50 to 0.75 = moderate to good relationship and >0.75 = good to excellent relationship (Portney & Watkins, 2009). Welch's ANOVA with a Games-Howell post hoc test was used to compare the Child Feeding Questionnaire, impact of illness scores and Index of Social Competency scores with BMI as a categorical variable.

Independent t-test (for comparison of means between 2 groups) and Kendall tau-c (for categorical variables comparison) were used to investigate the relationship between each of the following factors and reported BMI as a continuous or categorical variable: sex, food and physical activity behaviours, accommodation type, friendships, financial stress and family income. Each factor was also individually examined by sex. Simple and multiple linear regressions were carried out to investigate the association between reported BMI and pertinent risk factors including sex, fast food frequency, main meal setting, food preparation skills, accommodation type and family income. Unadjusted and adjusted regression coefficients and their 95% confidence intervals were reported. The level of statistical significance was set at alpha=0.05 and all *P* values were estimated using two-tailed tests. All analyses were performed in SPSS (IBM Corp. Released 2016. IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp). Qualitative data from the Down syndrome NOW 2004 questionnaire were read and grouped into themes using common key words and ideas. Microsoft Excel 2013 was used to group data into themes.

3.3 Results

3.3.1 Participants

Questionnaires were returned for 363 of 500 eligible participants in the 2004 wave (72.6% response fraction), 203 of 269 eligible participants in the 2009 wave (75.5% response fraction), and 197 of 223 eligible participants in the 2011 wave (88.3% response fraction) (see Figure 3.1). Of the 363 participants for whom consent was provided in the 2004 wave, slightly more than a quarter (n=100, 27.5%) were adolescents aged 12-17 years and 96 (26.4%) were young adults aged 18 years and older. Due to an older target age group, a smaller percentage of participants in the 2009 wave (n=41, 20.2%) and 2011 wave (n=11, 5.6%) were adolescents with the majority in the young adult age group.

Of the 377 participants who were eligible for the PANDs study, 61 family members/carers provided consent and 59 completed the study. Details on how participants were contacted and consent provided are provided in Chapter 4. Of these 59 participants, 37 had previously participated in the Down syndrome NOW 2011 wave and their results were included with this study. The remaining 22 participants who had not participated in the Down syndrome NOW 2011 wave were provided with an abridged version of the questionnaire to complete. Of these 22 participants, 21 questionnaires were returned from the families of 13 adolescents and 8 young adults (see Figure 3.1).

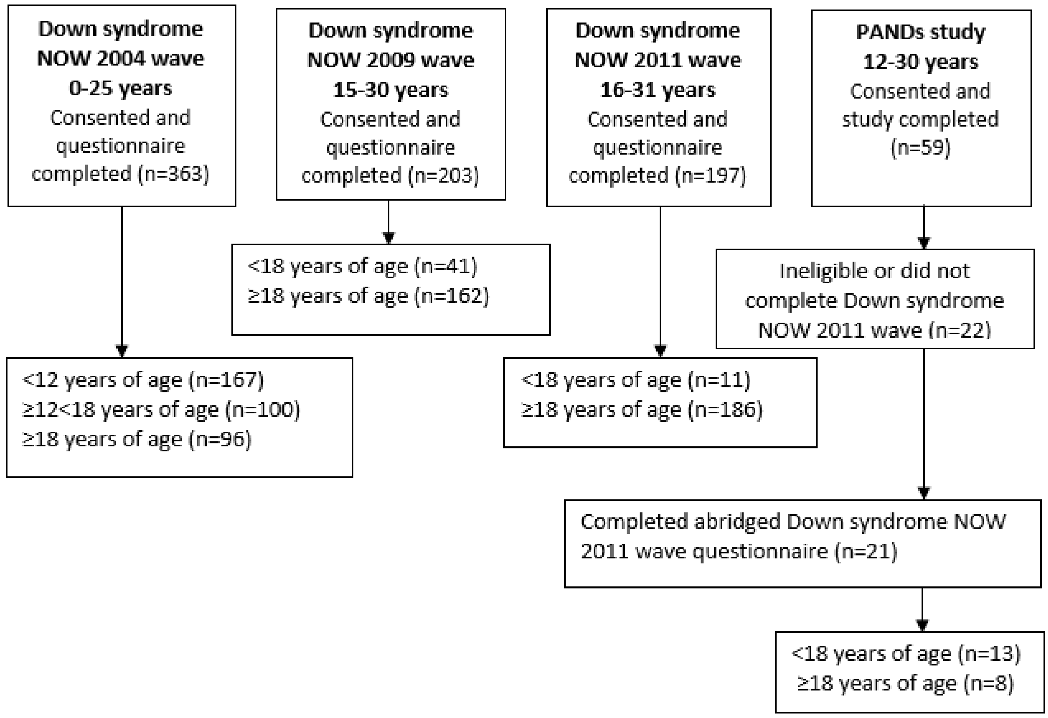


Figure 3.1 Data collection flowchart for the Down syndrome NOW and PANDs studies

Both height and weight were reported for 149 (76.0%), 124 (61.1%) and 143 (72.6%) participants in the 2004, 2009 and 2011 waves, respectively, with either height and/or weight not provided for the remaining participants in the adolescent and young adult age groups. Of the 149 adolescent and young adult participants in the 2004 Down syndrome NOW study with a reported BMI, 66 participated and had a reported BMI in the 2009 study (2004/2009 cohort), and 82 participated and had a reported BMI in the 2011 study (2004/2011 cohort) (Table 3.6).

In the 2011 wave BMI was reported for 7 adolescents and 136 young adults (see Table 3.6). As the youngest adolescent was aged 17.1 years and the BMI classifications for all adolescents were the same when using both the CDC BMI percentile calculator for child and teen (CDC, 2018) and the NHMRC cut-points (NHMRC, 2013b), reported height, weight and BMI data for these individuals were included with young adult data for analysis.

Table 3.6 Participants with reported BMI in the 2004, 2009 and 2011 Down syndrome NOW studies

Down syndrome NOW study	Adolescent n (row %)	Young adult n (row %)	Total n (row %)
2004	72 (48.3)	77 (51.7)	149 (100)
2009	24 (19.4)	100 (80.6)	124 (100)
2011	7 (4.9)	136 (95.1)	143 (100)
Down syndrome NOW cohorts	**Male n (row %)**	**Female n (row %)**	**Total n (row %)**
2004/2009	37 (56.1)	29 (43.9)	66 (100)
2004/2011	41 (50.0)	41 (50.0)	82 (100)

Reported BMI and perception of overweight/obesity data from the 21 questionnaires completed as part of the PANDs study were not included in the analysis as responses may have been influenced by participation in the PANDs study where participants were weighed and measured.

3.3.2 Reported anthropometry of adolescents and young adults with Down syndrome

Tables 3.7, 3.8 and 3.9 present the reported anthropometric data for participants in the 2004, 2009 and 2011 Down syndrome NOW study waves. In all three study waves males were taller than females (2004: 8.3, 95% confidence interval [CI] 5.3,11.2; 2009: 7.0, 95% CI 4.4,9.5; 2011: 9.4, 95% CI 7.1,11.8). In the 2011 wave the reported BMI of young adult males was lower than the reported BMI of young adult females (-4.9, 95% CI -7.3,-2.5) but this was not evident in the previous waves. Table 3.10 presents the classification of anthropometric data of participants in the 2004, 2009 and 2011 Down syndrome NOW study waves using standard BMI cut-points (CDC, 2018; NHMRC, 2013b). In the 2004 study 43.1% (31/72) of adolescents and 64.9% (50/76) of young adults had a reported BMI classified as overweight or obese. In the 2009 study 66.7% (16/24) of adolescents and 64.0% (64/100) of young adults had a reported BMI classified as overweight or obese and in the 2011 study 70.0% (100/143) of young adults had a reported BMI classified as overweight or obese. Results from the 2004, 2009 and 2011 waves cannot be directly compared due to differences in the mean age of participants (younger mean age in the 2004 study wave compared to 2009 and 2011 study waves).

As shown in Table 3.11, a greater proportion of young adult females in the 2011 study wave had a reported BMI classified as overweight or obese (82.4%, 56/68) compared to young adult males (58.7%, 44/75), corresponding with results in Table 3.9 which showed a higher mean reported BMI for young adult females compared to males.

Table 3.7 Reported anthropometry of participants in the Down syndrome NOW 2004 study wave

	Male Mean ± SD	**Female Mean ± SD**	**Total Mean ± SD**	**Difference in means (95% CI) [male v. female]**	***P* value^**
Adolescent n (%)	**43 (59.7)**	**29 (40.3)**	**72 (100)**		
Age (y)	14.6 ± 1.4	14.6 ± 1.5	14.6 ± 1.5	-0.03 (-0.7, 0.8)	0.886
Height (cm)	153.4 ± 8.2	146.7 ± 7.6	150.7 ± 8.6	6.6 (2.9, 10.4)	0.001#
Weight (kg)	53.7 ± 11.6	52.7 ± 10.4	53.3 ± 11.1	1.0 (-4.2, 6.3)	0.389
BMI (kg/m^2)	22.7 ± 3.8	24.4 ± 4.2	23.4 ± 4.0	-1.7 (-3.7, 0.2)	0.080
BMI percentile	69 ± 24	78 ± 21	73 ± 23	-8.1 (-18.6, 2.5)	0.132
Young adult n (%)	**44 (57.1)**	**33 (42.9)**	**77 (100)**		
Age (y)	20.8 ± 2.1	20.6 ± 2.2	20.7 ± 2.1	0.2 (-0.8, 1.2)	0.706
Height (cm)	157.1 ± 10.9	147.2 ± 9.1	152.8 ± 11.2	9.9 (5.3, 14.4)	<0.001#
Weight (kg)	68.2 ± 17.3	61.7 ± 15.2	65.4 ± 16.6	6.4 (-0.9, 13.9)	0.085
BMI (kg/m^2)	27.4 ± 6.0	28.6 ± 7.4	28.0 ± 6.6	-1.2 (-4.3, 2.0)	0.457
Total n (%)	**87 (58.4)**	**62 (41.6)**	**149 (100)**		
Age (y)	17.7 ± 3.6	17.8 ± 3.6	17.7 ± 3.6	0.05 (-1.2, 1.1)	0.933
Height (cm)	155.2 ± 9.8	147.0 ± 8.4	151.8 ± 10.1	8.3 (5.3, 11.2)	<0.001#
Weight (kg)	61.0 ± 16.4	57.5 ± 13.8	59.6 ± 15.4	3.5 (-1.4, 8.5)	0.156
BMI (kg/m^2)	25.1 ± 5.6	26.7 ± 6.4	25.8 ± 6.0	-1.6 (-3.6, 0.4)	0.125

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
#*P*<0.05

Table 3.8 Reported anthropometry of participants in the Down syndrome NOW 2009 study wave

	Male Mean ± SD	Female Mean ± SD	Total Mean ± SD	Difference in means (95% CI) [male v. female]	*P* value^
Adolescent n (%)	**14 (58.3)**	**10 (41.7)**	**24 (100)**		
Age (y)	16.2 ± 0.7	16.5 ± 0.5	16.3 ± 0.6	-0.3 (-0.8, 0.2)	0.266
Height (cm)	156.5 ± 7.4	147.9 ± 5.3	152.9 ± 7.8	8.5 (3.1, 14.0)	0.003[#]
Weight (kg)	68.4 ± 13.4	59.5 ± 14.1	64.7 ± 14.1	9.0 (-3.0, 21.0)	0.133
BMI (kg/m^2)	28.2 ± 6.6	27.3 ± 7.0	27.8 ± 6.6	0.9 (-5.1, 6.8)	0.756
BMI percentile	81 ± 26	77 ± 31	79 ± 28	4.9 (-20.4, 30.1)	0.690
Young adult n (%)	**58 (58.0)**	**42 (42.0)**	**100 (100)**		
Age (y)	23.4 ± 3.8	23.7 ± 3.7	23.5 ± 3.8	-0.4 (-1.9, 1.1)	0.622
Height (cm)	155.6 ± 8.1	149.0 ± 6.8	152.8 ± 8.2	6.6 (3.6, 9.6)	<0.001[#]
Weight (kg)	66.1 ± 12.0	66.4 ± 18.2	66.3 ± 14.8	-0.3 (-6.7, 6.2)	0.934
BMI (kg/m^2)	27.4 ± 5.0	29.9 ± 7.9	28.4 ± 6.4	-2.5 (-5.2, 0.3)	0.076
Total n (%)	**72 (58.1)**	**52 (41.9)**	**124 (100)**		
Age (y)	22.0 ± 4.5	22.3 ± 4.4	22.1 ± 4.4	-0.4 (-2.0, 1.2)	0.643
Height (cm)	155.8 ± 7.9	148.8 ± 6.5	152.9 ± 8.1	7.0 (4.4, 9.5)	<0.001[#]
Weight (kg)	66.6 ± 12.2	65.1 ± 17.6	66.0 ± 14.7	1.5 (-4.1, 7.2)	0.595
BMI (kg/m^2)	27.6 ± 5.3	29.4 ± 7.7	28.3 ± 6.5	-1.8 (-4.3, 0.6)	0.142

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
[#]*P*<0.05

Table 3.9 Reported anthropometry of participants in the Down syndrome NOW 2011 study wave

	Male Mean ± SD	Female Mean ± SD	Total Mean ± SD	Difference in means (95% CI) [male v. female]	*P* value^
Young adult n (%)	**75 (52.4)**	**68 (47.6)**	**143 (100)**		
Age (y)	23.7 ± 4.3	24.6 ± 4.4	24.1 ± 4.4	-0.9 (-2.4, 0.5)	0.209
Height (cm)	158.0 ± 6.5	148.6 ± 7.8	153.5 ± 8.6	9.4 (7.1, 11.8)	<0.001[#]
Weight (kg)	68.4 ± 15.0	71.0 ± 18.6	69.7 ± 16.8	-2.6 (-8.2, 3.0)	0.362
BMI (kg/m^2)	27.3 ± 5.4	32.2 ± 8.6	29.7 ± 7.5	-4.9 (-7.3, -2.5)	<0.001[#]

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
[#]*P*<0.05

Table 3.10 Classification of reported anthropometric data of participants in the Down syndrome NOW study waves

	Underweight		Healthy weight		Overweight		Obese	
2004 wave	**n**	**row %**	**n**	**row %**	**n**	**row %**	**n**	**row %**
Adolescent n=72	0	0	41	56.9	17	23.6	14	19.4
Male n=43	0	0	26	60.5	9	20.9	8	18.6
Female n=29	0	0	15	51.7	8	27.6	6	20.7
Young adult n=77**	3	3.9	23	30.3	25	32.9	25	32.9
Male n=44	2	4.5	14	31.8	16	36.4	12	27.3
Female n=33	1	3.0	10	30.3	9	27.3	13	39.4
Total wave n=149	3	2.0	65	43.6	42	28.2	39	26.2
Male n=87	2	2.3	40	46.0	25	28.7	20	23.0
Female n=62	1	1.6	25	40.3	17	27.4	19	30.6
2009 wave								
Adolescent n=24*	0	0	8	33.3	5	20.8	11	45.8
Male n=14	0	0	5	35.7	2	14.3	7	50.0
Female n=10	0	0	3	30.0	3	30.0	4	40.0
Young adult n=100**	0	0	36	36.0	30	30.0	34	34.0
Male n=58	0	0	24	41.4	16	27.6	18	31.0
Female n=42	0	0	12	28.6	14	33.3	16	38.1
Total wave n=124	0	0	44	35.5	35	28.2	45	36.3
Male n=72	0	0	29	40.3	18	25.0	25	34.7
Female n=52	0	0	15	28.8	17	32.7	20	38.5
2011 wave								
Young adult n=143**	3	2.1	40	28.0	39	27.3	61	42.7
Male n=75	2	2.7	29	38.7	21	28.0	23	30.7
Female n=68	1	1.5	11	16.2	18	26.5	38	55.9

*BMI of adolescents classified using CDC BMI percentile calculator for child and teen (CDC, 2018); **BMI of young adults classified using NHMRC cut-points (NHMRC, 2013b)

Table 3.11 Relationship between reported BMI categories and sex for participants in each of the Down syndrome NOW waves

	BMI category				
	Not overweight/obese	**Overweight/obese**	**Total**	χ^2	***P* value^**
2004 wave					
Adolescent*				0.54	0.463
Male (n)	26	17	43		
% within sex category	60.5	39.5	100		
% within BMI category	63.4	54.8	59.7		
Female	15	14	29		
% within sex category	51.7	48.3	100		
% within BMI category	36.6	45.2	40.3		
Young adult**				0.08	0.783
Male (n)	16	28	44		
% within sex category	36.4	63.6	100		
% within BMI category	59.3	56.0	57.1		
Female (n)	11	22	33		
% within sex category	33.3	66.7	100		
% within BMI category	40.7	44.0	42.9		
2009 wave					
Adolescent*				0.09	0.770
Male (n)	5	9	14		
% within sex category	35.7	64.3	100		
% within BMI category	62.5	56.3	58.3		
Female (n)	3	7	10		
% within sex category	30.0	70.0	100		
% within BMI category	37.5	43.8	41.7		
Young adult**				1.73	0.188
Male (n)	24	34	58		
% within sex category	41.4	58.6	100		
% within BMI category	66.7	53.1	58.0		
Female (n)	12	30	42		
% within sex category	28.6	71.4	100		
% within BMI category	33.3	46.9	42.0		
2011 wave**				9.52	0.002[#]
Male (n)	31	44	75		
% within sex category	41.3	58.7	100		
% within BMI category	72.1	44.0	52.4		
Female (n)	12	56	68		
% within sex category	17.6	82.4	100		
% within BMI category	27.9	56.0	47.6		

*BMI of adolescents classified using CDC BMI percentile calculator for child and teen (CDC, 2018); **BMI of young adults classified using NHMRC cut-points (NHMRC, 2013b)
^Two-tailed Pearson's chi-squared test of independence *P* value
[#]$P<0.05$

3.3.2.1 Changes in reported BMI within cohorts

Tables 3.12 and 3.13 present changes in reported BMI and BMI classification of the 66 participants who participated in both the 2004 and 2009 studies (2004/2009 cohort). Tables 3.14 and 3.15 present changes in reported BMI and BMI classification of the 82 participants who participated in both the 2004 and 2011 studies (2004/2011 cohort).

For the participants in both cohorts the proportion of reported BMI classified as overweight and obese increased over time, from 59.1% (39/66) to 69.7% (46/66) in the 2004/2009 cohort and from 58.5% (48/82) to 73.1% (60/82) in the 2004/2011 cohort. Whilst reported BMI increased over time for males and females in both cohorts (e.g. 2004/2009: male 1.9, 95% CI 0.8, 3.0, female 3.1, 95% CI 1.1, 5.2; see Tables 3.12 and 3.14) there was no difference in the increase between males and females in either cohort (2004/2009: -1.2, 95% CI -3.5, 1.1; 2009/2011: -2.4, 95% CI -5.0, 0.2).

In terms of reported BMI category, for males in the 2004/2009 cohort the relative risk for overweight/obesity was 1.1 (95% CI 0.8, 1.4; *P*=0.739) and for females the relative risk was 1.3 (95% CI 1.1, 1.6; *P*=0.015). The ratio of relative risk of overweight/obesity comparing female to male participants was 1.3 (95% CI 0.9, 1.8; *P*=0.223). For males in the 2004/2011 cohort the relative risk for overweight/obesity was 1.3 (95% CI 1.0, 1.6; *P*=0.096) and for females the relative risk was also 1.3 (95% CI 1.1, 1.5; *P*=0.008). The ratio of relative risk of overweight/obesity comparing female to male participants was 1.0 (95% CI 0.7, 1.4; *P*=1.000).

Table 3.12 Differences in mean reported BMI using serial reported measurements of participants in the 2004/2009 cohort

	BMI					
	2004 mean ± SD	**2009 mean ± SD**	**Difference in means (95% CI) [2009 v. 2004]**	***P* value^**	**Difference in differences (95% CI) [male v. female]**	***P* value^^**
Male n=37 (56.1%)	24.9 ± 4.8	26.8 ± 4.6	1.9 (0.8, 3.0)	0.001#	-1.2 (-3.5, 1.1)	0.302
Female n=29 (43.9%)	28.2 ± 6.2	31.3 ± 7.7	3.1 (1.1, 5.2)	0.004#		
Total n=66 (100%)	26.3 ± 5.7	28.8 ± 6.4	2.5 (1.4, 3.5)	<0.001#		

SD=standard deviation; CI=confidence interval
^Two-tailed, paired samples t-test *P* value
^^Two-tailed, independent samples t-test *P* value
#*P*<0.05

Table 3.13 Changes in reported BMI category* using serial reported measurements of participants in the 2004/2009 cohort

	Down syndrome NOW 2009 wave			
Down syndrome NOW 2004 wave	**Healthy weight**	**Overweight**	**Obese**	**Total**
Male n (row %)				
Healthy weight	12 (70.6)	4 (23.5)	1 (5.9)	17 (100)
Overweight	2 (15.4)	6 (46.2)	5 (38.5)	13 (100)
Obese	2 (28.6)	1 (14.3)	4 (57.1)	7 (100)
Total	16 (43.2)	11 (29.7)	10 (27.0)	37 (100)
Female n (row %)				
Healthy weight	4 (40.0)	5 (50.0)	1 (10.0)	10 (100)
Overweight	0 (0.0)	5 (71.4)	2 (28.6)	7 (100)
Obese	0 (0.0)	1 (8.3)	11 (91.7)	12 (100)
Total	4 (13.8)	11 (37.9)	14 (48.3)	29 (100)
Total n (row %)				
Healthy weight	16 (59.3)	9 (33.3)	2 (7.4)	27 (100)
Overweight	2 (10.0)	11 (55.0)	7 (35.0)	20 (100)
Obese	2 (10.5)	2 (10.5)	15 (78.9)	19 (100)
Total	20 (30.3)	22 (33.3)	24 (36.4)	66 (100)

*BMI category classified using standard cut-points (CDC, 2018; NHMRC, 2013b)

Table 3.14 Differences in mean reported BMI using serial reported measurements of participants in the 2004/2011 cohort

	BMI					
	2004 mean ± SD	**2011 mean ± SD**	**Difference in means (95% CI) [2011 v. 2004]**	***P* value^**	**Difference in differences (95% CI) [male v. female]**	***P* value^^**
Male n=41 (50%)	25.2 ± 5.5	27.5 ± 5.3	2.3 (1.2, 3.3)	<0.001#	-2.4 (-5.0, 0.2)	0.068
Female n=41 (50%)	28.1 ± 6.6	32.8 ± 8.6	4.7 (2.3, 7.1)	<0.001#		
Total n=82 (100%)	26.7 ± 6.2	30.1 ± 7.6	3.5 (2.2, 4.8)	<0.001#		

SD=standard deviation; CI=confidence interval
^Two-tailed, paired samples t-test *P* value
^^Two-tailed, independent samples t-test *P* value
#*P*<0.05

Table 3.15 Changes in reported BMI category* using serial reported measurements of participants in the 2004/2011 cohort

	Down syndrome NOW 2011 wave				
Down syndrome NOW 2004 wave	**Underweight**	**Healthy weight**	**Overweight**	**Obese**	**Total**
Male n (%)					
Healthy weight	1 (4.8)	13 (61.9)	7 (33.3)	0 (0.0)	21 (100)
Overweight	0 (0.0)	1 (9.1)	4 (36.4)	6 (54.5)	11 (100)
Obese	0 (0.0)	1 (11.1)	3 (33.3)	5 (55.6)	9 (100)
Total	1 (2.4)	15 (36.6)	14 (34.1)	11 (26.8)	41 (100)
Female n (%)					
Healthy weight	0 (0.0)	6 (46.2)	4 (30.8)	3 (23.1)	13 (100)
Overweight	0 (0.0)	0 (0.0)	5 (45.5)	6 (54.5)	11 (100)
Obese	0 (0.0)	0 (0.0)	3 (17.6)	14 (82.4)	17 (100)
Total	0 (0.0)	6 (14.6)	12 (29.3)	23 (56.1)	41 (100)
Total n (%)					
Healthy weight	1 (2.9)	19 (55.9)	11 (32.4)	3 (8.8)	34 (100)
Overweight	0 (0.0)	1 (4.5)	9 (40.9)	12 (54.5)	22 (100)
Obese	0 (0.0)	1 (3.8)	6 (23.1)	19 (73.1)	26 (100)
Total	1 (1.2)	21 (25.6)	26 (31.7)	34 (41.5)	82 (100)

*BMI category classified using standard cut-points (CDC, 2018; NHMRC, 2013b)

3.3.2.2 Difficulties associated with maintaining a healthy weight

In the 2004 Down syndrome NOW questionnaire, family members/carers were asked if their young person with Down syndrome experienced any difficulties maintaining a healthy weight and to comment on why they thought there have been problems with maintaining a healthy weight. Of the 363 respondents, 38.9% (n=141) indicated that they thought their young person was experiencing difficulties maintaining a healthy weight. Of the 141, 42 (29.8%) were family members/carers of adolescents and 53 (37.6%) were family members/carers of young adults. The remaining 46 (32.6%) were family members/carers of children less than 12 years of age and their comments were not included in the analysis.

Family members/carers cited three main factors which influenced their young person with Down syndrome's ability to maintain a healthy weight – physical activity, dietary intake and the impact of physiological conditions. These themes are described below with illustrative quotes in italics.

1. Family members/carers thought their young person disliked physical activity and lacked motivation to participate.

> *…doesn't like physical activities (walking etc.)*
> *Hates to walk…*
> *Lack of exercise is the biggest problem. He has to be coaxed to do any*
> *(Participant) is not keen on physical exertion. She also would be quite happy to watch tv/videos and snack*
> *Dislikes exercise and will stop when feeling a little tired*
> *Unable to keep her interested in exercise*

2. Family members/carers thought their young person with Down syndrome lacked self-control when eating and would eat too much, especially when out of the care of family members/carers.

> *...has tendency to be overweight due to excessive eating*
> *Can't stop eating*
> *Will overeat to the point of vomiting if unsupervised*
> *Is obsessed with food*
> *I don't think he knows when he is full*
> *Eats too much when at work, unsupervised*
> *…diet is controlled at home, but impossible to monitor when away from home*

3. Family members/carers thought their young person with Down syndrome consumed too many energy dense nutrient poor foods.

Will gain weight very quickly especially as a number of meals are eaten outside the home i.e. fast foods.

If left to his own devices he will eat too much fatty and salty foods (confectionary too).

…drinks too much coke

…she loves eating and drinking the wrong things, e.g. fast food and soft drink

Loves junk food - chocolate, hamburgers, chips etc.

Eats whenever he has the opportunity and usually hamburgers and/or chips

4. Family members/carers thought that there were physiological reasons for why their young person could not maintain a healthy weight, including impacting on their ability to exercise.

Has unactive thyroid

Hormones

Medication - depoprovera (put a lot of weight on her)

Would love to play sport but feet won't allow it (due to flat feet)

Is not able to exercise adequately due to arthritis…

Lack of exercise due to heart condition and knees

3.3.3 Perception of overweight and obesity

In the 2011 Down syndrome NOW study the family member/carer perception of overweight/obesity was reported along with reported weight and height which was converted to BMI and classified using standard cut-points (NHMRC, 2013b).

As shown in Table 3.16, 65.9% (29/44) of young adult males and 89.3% (50/56) of young adult females with a reported BMI classified as overweight/obese were perceived as overweight or obese by their family member/carer. Whilst the perception of overweight/obesity by the family members/carers of young males was related to reported BMI categories (*P*=0.002), this was not observed for young adult females. Only 6.5% (2/31) of young adult males with a reported BMI not classified as overweight/obese were perceived to be overweight/obese by their family member/carer, compared to 50% (6/12) of females.

Table 3.16 Relationship between family member/carer perception of overweight/obesity and reported BMI category of participants in Down syndrome NOW 2011 study

	BMI category*				
	Overweight/ obese		Not overweight/obese		*P* value^
Perceived BMI category	**N**	**%**	**n**	**%**	
Male (n=75)					0.002#
Overweight/obese	29	65.9	2	6.5	
Not overweight/obese	15	34.1	29	93.5	
Female (n=68)					1.000
Overweight/obese	50	89.3	6	50.0	
Not overweight/obese	6	10.7	6	50.0	
Total (n=143)					0.024#
Overweight/obese	79	79.0	8	18.6	
Not overweight/obese	21	21.0	35	81.4	

*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Two-tailed, exact McNemar's test *P* value
#*P*<0.05

3.3.4 Feeding behaviours of family members/carers of adolescents and young adults with Down syndrome

A modified version of the Child Feeding Questionnaire (Birch et al., 2001) was included in both the Down syndrome NOW 2011 and PANDs study questionnaires. Data from both cohorts are included in Tables 3.17, 3.18 and 3.19. Of the possible 218 participants in both studies, between 203 and 206 family members/carers completed the questions for each of the Child Feeding Questionnaire factors (see Table 3.17). Of the 203 family members/carers who completed the 'monitoring' factor questions, 50 (24.6%) confirmed their young adult consumed alcohol and provided the frequency of monitoring. Internal consistency was high (0.84 and above) for all factors except 'pressure to eat'; this was maintained when the question on alcohol consumption was added to the 'monitoring' factor (see Table 3.17).

Table 3.17 Internal consistency of factors in the Child Feeding Questionnaire

Factor	n	Missing	Question number	Range	Internal consistency*
Perceived responsibility	205	13	1-3	1-5	0.84
Concern about child weight	206	12	4-16	1-5	0.92
Restriction	205	13	17-23	1-5	0.84
Pressure to eat	205	13	24-27	1-5	0.68
Monitoring	203	15	28-31	1-5	0.89
Monitoring (including alcohol)	50		28-32	1-5	0.90

*Internal consistency as determined by Cronbach's alpha

Tables 3.18 and 3.19 display the descriptive statistics for each of the Child Feeding Questionnaire factor scores as well as any difference between age group and sex. The mean score for 'monitoring' behaviour was higher for family members/carers of adolescents than young adults (0.4, 95% CI 0.1, 0.8; (see Table 3.18).

For young adults with Down syndrome, the mean score for 'concern about child weight' and 'restriction' were lower for males compared to females (concern: -0.7, 95% CI -1.1, -0.3; restriction: -0.3, 95% CI -0.6, 0.0). Additionally, the mean score for 'pressure to eat' was higher for males than females (0.2, 95% CI 0.0, 0.5). These effects were not observed in the corresponding factor scores for adolescents with Down syndrome which may be related to the low sample number (see Table 3.19).

Table 3.18 Child Feeding Questionnaire factor score by age group

	Adolescent		Young adult		Total			
Factor	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**Difference in means (95% CI) [adolescent v. young adult]**	***P* value^**
Perceived responsibility	24	4.3 ± 0.6	181	4.1 ± 0.8	205	4.1 ± 0.8	0.2 (-0.1, 0.4)	0.239
Concern for child weight	24	3.7 ± 1.0	182	3.3 ± 1.4	206	3.3 ± 1.4	0.4 (-0.0, 0.9)	0.055
Restriction	24	3.5 ± 0.8	181	3.2 ± 1.0	205	3.2 ± 1.0	0.3 (-0.1, 0.7)	0.097
Pressure to eat	24	1.7 ± 0.7	181	1.7 ± 0.9	205	1.7 ± 0.8	0.0 (-0.3, 0.4)	0.846
Monitoring	24	4.3 ± 0.7	179	3.9 ± 1.0	203	4.0 ± 1.0	0.4 (0.1, 0.8)	0.020[#]

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
[#] $P<0.05$

Table 3.19 Child Feeding Questionnaire factor scores by sex and age group

	Adolescent						Young adult					
	Male		Female				Male		Female			
Factor	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**Difference in means (95% CI) [male v. female]**	***P* value^**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**Difference in means (95% CI) [male v. female]**	***P* value^**
Responsibility	12	4.2 ± 0.5	12	4.3 ± 0.6	-0.1 (-0.6, 0.4)	0.618	99	4.2 ± 0.7	82	4.0 ± 0.9	0.1 (-0.1, 0.4)	0.232
Concern	12	3.6 ± 0.9	12	3.9 ± 1.1	-0.3 (-1.1, 0.5)	0.438	100	3.0 ± 1.4	82	3.7 ± 1.3	-0.7 (-1.1, -0.3)	0.001[#]
Restriction	12	3.6 ± 0.8	12	3.4 ± 0.8	0.2 (-0.5, 0.9)	0.523	99	3.1 ± 1.1	82	3.4 ± 0.9	-0.3 (-0.6, -0.0)	0.027[#]
Pressure	12	1.7 ± 0.8	12	1.8 ± 0.7	-0.0 (-0.7, 0.6)	0.907	99	1.8 ± 0.9	82	1.6 ± 0.8	0.3 (0.0, 0.5)	0.032[#]
Monitoring	12	4.3 ± 0.8	12	4.3 ± 0.7	0.0 (-0.6, 0.7)	0.894	98	3.9 ± 1.0	81	4.0 ± 1.0	-0.1 (-0.4, 0.2)	0.327

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
[#]$P<0.05$

Tables 3.20, 3.21 and 3.22 present Child Feeding Questionnaire and proxy-reported BMI data from the Down syndrome NOW 2011 wave. Data from the PANDs study questionnaires were excluded as proxy-reported BMI may have been affected by participation in the study. In Tables 3.21 and 3.22 data from young adult participants with a reported BMI classified as underweight using standard BMI cut-points (NHMRC, 2013b) were combined with data from participants with a reported BMI classified as healthy weight due to numbers (n=3). For all three participants with a reported BMI classified as underweight, reported BMI was >18 kg/m^2, however as height and weight data was proxy-reported, accuracy was undetermined. Combining a small sample of participants classified as underweight with the participants classified as healthy weight (n=3) has been included in previous research (Nordstrøm et al., 2013).

There was a fair to moderate positive rank order relationship between reported BMI as a continuous variable and the score for 'concern about child weight' (rho=0.527, P<0.001), 'restriction' (rho=0.318, P<0.001) and 'monitoring' (rho=0.220, P=0.010) with a higher reported BMI associated with a higher level of family member/control (see Table 3.20). This was observed for both sexes except for the relationship between reported BMI and 'monitoring' which was just observed in males.

Table 3.20 Relationship between Child Feeding Questionnaire factor scores and reported BMI for participants in the Down syndrome NOW 2011 wave

	Male			Female			Total		
Factor	**n**	**rho**	***P* value**	**n**	**rho**	***P* value**	**n**	**rho**	***P* value**
Responsibility	71	-0.049	0.687	65	-0.043	0.731	136	-0.043	0.623
Concern	71	0.491	<0.001#	65	0.427	<0.001#	136	0.527	<0.001#
Restriction	71	0.289	0.014#	65	0.246	0.049#	136	0.318	<0.001#
Pressure	71	0.075	0.537	65	0.028	0.825	136	-0.010	0.908
Monitoring	70	0.302	0.011#	65	0.067	0.598	135	0.220	0.010#

rho=Spearman's rank correlation coefficient
#P<0.05

As shown in Table 3.21 and 3.22, there were a higher scores for 'concern about child weight' from family members/carers of both young adult male (-1.4, 95% CI -2.0, -0.7) and female participants (-1.5, 95% CI -2.3, -0.6) with a reported BMI classified as obese compared to participants with a reported BMI classified as healthy weight. There was also a higher score for 'monitoring' reported by family members/carers of young adult males with a reported BMI classified as obese compared to males with a reported BMI classified as healthy weight (-0.7, 95% CI -1.3, -0.2) but this was not observed in females. There was a higher score for 'restriction' reported by family members/carers of young adult participants with a reported BMI classified as obese compared to participants with a reported BMI classified as healthy weight (-0.5, 95% CI -0.9, -0.1) but this was not observed within individual sexes.

Table 3.21 Child Feeding Questionnaire factors by reported BMI category* for young adults in the 2011 Down syndrome NOW wave

	Child Feeding Questionnaire factor means									
Male	**Healthy weight**		**Overweight**		**Obese**		**Total**		$F_{2,68}$	***P* value^**
	n	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**		
Responsibility	28	4.1 ± 0.8	21	4.0 ± 0.6	22	4.2 ± 0.7	71	4.1 ± 0.7	0.19	0.825
Concern	28	2.4 ± 1.2[a]	21	2.9 ± 1.3[a,c]	22	3.8 ± 1.1[b,c]	71	3.0 ± 1.3	8.39	0.001[#]
Restriction	28	2.9 ± 1.1	21	3.1 ± 1.0	22	3.4 ± 1.1	71	3.1 ± 1.1	1.26	0.294
Pressure	28	1.8 ± 1.0	21	1.8 ± 0.8	22	1.9 ± 0.7	71	1.8 ± 0.8	0.11	0.893
Monitoring	28	3.5 ± 1.1[a]	21	4.0 ± 0.8[a,c]	21	4.3 ± 0.7[b,c]	70	3.9 ± 1.0	3.98	0.026[#]
Female	**Healthy weight**		**Overweight**		**Obese**		**Total**		$F_{2,62}$	***P* value^**
	n	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**		
Responsibility	11	4.3 ± 0.6	18	3.8 ± 1.1	36	4.0 ± 1.0	65	4.0 ± 0.9	1.12	0.339
Concern	11	2.8 ± 1.2[a]	18	3.7 ± 1.2[a,c]	36	4.3 ± 1.0[b,c]	65	3.8 ± 1.2	7.50	0.003[#]
Restriction	11	3.3 ± 0.8	18	3.4 ± 0.9	36	3.6 ± 0.7	65	3.5 ± 0.7	1.18	0.325
Pressure	11	1.7 ± 1.0	18	1.5 ± 0.9	36	1.6 ± 0.9	65	1.6 ± 0.9	0.11	0.894
Monitoring	11	4.1 ± 0.9	18	3.9 ± 1.2	36	4.2 ± 0.9	65	4.1 ± 1.0	0.70	0.505
Total	**Healthy weight**		**Overweight**		**Obese**		**Total**		$F_{2,133}$	***P* value^**
	n	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**		
Responsibility	39	4.2 ± 0.7	39	3.9 ± 0.9	58	4.1 ± 0.9	136	4.1 ± 0.8	0.88	0.420
Concern	39	2.5 ± 1.2[a]	39	3.3 ± 1.3[b]	58	4.1 ± 1.1[c]	136	3.4 ± 1.3	21.82	<0.001[#]
Restriction	39	3.0 ± 1.0[a]	39	3.2 ± 0.9[a,c]	58	3.5 ± 0.9[b,c]	136	3.3 ± 1.0	3.90	0.024[#]
Pressure	39	1.7 ± 1.0	39	1.7 ± 0.9	58	1.7 ± 0.8	136	1.7 ± 0.9	0.04	0.958
Monitoring	39	3.7 ± 1.1[a]	39	3.9 ± 1.0[a,c]	57	4.3 ± 0.8[b,c]	135	4.0 ± 1.0	4.13	0.020[#]

SD=standard deviation
*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Welch's ANOVA *P* value
[a, b, c] means sharing the same superscript do not differ significantly by a Games-Howell post hoc test
[#]*P*<0.05

Table 3.22 Differences in Child Feeding Questionnaire scores between young adults 2011 Down syndrome NOW wave with a reported BMI* classified as healthy weight or obese

		Healthy weight		Obese		
Male	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**Difference in means (95% CI) [healthy weight v. obese]**	***P* value^**
Responsibility	28	4.1 ± 0.8	22	4.2 ± 0.7	-0.0 (-0.5, 0.4)	0.835
Concern	28	2.4 ± 1.2	22	3.8 ± 1.1	-1.4 (-2.0, -0.7)	<0.001#
Restriction	28	2.9 ± 1.1	22	3.4 ± 1.1	-0.5 (-1.1, 0.1)	0.117
Pressure	28	1.8 ± 1.0	22	1.9 ± 0.7	-0.1 (-0.6, 0.4)	0.638
Monitoring	28	3.5 ± 1.1	21	4.3 ± 0.7	-0.7 (-1.3, -0.2)	0.007#
Female						
Responsibility	11	4.3 ± 0.6	36	4.0 ± 1.0	0.2 (-0.3, 0.7)	0.380
Concern	11	2.8 ± 1.2	36	4.3 ± 1.0	-1.5 (-2.3, -0.6)	0.002#
Restriction	11	3.3 ± 0.8	36	3.6 ± 0.7	-0.4 (-0.9, 0.2)	0.195
Pressure	11	1.7 ± 1.0	36	1.6 ± 0.9	0.1 (-0.6, 0.8)	0.766
Monitoring	11	4.1 ± 0.9	36	4.2 ± 0.9	-0.1 (-0.8, 0.5)	0.689
Total						
Responsibility	39	4.2 ± 0.7	58	4.1 ± 0.9	0.1 (-0.3, 0.4)	0.674
Concern	39	2.5 ± 1.2	58	4.1 ± 1.1	-1.6 (-2.0, -1.1)	<0.001#
Restriction	39	3.0 ± 1.0	58	3.5 ± 0.9	-0.5 (-0.9, -0.1)	0.008#
Pressure	39	1.7 ± 1.0	58	1.7 ± 0.8	0.1 (-0.3, 0.4)	0.782
Monitoring	39	3.7 ± 1.1	57	4.3 ± 0.8	-0.6 (-1.0, -0.1)	0.008#

SD=standard deviation; CI=confidence interval
*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Two-tailed, independent samples t-test *P* value
#*P*<0.05

3.3.5 Food and physical activity behaviours of adolescents and young adults with Down syndrome

Tables 3.23, 3.24, 3.25, 3.26, 3.27 and Figure 3.2 present data from the Down syndrome NOW 2011 questionnaire and the PANDs study questionnaire. Table 3.23 shows how many participants from both studies completed the questions 'how often does your son/daughter eat fast foods', 'which describes how your son/daughter eats their main meal of the day', the 'preparing food' question from the Index of Social Competency questionnaire section and 'on how many of the last 7 days was your son/daughter physically active for 60 minutes or more'.

Table 3.23 Completion of food and physical activity behaviour questions

	Down syndrome NOW 2011 n=197				PANDs study n=21			
Question	**Completed**		**Missing**		**Completed**		**Missing**	
	n	**row %**	**n**	**row %**	**n**	**row %**	**n**	**row %**
Fast food consumption frequency	185	93.9	12	6.1	21	100	0	0
Main meal setting	186	94.4	11	5.6	21	100	0	0
Food preparation skills	196	99.5	1	0.5	21	100	0	0
Number of days physically active for ≥60 minutes	183	92.9	14	7.1	21	100	0	0

Most adolescent and young adult participants in the 2011 Down syndrome NOW and PANDs studies consumed fast food once or less than once a week (47.1%, 97/206) with the second most frequent response being once or less than once a month (21.8%, 45/206) (see Table 3.24). No participant consumed fast food daily and few consumed fast food 4-6 times per week. A quarter of young males (28/112) and 16.0% (15/94) of young females consumed fast food at least two to three times per week (see Table 3.24).

Most adolescent and young adult participants (84.6%, 175/207) consumed their main meal of the day at the dining table, mostly with other people. The 'other setting' responses included 'in the participant's bedroom' and 'at the computer' (see Table 3.25).

As shown in Table 3.26, 10.1% (22/217) of adolescents and young adults were able to prepare a variety of meals without supervision, 21.7% (47/217) of adolescents and young adults could prepare simple hot food (eggs, warm soup) and a further 30.9% (67/217) could prepare cold foods without supervision (cereal, sandwiches). Slightly more than a quarter (26.7%, 58/217) of adolescents and young adults could prepare simple foods with supervision and 10.6% (23/217) needed all food prepared.

Table 3.24 Fast food consumption frequency of adolescents and young adults with Down syndrome

Fast food frequency	**Adolescent**		**Young adult**		**Total**	
Male	**n**	**col %**	**n**	**col %**	**n**	**col %**
4-6 times per week	0	0	2	2.0	2	1.8
2-3 times per week	3	25.0	23	23.0	26	23.2
Once or less than once per week	7	58.3	46	46.0	53	47.3
Twice a month	1	8.3	9	9.0	10	8.9
Once or less than once per month	1	8.3	20	20.0	21	18.8
Total	12	100	100	100	112	100
Female	**n**	**col %**	**n**	**col %**	**n**	**col %**
4-6 times per week	0	0	0	0	0	0
2-3 times per week	2	16.7	13	15.9	15	16.0
Once or less than once per week	5	41.7	39	47.6	44	46.8
Twice a month	0	0	11	13.4	11	11.7
Once or less than once per month	5	41.7	19	23.2	24	25.5
Total	12	100	82	100	94	100
Total	**n**	**col %**	**n**	**col %**	**n**	**col %**
4-6 times per week	0	0	2	1.1	2	1.0
2-3 times per week	5	20.8	36	19.8	41	19.9
Once or less than once per week	12	50.0	85	46.7	97	47.1
Twice a month	1	4.2	20	11.0	21	10.2
Once or less than once per month	6	25.0	39	21.4	45	21.8
Total	24	100	182	100	206	100

col=column

Table 3.25 Main meal consumption setting of adolescents and young adults with Down syndrome

Main meal setting	**Adolescent**		**Young adult**		**Total**	
Male	**n**	**col %**	**n**	**col %**	**n**	**col %**
Eating alone at dining table	0	0	2	2.0	2	1.8
Eating with others at dining table	10	90.9	84	83.2	94	83.9
Eating alone on couch	0	0	5	5.0	5	4.5
Eating with others on couch	0	0	6	5.9	6	5.4
Other	1	9.1	4	4.0	4	4.5
Total	11	100	101	100	112	100
Female	**n**	**col %**	**n**	**col %**	**n**	**col %**
Eating alone at dining table	0	0	6	6.2	6	6.3
Eating with others at dining table	10	83.3	63	75.9	73	76.8
Eating alone on couch	0	0	5	6.0	5	5.3
Eating with others on couch	1	8.3	7	8.4	8	8.4
Other	1	8.3	2	2.4	3	3.2
Total	12	100	83	100	95	100
Total	**n**	**col %**	**n**	**col %**	**n**	**col %**
Eating alone at dining table	0	0	8	4.3	8	3.9
Eating with others at dining table	20	87.0	147	79.9	167	80.7
Eating alone on couch	0	0	10	5.4	10	4.8
Eating with others on couch	1	4.3	13	7.1	14	6.8
Other	2	8.7	6	3.3	8	3.9
Total	23	100	184	100	207	100

col=column

Table 3.26 Food preparation skills of adolescents and young adults with Down syndrome

Food Preparation Skill Level	**Adolescent**		**Young adult**		**Total**	
Male	**n**	**col %**	**n**	**col %**	**n**	**col %**
Can prepare an adequate variety of meals without supervision	1	8.3	14	13.1	15	12.6
Simple hot food without supervision	4	33.3	23	21.5	27	22.7
Simple cold food without supervision	3	25.0	34	31.8	37	31.1
Simple foods with supervision	4	33.3	26	24.3	30	25.2
Needs all food prepared	0	0	10	9.3	10	8.4
Total	12	100	107	100	119	100
Female	**n**	**col %**	**n**	**col %**	**n**	**col %**
Can prepare an adequate variety of meals without supervision	1	8.3	6	7.0	7	7.1
Simple hot food without supervision	2	16.7	18	20.9	20	20.4
Simple cold food without supervision	7	58.3	23	26.7	30	30.6
Simple foods with supervision	1	8.3	27	31.4	28	28.6
Needs all food prepared	1	8.3	12	14.0	13	13.3
Total	12	100	86	100	98	100
Total	**n**	**col %**	**n**	**col %**	**n**	**col %**
Can prepare an adequate variety of meals without supervision	2	8.3	20	10.4	22	10.1
Simple hot food without supervision	6	25.0	41	21.2	47	21.7
Simple cold food without supervision	10	41.7	57	29.5	67	30.9
Simple foods with supervision	5	20.8	53	27.5	58	26.7
Needs all food prepared	1	4.2	22	11.4	23	10.6
Total	24	100	193	100	217	100

col=column

As shown in Table 3.27, 30.4% (62/204) of adolescents and young adults were active for 60 minutes or more on 3-4 days prior to the survey. Less than 7% (6.9%, 14/204) of participants were not active for 60 minutes for any days in the week prior to completing the survey.

Walk/ride to and from school (62.5%, 15/24), swimming (58.3%, 14/24), physical education class (58.3%, 14/24), dancing (37.5%, 9/24) and housework (37.5%, 9/24) were the most popular forms of physical activity for adolescents in the week prior to the survey. For young adults the most popular forms of physical activity in the week prior to the survey were walk/ride to and from school (52.6%, 102/194), housework (42.3%, 82/194), dancing (41.8%, 81/194) and swimming (35.6% 69/194) (see Table 3.28). Overall the most popular forms of physical activity in the week prior to the survey were walk/ride to and from school (53.7%, 117/218), housework (41.7% 91/218), dancing (41.3% 90/218) and swimming (38.1%, 83/218) (see Table 3.28 and Figure 3.2). In the 'other' category the most frequently cited forms of physical activity included bowling (which is represented separately in Table 3.28 and Figure 3.2), gardening, trampoline, golf and football.

Table 3.27 Number of days in the previous week adolescents and young adults with Down syndrome were physically active for 60 minutes or more

Number of days physically active	**Adolescent**		**Young adult**		**Total**	
Male	**n**	**col %**	**n**	**col %**	**n**	**col %**
0	0	0	5	5.1	5	4.5
1-2	5	41.7	24	24.2	29	26.1
3-4	2	16.7	24	24.2	26	23.4
5-6	2	16.7	24	24.2	26	23.4
7	3	25.0	22	22.2	25	22.5
Total	12	100	99	100	111	100
Female	**n**	**col %**	**n**	**col %**	**n**	**col %**
0	1	8.3	8	9.9	9	9.7
1-2	2	16.7	19	23.5	21	22.6
3-4	3	25.0	33	40.7	36	38.7
5-6	4	33.3	13	16.0	17	18.3
7	2	16.7	8	9.9	10	10.8
Total	12	100	81	100	93	100
Total	**n**	**col %**	**n**	**col %**	**n**	**col %**
0	1	4.2	13	7.2	14	6.9
1-2	7	29.2	43	23.9	50	24.5
3-4	5	20.8	57	31.7	62	30.4
5-6	6	25.0	37	20.6	43	21.1
7	5	20.8	30	16.7	35	17.2
Total	24	100	180	100	204	100

col=column

Table 3.28 Types of physical activity participated in by adolescents and young adults with Down syndrome in the week prior to the survey

Physical Activity	**Adolescent n=24**	**col %**	**Young adult n=194**	**col %**	**Male n=119**	**col %**	**Female n=99**	**col %**	**Total n=218**	**col %**
Jogging/Running	3	12.5	16	8.2	11	9.2	8	8.0	19	8.7
Swimming	14	58.3	69	35.6	44	37.0	39	39.4	83	38.1
Gym	5	20.8	53	27.3	38	31.9	20	20.2	58	26.6
Dancing	9	37.5	81	41.8	39	32.8	51	51.5	90	41.3
Basketball	6	25.0	21	10.8	20	16.8	7	7.1	27	12.4
Netball	1	4.2	1	0.5	0	0.0	2	2.0	2	0.9
Movement video games	3	12.5.	27	13.9	19	16.0	11	11.1	30	13.8
Bike riding	6	25.0	25	12.9	23	19.3	8	8.1	31	14.2
Play with pets	5	20.8	42	21.6	30	25.2	17	17.2	47	21.6
Physical education class	14	58.3	9	4.6	16	13.4	7	7.1	23	10.6
Walk/ride to and from school*	15	62.5	102	52.6	60	50.4	57	57.6	117	53.7
Housework	9	37.5	82	42.3	47	39.5	44	44.4	91	41.7
Bowling	1	4.2	18	9.3	9	7.6	10	10.1	19	8.7
Other	5	20.8	45	23.2	32	26.9	18	18.2	50	22.9

col=column

*Walk/ride to school included other walking

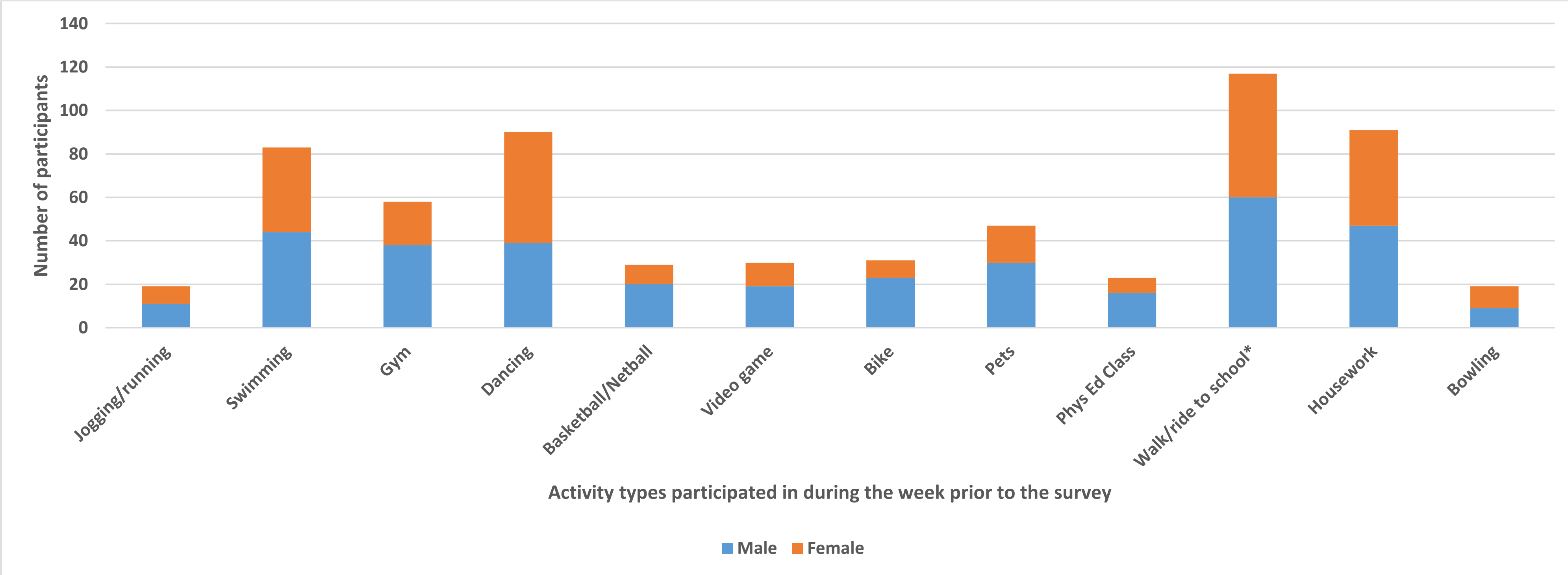


Figure 3.2 Activity participation by adolescents and young adults with Down syndrome in the week prior to the survey

*Walk/ride to school included other walking

3.3.5.1 Relationships between BMI, food and physical activity behaviours

In the Down syndrome NOW 2011 questionnaire, reported BMI was available for 143 participants. Of these participants, more than 94% had a response recorded for the food and physical activity behaviour questions (see Table 3.29).

Table 3.29 Completion of food and physical activity behaviour questions

	Down syndrome NOW 2011 with valid BMI n=143			
Question	**Completed**		**Missing**	
	n	**row %**	**n**	**row %**
Fast Food consumption frequency	138	96.5	5	3.5
Main meal setting	138	96.5	5	3.5
Food preparation skills	143	100	0	0.0
Number of days physically active for ≥60 minutes	135	94.4	8	5.6

Tables 3.30 to 3.37 present the relationships between reported BMI, food and physical activity data from the Down syndrome NOW 2011 questionnaire. Due to reasons discussed in 3.3.5 data of young adults classified as underweight (n=3) were included with the data of young adults classified as healthy weight.

Higher reported BMI was observed in young adult females who consumed fast food more than once a week compared to those who consumed fast food less than or equal to once a week (8.2, 95% CI 0.6,15.8). However, in young adult males or young adults as a whole the mean reported BMIs were similar (see Table 3.30). As shown in Table 3.31 all young adult females with a reported BMI in the healthy weight category (100%, 11/11) consumed fast food once or less a week whereas 0% (0/12) and 75.0% (9/12) of females who consumed fast food more than once a week had a reported BMI classified as healthy weight and obese respectively (P=0.040).

For young adults as a whole, compared to not eating at the dining table with others category, individuals who ate at the dining table with others had a lower mean reported BMI (-4.6, 95% CI -8.3, -1.0), but this was not observed with young adult males or females separately (see Table 3.32). As shown in Table 3.33, 72.2% (13/18) of young adult females who did not eat their main meal at the dining table with others had a reported BMI classified as obese compared with none of the young adult females with a reported BMI classified as healthy weight (P=0.019).

As shown in Table 3.34 food preparation without supervision was associated with higher reported BMI in the total cohort (3.0, 95% CI 0.5, 5.4). In young adult males, 82.6% (19/23) with a reported BMI classified as obese were able to prepare simple food without supervision (p=0.041) compared to 58.1% (18/31) of young adult males with a reported BMI classified as healthy weight (see Table 3.35). Additionally, 41.9% (13/31) of males with a reported BMI classified as healthy weight required support to prepare simple or all food compared to 17.4% (4/23) of males with a reported BMI classified as obese.

There was no discernible relationship between reported BMI (either as a continuous or categorical variable) and the number of days physically active for 60 minutes or more for male and female young adults with Down syndrome in the week prior to the survey (see Tables 3.36 and 3.37 in Appendix F).

Table 3.30 Mean reported BMI and fast food consumption frequency of participants in the Down syndrome NOW 2011 wave

	BMI						Difference in means [more than once a week vs. once a week or less]					
	Male		Female		Total		Male		Female		Total	
Fast food frequency	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**
≤ once a week	51	27.6 ± 5.5	54	30.7 ± 6.8	105	29.2 ± 6.4	-0.7 (-3.5,2.2)	0.634	8.2 (0.6,15.8)	0.036[#]	2.1 (-1.6, 5.8)	0.262
> once a week	21	26.9 ± 5.3	12	38.9 ± 11.7	33	31.3 ± 10.0						
Total	72	27.4 ± 5.4	66	32.2 ± 8.4	138	29.7 ± 7.4						

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
[#]*P*<0.05

Table 3.31 Fast food consumption frequency of participants in the Down syndrome NOW 2011 wave by reported BMI category

	BMI category*					
Fast Food Consumption	**Healthy weight**	**Overweight**	**Obese**	**Total**	**T^c^**	***P* value^**
Male					-0.94	0.349
Once a week or less (n)	18	17	16	51		
% within frequency category	35.3	33.3	31.4	100		
% within BMI category	62.1	81.0	72.7	70.8		
More than once a week (n)	11	4	6	21		
% within frequency category	52.4	19.0	28.6	100		
% within BMI category	37.9	19.0	27.3	29.2		
Total (n)	29	21	22	72		
% within frequency category	40.3	29.2	30.6	100		
% within BMI category	100	100	100	100		
Female					2.05	0.040#
Once a week or less (n)	11	15	28	54		
% within frequency category	20.4	27.8	51.9	100		
% within BMI category	100	83.3	75.7	81.8		
More than once a week (n)	0	3	9	12		
% within frequency category	0	25.0	75.0	100		
% within BMI category	0	16.7	24.3	18.2		
Total (n)	11	18	37	66		
% within frequency category	16.7	27.3	56.1	100		
% within BMI category	100	100	100	100		
Total					-0.07	0.946
Once a week or less (n)	29	32	44	105		
% within frequency category	27.6	30.5	41.9	100		
% within BMI category	72.5	82.1	74.6	76.1		
More than once a week (n)	11	7	15	33		
% within frequency category	33.3	21.2	45.5	100		
% within BMI category	27.5	17.9	25.4	23.9		
Total (n)	40	39	59	138		
% within frequency category	29.0	28.3	42.8	100		
% within BMI category	100	100	100	100		

*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Kendall's tau-c *P* value
#*P*<0.05

Table 3.32 Mean reported BMI and main meal consumption setting of participants in the Down syndrome NOW 2011 wave

	BMI						Difference in means [at the dining table with others vs. not at the dining table with others]					
	Male		Female		Total		Male		Female		Total	
Main meal consumption setting	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**Difference (95% CI)**	***P* value^**	**Mean difference (95% CI)**	***P* value^**	**Mean difference (95% CI)**	***P* value^**
At the dining table with others	60	27.0 ± 5.3	48	30.7 ± 7.2	108	28.6 ± 6.4	-2.3 (-6.3, 1.7)	0.240	-5.2 (-10.7, 0.2)	0.059	-4.6 (-8.3, -1.0)	0.015[#]
Not at the dining table with others	12	29.3 ± 6.0	18	36.0 ± 10.3	30	33.3 ± 9.4						
Total	72	27.4 ± 5.4	66	32.2 ± 8.4	138	29.7 ± 7.4						

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
[#]*P*<0.05

Table 3.33 Main meal consumption setting of participants in the Down syndrome NOW 2011 wave by reported BMI category

	BMI category*					
Main meal setting	**Healthy**	**Overweight**	**Obese**	**Total**	**T^c**	***P* value^**
Male					1.06	0.287
Dining table with others (n)	25	19	16	60		
% within main meal setting category	41.7	31.7	26.7	100		
% within BMI category	86.2	90.5	72.7	83.3		
Not dining table with other (n)	4	2	6	12		
% within main meal setting category	33.3	16.7	50.0	100		
% within BMI category	13.8	9.5	27.3	16.7		
Total (n)	29	21	22	72		
% within main meal setting category	40.3	29.2	30.6	100		
% within BMI category	100	100	100	100		
Female					2.36	0.019#
Dining table with others (n)	11	13	24	48		
% within main meal setting category	22.9	27.1	50.0	100		
% within BMI category	100	72.2	64.9	72.7		
Not dining table with other (n)	0	5	13	18		
% within main meal setting category	0	27.8	72.2	100		
% within BMI category	0	27.8	35.1	27.3		
Total (n)	11	18	37	66		
% within main meal setting category	16.7	27.3	56.1	100		
% within BMI category	100	100	100	100		
Total					2.85	0.004#
Dining table with others (n)	36	32	40	108		
% within main meal setting category	33.3	29.6	37.0	100		
% within BMI category	90.0	82.1	67.8	78.3		
Not dining table with other (n)	4	7	19	30		
% within main meal setting category	13.3	23.3	63.3	100		
% within BMI category	10.0	17.9	32.2	21.7		
Total (n)	40	39	59	138		
% within main meal setting category	29.0	28.3	42.8	100		
% within BMI category	100	100	100	100		

*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Kendall's tau-c *P* value
#$P<0.05$

Table 3.34 Mean reported BMI and food preparation skills of participants in the Down syndrome NOW 2011 wave

	BMI						Difference in means [without supervision vs with supervision/support]					
	Male		Female		Total		Male		Female		Total	
Food preparation skills	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**
Can prepare food without supervision	52	28.1 ± 5.2	51	32.9 ± 9.3	103	30.5 ± 7.8	2.6 (-0.2, 5.3)	0.068	2.7 (-1.1, 6.6)	0.163	3.0 (0.5, 5.4)	0.018[#]
Requires supervision/ support	23	25.6 ± 5.5	17	30.2 ± 5.8	40	27.5 ± 6.0						
Total	75	27.3 ± 5.4	68	32.2 ± 8.6	143	29.7 ± 7.5						

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
[#]*P*<0.05

Table 3.35 Food preparation skills of participants in the Down syndrome NOW 2011 wave by reported BMI category

	BMI category*					
Food preparation skills	**Healthy weight**	**Overweight**	**Obese**	**Total**	**T^c**	***P value^***
Male					-2.04	0.041#
Without supervision (n)	18	15	19	52		
% within food preparation category	34.6	28.8	36.5	100		
% within BMI category	58.1	71.4	82.6	69.3		
Requires supervision/support (n)	13	6	4	23		
% within food preparation category	56.5	26.1	17.4	100		
% within BMI category	41.9	28.6	17.4	30.7		
Total (n)	31	21	23	75		
% within food preparation category	41.3	28.0	30.7	100		
% within BMI category	100	100	100	100		
Female					-0.22	0.823
Without supervision (n)	9	13	29	51		
% within food preparation category	17.6	25.5	56.9	100		
% within BMI category	75.0	72.2	76.3	75.0		
Requires supervision/support (n)	3	5	9	17		
% within food preparation category	17.6	29.4	52.9	100		
% within BMI category	25.0	27.8	23.7	25.0		
Total (n)	12	18	38	68		
% within food preparation category	17.6	26.5	55.9	100		
% within BMI category	100	100	100	100		
Total					-1.76	0.078
Without supervision (n)	27	28	48	103		
% within food preparation category	26.2	27.2	46.6	100		
% within BMI category	62.8	71.8	78.7	72.0		
Requires supervision/support (n)	16	11	13	40		
% within food preparation category	40.0	27.5	32.5	100		
% within BMI category	37.2	28.2	21.3	28.0		
Total (n)	43	39	61	143		
% within food preparation category	30.1	27.3	42.7	100		
% within BMI category	100	100	100	100		

*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Kendall's tau-c *P* value
#*P*<0.05

3.3.6 Relationships between reported BMI, impact of illness, level of functioning, accommodation, friendships, family financial stress and income

In the Down syndrome NOW 2011 questionnaire, reported BMI was available for 143 participants. Of these participants, more than 90% had a response recorded for the impact of illness, level of functioning, accommodation, friendships, family financial stress and income questions (see Table 3.38).

Table 3.38 Completion of impact of illness, functioning, accommodation, friendships and financial questions

	Down syndrome NOW 2011 with valid BMI n=143			
Question	**Completed**		**Missing**	
	n	**row %**	**n**	**row %**
Impact of illness	143	100	0	0
Level of functioning	143	100	0	0
Accommodation	137	95.8	6	4.2
Friendships	142	99.3	1	0.7
Financial stress	138	96.5	5	3.5
Family income	130	90.9	13	9.1

Tables 3.39 to 3.50 present the relationships between reported BMI, impact of illness, level of functioning, accommodation, friendships, family financial stress and income data from the Down syndrome NOW 2011 questionnaire. Due to reasons discussed in 3.3.5 data of young adults classified as underweight (n=3) were included with the data of young adults classified as healthy weight.

There was no apparent relationship between the impact of illness and reported BMI, either as a continuous or categorical variable for young adult males or females (see Tables 3.39 and 3.40 in Appendix F).

There was no strong rank order relationship between the level of function as measured using the Index of Social Competence and reported BMI. The positive rank order correlation between community skills and reported BMI was weak (rho=0.172, P=0.040) and the level of significance may be due to the larger sample size (Portney & Watkins, 2009) (see Table 3.41). There was no relationship between reported BMI categories and either the factors or total score for the Index of Social Competence for males, females or the cohort as a whole (see Table 3.42).

Mean reported BMI for young adults living in the family home was lower compared to the mean reported BMI of those not living in the family home (-4.2, 95% CI -8.2, -0.07, *P*=0.046) (see Table 3.43). There was also a relationship between reported BMI categories and accommodation for young adult females with 100% of young adult females with a reported BMI classified as healthy weight (11/11) living in the family home compared with none who did not live in the family home (*P*=0.002). Additionally 90.9% of young adult females who did not live in the family home (10/11) had a reported BMI classified as obese as compared to 50.0% (27/54) of young women who lived in the family home (see Table 3.44).

There was no apparent relationship between the number of friendships and reported BMI, either as a continuous or categorical variable for young adult males or females (see Tables 3.45 and 3.46 in Appendix F). Similarly, there was no notable relationship between family financial stress and reported BMI (see Tables 3.47 and 3.48 in Appendix F).

As shown in Table 3.49, for young adults there was a relationship between family income level and reported BMI with a higher level of income associated with lower reported BMI (-3.1, 95% CI -6.0, -0.26, *P*=0.033). This was also observed when using standard BMI categories with 67.6% (25/37) of participants with a reported BMI classified as healthy weight having a family income ≥$52,000 compared to the lower income group (32.4%, 12/37) (*P*=0.043) (see Table 3.50). This relationship was not observed for separate sexes.

Table 3.51 presents the univariate and multivariate linear regressions for the relationships between reported BMI and sex, fast food consumption frequency, main meal setting, food preparation skills, accommodation and family income as binary variables for young adults in the Down syndrome NOW 2011 study. Although there was no univariate association between reported BMI and fast food consumption frequency, being female, not eating at the dining table with others, being able to prepare food without supervision, not living in the family home and having a family income less than $52,000 were associated with a higher reported BMI. In the multiple regression model a higher reported BMI was associated with being female, being able to prepare food without supervision and having a family income less than $52,000.

Table 3.41 Relationship between Index of Social Competence factor scores and reported BMI for participants in the Down syndrome NOW 2011 wave

	Male n=75		**Female n=68**		**Total n=143**	
Index of Social Competence factor	**rho**	***P* value**	**rho**	***P* value**	**rho**	***P* value**
Communication skills	0.043	0.712	0.160	0.193	0.148	0.078
Self-care skills	0.157	0.178	0.069	0.577	0.150	0.075
Community skills	0.074	0.525	0.212	0.082	0.172	0.040#
Total score	0.099	0.397	0.153	0.214	0.173	0.039#

rho=Spearman's rank correlation coefficient
#$P<0.05$

Table 3.42 Differences in the means of Index of Social Competence factor scores by reported BMI category* for young adults in the Down syndrome NOW 2011 wave

	Index of Social Competence factor means									
Male	**Healthy weight**		**Overweight**		**Obese**		**Total**		**$F_{2,72}$**	***P* value^**
	n	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**		
Communication skills	31	5.4 ± 1.6	21	5.6 ± 1.1	23	5.5 ± 1.7	75	5.5 ± 1.5	0.18	0.838
Self-care skills	31	19.0 ± 4.7	21	19.4 ± 2.8	23	20.7 ± 4.4	75	19.6 ± 4.2	1.00	0.375
Community skills	31	10.2 ± 4.3	21	10.1 ± 3.4	23	11.1 ± 3.8	75	10.5 ± 3.9	0.50	0.608
Total score	31	34.6 ± 9.6	21	35.1 ± 6.2	23	37.4 ± 8.9	75	35.6 ± 8.5	0.68	0.511
Female	**Healthy weight**		**Overweight**		**Obese**		**Total**		**$F_{2,65}$**	***P* value^**
	n	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**		
Communication skills	12	5.6 ± 2.0	18	6.0 ± 1.0	38	6.1 ± 1.3	68	6.0 ± 1.4	0.35	0.705
Self-care skills	12	20.0 ± 5.2	18	20.7 ± 3.2	38	20.8 ± 3.3	68	20.6 ± 3.6	0.12	0.889
Community skills	12	11.7 ± 4.8	18	11.5 ± 3.9	38	12.6 ± 4.5	68	12.1 ± 4.4	0.49	0.620
Total score	12	37.3 ± 11.7	18	38.2 ± 7.2	38	39.5 ± 8.0	68	38.8 ± 8.5	0.29	0.749
Total	**Healthy weight**		**Overweight**		**Obese**		**Total**		**$F_{2,141}$**	***P* value^**
	n	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**		
Communication skills	43	5.4 ± 1.7	39	5.8 ± 1.1	61	5.9 ± 1.5	143	5.7 ± 1.5	1.09	0.342
Self-care skills	43	19.3 ± 4.8	39	20.0 ± 3.0	61	20.8 ± 3.7	143	20.1 ± 4.0	1.52	0.225
Community skills	43	10.6 ± 4.4	39	10.7 ± 3.7	61	12.0 ± 4.3	143	11.3 ± 4.2	1.80	0.171
Total score	43	35.3 ± 10.2	39	36.6 ± 6.8	61	38.7 ± 8.3	143	37.1 ± 8.6	1.87	0.161

SD=standard deviation
*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Welch's ANOVA P value
#*P*<0.05

Table 3.43 Mean reported BMI and accommodation of participants in the Down syndrome NOW 2011 wave

	BMI						Difference in means [in the family home vs not in the family home]					
	Male		Female		Total		Male		Female		Total	
Accommodation	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**
In the family home	64	26.9 ± 5.0	54	31.7 ± 8.8	118	29.1 ± 7.4	-2.6 (-9.3, 4.1)	0.400	-4.3 (-9.6, 1.0)	0.105	-4.2 (-8.2, -0.07)	0.046[#]
Not in the family home	8	29.5 ± 8.0	11	36.0 ± 7.3	19	33.3 ± 8.1						
Total	72	27.2 ± 5.4	65	32.4 ± 8.7	137	29.7 ± 7.6						

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
[#]$P<0.05$

Table 3.44 Accommodation type of participants in the Down syndrome NOW 2011 wave by reported BMI category*

Accommodation	BMI Category: Healthy weight	Overweight	Obese	Total	T^c	*P* value^
Male					0.42	0.676
In the family home (n)	27	19	18	64		
% within accommodation category	42.2	29.7	28.1	100		
% within BMI category	90.0	90.5	85.7	88.9		
Not in the family home (n)	3	2	3	8		
% within accommodation category	37.5	25.0	37.5	100		
% within BMI category	10.0	9.5	14.3	11.1		
Total (n)	30	21	21	72		
% within accommodation category	41.7	29.2	29.2	100		
% within BMI category	100	100	100	100		
Female					3.14	0.002#
In the family home (n)	11	16	27	54		
% within accommodation category	20.4	29.6	50.0	100		
% within BMI category	100	94.1	73.0	83.1		
Not in the family home (n)	0	1	10	11		
% within accommodation category	0.0	9.1	90.9	100		
% within BMI category	0.0	5.9	27.0	16.9		
Total (n)	11	17	37	65		
% within accommodation category	16.9	26.2	56.9	100		
% within BMI category	100	100	100	100		
Total					2.30	0.022#
In the family home (n)	38	35	45	118		
% within accommodation category	32.2	29.7	38.1	100		
% within BMI category	92.7	92.1	77.6	86.1		
Not in the family home (n)	3	3	13	19		
% within accommodation category	15.8	15.8	68.4	100		
% within BMI category	7.3	7.9	22.4	13.9		
Total (n)	41	38	58	137		
% within accommodation category	29.9	27.7	42.3	100		
% within BMI category	100	100	100	100		

*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Kendall's tau-c *P* value
#*P*<0.05

Table 3.49 Mean reported BMI and annual family income of participants in the Down syndrome NOW 2011 wave

	BMI						Difference in means [higher income vs lower income]					
	Male		Female		Total		Male		Female		Total	
Income	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**
≥$52,000	46	27.0 ± 5.0	37	30.3 ± 6.6	83	28.5 ± 6.0	-1.5 (-4.4, 1.4)	0.313	-4.9 (-9.8, 0.04)	0.052	-3.1 (-6.0, -0.3)	0.033[#]
<$52,000	25	28.5 ± 6.2	22	35.2 ± 10.1	47	31.6 ± 8.8						
Total	71	27.6 ± 5.4	59	32.1 ± 8.4	130	29.6 ± 7.3						

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
[#]*P*<0.05

Table 3.50 Family income of participants in the Down syndrome NOW 2011 wave by reported BMI category*

	BMI Category					
Family income	**Healthy weight**	**Overweight**	**Obese**	**Total**	**T^c**	***P* value^**
Male					1.21	0.228
≥$52,000 per annum (n)	18	17	11	46		
% within income category	39.1	37.0	23.9	100		
% within BMI category	66.7	81.0	47.8	64.8		
<$52,000 per annum (n)	9	4	12	25		
% within income category	36.0	16.0	48.0	100		
% within BMI category	33.3	19.0	52.2	35.2		
Total (n)	27	21	23	71		
% within income category	38.0	29.6	32.4	100		
% within BMI category	100	100	100	100		
Female					1.67	0.096
≥$52,000 per annum (n)	7	12	18	37		
% within income category	18.9	32.4	48.6	100		
% within BMI category	70.0	80.0	52.9	62.7		
< $52,000 per annum (n)	3	3	16	22		
% within income category	13.6	13.6	72.7	100		
% within BMI category	30.0	20.0	47.1	37.3		
Total (n)	10	15	34	59		
% within income category	16.9	25.4	57.6	100		
% within BMI category	100	100	100	100		
Total					2.02	0.043#
≥$52,000 per annum (n)	25	29	29	83		
% within income category	30.1	34.9	34.9	100		
% within BMI category	67.6	80.6	50.9	63.8		
<$52,000 per annum (n)	12	7	28	47		
% within income category	25.5	14.9	59.6	100		
% within BMI category	32.4	19.4	49.1	36.2		
Total (n)	37	36	57	130		
% within income category	28.5	27.7	43.8	100		
% within BMI category	100	100	100	100		

*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Kendall's tau-c *P* value
#$P<0.05$

Table 3.51 Regression analysis of the linear association between reported BMI and sex, fast food consumption, main meal setting, food preparation skills, accommodation and family income

Variable	n	BMI Mean ± SD	Regression coefficient, unadjusted	95% CI	*P* value	Regression coefficient, adjusted	95% CI	*P* value
Sex								
Male	75	27.3 ± 5.4	Ref	Ref	Ref	Ref	Ref	Ref
Female	68	32.2 ± 8.6	4.9	2.6, 7.2	<0.001#	4.0	1.6, 6.4	0.001#
Fast food frequency								
≤ once a week	105	29.2 ± 6.4	Ref	Ref	Ref	Ref	Ref	Ref
> once a week	33	31.3 ± 10.0	2.1	-0.8, 5.0	0.156	2.3	-0.6, 5.1	0.118
Main meal setting								
At the dining table with others	108	28.6 ± 6.4	Ref	Ref	Ref	Ref	Ref	Ref
Not at the dining table with others	30	33.3 ± 9.4	4.6	1.7, 7.6	0.002#	2.9	-0.1, 5.9	0.055
Food preparation skills								
Without supervision	103	30.5 ± 7.8	Ref	Ref	Ref	Ref	Ref	Ref
Requires supervision	40	27.5 ± 6.0	-3.0	-5.7, -0.2	0.033#	-3.0	-5.6, -0.4	0.024#
Accommodation								
In the family home	118	29.1 ± 7.4	Ref	Ref	Ref	Ref	Ref	Ref
Not in the family home	19	33.3 ± 8.1	4.2	0.5, 7.8	0.026#	1.1	-2.7, 4.9	0.570
Family income								
≥$52,000	83	28.5 ± 6.0	Ref	Ref	Ref	Ref	Ref	Ref
<$52,000	47	31.6 ± 8.8	3.1	0.6, 5.7	0.017#	3.5	1.0, 6.0	0.007#

SD=standard deviation; CI=confidence interval; Ref=reference category; #*P*<0.05

3.4 Discussion

The aim of this study was to investigate the prevalence of overweight and obesity in adolescents and young adults with Down syndrome and describe the relationships between proxy-reported BMI, food and physical activity related behaviours, health, level of function, family socioeconomic status, place of residence and social networks. Using standard cut-points a high proportion of adolescents and young adults were overweight and obese, which increased over time and was greater in females than males. Family members/carers underestimated the presence of overweight/obesity in young adult males and were concerned about the weight of their young adult with Down syndrome, especially young women. Family members/carers felt responsible for their young person's food intake and engaged in restrictive and monitoring feeding behaviours which became more prevalent with increasing reported BMI. For young adults with Down syndrome there were univariate relationships between increasing reported BMI and frequency of fast food consumption, being able to prepare food without supervision, living out of home, family income and not eating with others at the dining table. There were no univariate relationships between reported BMI and physical activity, health, number of friendships or family financial stress. Multivariate analysis identified strong associations between increasing reported BMI and being female, able to prepare food without supervision and having lower family income.

Across all three waves of the Down syndrome NOW study a high proportion of adolescents and young adults with Down syndrome had a reported BMI classified as overweight and obese when applying standard BMI cut-points. In the most recent 2011 wave 70.0% of young adults had a reported BMI classified as overweight or obese. These high proportions of overweight and obesity are similar to those reported in other studies of adolescents and young adults with Down syndrome (Bertapelli et al., 2016; Havercamp et al., 2017) and are higher than those of Australian adolescents and young adults without Down syndrome (Australian Bureau of Statistics, 2015b). Although these higher proportions of overweight and obesity in adolescents and young adults with Down syndrome are concerning, the use of standard BMI cut-points to classify overweight and obesity may be contributing to an increase in proportions due to the shorter height and limb length observed in people with Down syndrome (Hatch-Stein et al., 2016).

Consistent with previous research (Jankowicz-Szymanska et al., 2013; Krause et al., 2016; Soler Marin & Xandri Graupera, 2011), the proportions of those with a reported BMI classified as overweight and obese were higher among adolescent and young adult females compared to males in all three waves of the Down syndrome NOW study, however the difference in reported BMI only reached statistical significance in the 2011 wave. In the multivariate analysis, there was a strong association between female sex and reported BMI among young adults in the Down syndrome NOW 2011 study. Higher proportions of overweight and obesity in adolescent and young adult females have also been reported in the Australian population without Down syndrome (Australian Bureau of Statistics, 2015b), highlighting young women as an important target group for intervention (Hatch-Stein et al., 2016).

This is one of the first studies to report changes in reported BMI of a cohort of young people with Down syndrome as they matured from adolescence to young adulthood. Although not significant, in both the 2004/2009 and 2004/2011 cohorts reported BMI increased over time with a greater increase observed in females. In both cohorts the relative risk of having a reported BMI classified as overweight and obese increased for both sexes, however the risk was greater for females in the 2004/2009 cohort with no differences in the ratio of relative risk in the 2004/2011 cohort. An increase in the proportion of overweight and obesity as adolescents mature to adulthood has been observed in previous research involving young people with (Miyazaki & Okumiya, 2004) and without Down syndrome (Patton et al., 2011; Zalbahar, Najman, McIntyre, & Mamun, 2017), highlighting the need for intervention and support for all adolescents as they transition to adulthood.

For adolescents and young adults with Down syndrome, as reported BMI increased so did the level of concern family members/carers felt about their young person's weight which is consistent with research involving parents of adolescents without Down syndrome (Kaur et al., 2006; Shrewsbury et al., 2012). Along with the higher proportions of overweight and obesity, the level of concern about weight was higher among family members/carers of adolescent and young adult females compared to young adult males. In their research with mothers of adolescents without Down syndrome, Shrewsbury et al. (2012) suggested that the higher level of concern for females may be due to social pressures and expectations around body size, and this may also impact on the family members/carers of young women with Down syndrome.

Although there was an underestimation of the presence of overweight/obesity in young adult males with Down syndrome (34.1% [15/44] of family members/carers perceived their young adult male with a BMI classified as overweight/obese as not overweight/obese), the result may be more a reflection of the impact of standard BMI cut-points on reported BMI classification rather than a true underestimation of overweight and obesity. Conversely there was an overestimation of overweight/obesity by family members/carers of young adult females (50.0% [6/12] of young adult females with a reported BMI not classified as overweight/obese were perceived to be overweight/obese) which could be related to the greater concern expressed about the weight of young adult females. Results may have been impacted by the small sample of young women with a reported BMI classified as not overweight/obese and the use of standard cut-points for overweight and obesity, and further research is required.

In the 2004 Down syndrome NOW questionnaire family members/carers identified behavioural factors which impacted on their adolescent and young adult maintaining a healthy weight. These included the lack of control of eating, especially when out of the home *"…diet is controlled at home, but impossible to monitor when away from home".* In the Child Feeding Questionnaire family members/carers of adolescents and young adults with Down syndrome reported higher mean scores for 'perceived responsibility' and 'monitoring' of dietary intake than 'restriction' and 'pressure to eat', with the parents of adolescents reporting a higher mean score for 'monitoring' of food intake than parents of young adults. There was no apparent relationship between the scores for 'perceived responsibility' and BMI suggesting that family members/carers felt responsible for the young person's dietary intake regardless of reported BMI. In this study, 10.1% (22/217) of adolescents and young adults could prepare an adequate variety of meals without supervision, fewer than the 71.4% of young adults without Down syndrome (n=309) who reported they could cook for themselves in an Australian study of university students enrolled in a food and nutrition unit (Thorpe, Kestin, Riddell, Keast, & McNaughton, 2013). This highlights the need for continued family member/carer support for adolescents and young adults with Down syndrome.

Similarly to parents of adolescents without Down syndrome (Kaur et al., 2006) higher scores for 'restriction' of food intake were reported by parents of young adults with higher reported BMI. Additionally, parents of young adults with a reported BMI classified as obese reported higher levels of restriction and monitoring compared to parents of young adults with a BMI classified as healthy weight, as also observed in a study of parents of children with Down syndrome (M. Polfuss et al., 2017). In their study of parents of adolescents without Down syndrome Loth, MacLehose, Fulkerson, Crow, and Neumark-Sztainer (2013) suggested that the relationship between BMI group and restrictive feeding behaviour may be bidirectional with each impacting on the other. As the direction of the relationship in this current study was not established, further research is needed.

In this current study, for young adults with Down syndrome there was no notable relationship between reported BMI and pressure to eat. This could be due to what parents have reported as a lack of self-control of food intake *"will overeat to the point of vomiting if unsupervised"* and possibly related to difficulties children with Down syndrome may experience with delayed gratification (Cuskelly, Gilmore, Glenn, & Jobling, 2016) and hyperphagia (Foerste et al., 2016).

In the 2004 Down syndrome NOW questionnaire parents reported that their young person with Down syndrome had a preference for energy dense nutrient poor foods *"…she loves eating and drinking the wrong things, e.g. fast food and soft drink".* This preference was also found in adolescents and young adults without Down syndrome, as in the 2014-15 Australian National Health Survey, 40% of energy consumed by 14-18 year olds and 35-36% of energy consumed by 19-30 year olds came from discretionary foods (Australian Bureau of Statistics, 2014). In the 2011 Down syndrome NOW and PANDs studies fast food was reported to have been consumed mostly once a week or less, however 25.0% (28/112) of males and 16.0% (15/94) of females were reported to have consumed fast food at least two to three times per week. Similar to the findings by George et al. (2011) in adolescents with intellectual disability, there was a positive univariate relationship between reported fast food consumption frequency and BMI (as a continuous variable), however in this study this was observed only for young adult females and not for young adult males. All young women with a BMI classified as healthy weight (11/11) were reported to have consumed fast food once or less a week compared to 75.7% (28/37) of young women with a BMI classified as obese. All young adult females who were reported to have consumed fast food more than once a week (12/12) had a reported BMI classified as overweight or obese. In the study by George et al. (2011) parents who reported buying fast food more frequently, as well as their adolescent children had a higher BMI, however results were not reported for individual sex and no research is available for adolescents with Down syndrome specifically.

Although most young adults with Down syndrome were reported to eat their main meal with others at the dining table, a positive univariate relationship between not eating at the dining table with others and reported BMI was observed for young adults. All young women who had a BMI classified as healthy weight (11/11) were reported to have consumed their main meal with others at the dining table, compared to 64.9% (24/37) of young adult women with a BMI classified as obese. Of the young adult females who were reported not to have consumed their main meal at the dining table with others (n=18), all had a reported BMI that was classified as overweight or obese. Authors of a large longitudinal USA study of young people without Down syndrome (n=2117) identified that eating the main meal with family in adolescence can be protective against overweight and obesity in young adulthood (Berge et al., 2015). Eating the main meal with family in adolescence was also associated in young adulthood with higher intakes of fruit and vegetables and lower intakes of soft-drink (Larson, Neumark-Sztainer, Hannan, & Story, 2007).

Over 10% (22/217) of adolescents and young adults could prepare an adequate variety of meals without supervision with a further 21.7% (41/217) able to prepare simple hot food without supervision. In a study of 322 Dutch adolescents with Down syndrome aged 16-19 years, Van Gameren-Oosterom et al. (2013) found 6.6% could prepare a simple hot meal however their sample was much younger. Van Gameren-Oosterom et al. (2013) also found that 55.5% of adolescents with Down syndrome could prepare breakfast independently and in the Down syndrome NOW and PANDs studies 62.7% (136/217) of adolescents and young adults were able to prepare simple cold foods e.g. cereal or sandwiches without supervision as a minimum. These emerging food preparation skills are a positive step towards developing independence and highlight the need to support food preparation skill development as young people transition to adulthood. Despite evidence in adolescents and young adults without Down syndrome linking food preparation behaviours with healthier food intake (Thorpe et al., 2013; Vaitkeviciute et al., 2015), for participants in the 2011 Down syndrome NOW study the ability to prepare simple foods without supervision was associated with a higher reported BMI, both in the univariate and multivariate analysis. This could possibly be due to the impact of lower nutrition knowledge/skills on foods prepared by participants, or greater opportunity to eat more if participants prepared their own food.

There appeared to be a further relationship between growing independence and reported BMI with the mean reported BMI of those not living in the family home being higher than the reported BMI of participants living in the family home. Almost all of the young adult females who lived out of the family home (10/11) had a reported BMI classified as obese, similar to the findings of a larger Scottish study of adults with intellectual disability where the odds ratio for obesity was 2.44 for females living independently (Melville et al., 2008). Living out of the family home can increase the opportunities for young adults with mild and moderate intellectual disabilities to make independent lifestyle choices (Stancliffe et al., 2011) which can translate to an increased risk of obesity, further highlighting the need for education and support (Hsieh et al., 2015).

The Australian Physical Activity Guidelines recommended that adolescents spend at least 60 minutes per day engaged in moderate to vigorous physical activity (Australian Government Department of Health, 2014). Of the adolescents in the 2011 Down syndrome NOW and PANDs studies, 25% (3/12) of males and 16.7% (2/12) of females met the time component of the Guideline for the week prior to the survey, however the intensity of the physical activity was unknown and the sample was small. Similarly in the 2004 Down syndrome NOW wave, less than 30% of children and adolescents met the Australian Physical Activity Guidelines in the week prior to the survey (Oates et al., 2011), suggesting a continued need to support increased participation in physical activity. Swimming, dancing, walking, physical education classes and housework were the most popular forms of physical activity for adolescents and young adults with Down syndrome in the 2011 Down syndrome study, similar to another study of young people with Down syndrome (S. J. Downs et al., 2013).

There was no obvious univariate relationship between reported BMI (either continuous or categorical) of adolescents and young adults with Down syndrome and the number of days physically active for at least 60 minutes in the week prior to the survey. Although one previous study which used interviews to recall data did find a positive relationship between physical activity and BMI in young adults with Down syndrome, it did not include an objective measurement of physical activity (Jobling et al., 2006). The accuracy of proxy-reported physical activity data can be limited by the family member/carer not being with the participant throughout the day (Foerste et al., 2016) and the impact of social desirability bias (Brenner & DeLamater, 2014). Previous objective studies have found no or weak relationships between physical activity and BMI for adolescents with Down syndrome (Esposito et al., 2012; Izquierdo-Gomez, Martínez-Gómez, et al., 2015). Objective measurement of physical activity data in adolescent and young adults in the PANDs study are presented in Chapter 7.

There was no discernible relationship between reported BMI and family financial stress in the 2011 Down syndrome NOW study, consistent with the findings of an Australian study of adolescents with intellectual disability (n=261) which included adolescents with Down syndrome (Krause et al., 2016). In the 2011 Down syndrome NOW study there was both a univariate relationship between lower family income and higher reported BMI in young adults with Down syndrome which persisted after adjusting for sex, reported fast food consumption frequency, main meal setting, food preparation skills and accommodation. In Australia socioeconomic disadvantage has been associated with higher rates of overweight and obesity, especially in women (Australian Institute of Health and Welfare, 2015). Further research is needed into the impact of family income on the health of young adults with Down syndrome.

There were several strengths to this research. The Down syndrome NOW study waves were population-based with high response fractions and the involvement of a consumer reference group. In the 2011 Down syndrome NOW questionnaire the question on perception of overweight/obesity was in a different section to the question asking for proxy reported height and weight, and although it is unknown if the completion of one question influenced the other, this is not expected. There was also acceptable internal consistency for the Child Feeding Questionnaire, as also reported in studies involving USA children with Down syndrome (O'Neill et al., 2005; M. Polfuss et al., 2017).

This research had several limitations. When analysing the relationship between reported BMI, food and physical activity behaviours and other factors, the data were cross-sectional and therefore the direction of any relationship is unknown. It is also unknown if these relationships would have continued over time. The impact on health outcomes is unknown thus longitudinal research which includes health outcomes or biochemical markers is recommended.

In the 2009 and 2011 Down syndrome NOW questionnaires the date on which proxy reported height and weight were recorded was not included. The age of participants was therefore calculated based on the date on which the questionnaire was returned. All BMI data were calculated from proxy-reported height and weight, however due to the number of participants and the geographical size of Western Australia, direct measurement would not have been time or cost efficient. A recent small study of young adult Special Olympics participants (n=21) has reported a high correlation between proxy-reported and measured anthropometric measurements (Dobranowski et al., 2018), however further research is needed with larger cohorts of young people with Down syndrome to confirm these findings.

Throughout this research reported BMI was classified using standard cut-points (CDC, 2018; NHMRC, 2013b). As discussed in 1.2, differences in anthropometry and body composition may invalidate these cut-points for adolescents and young adults with Down syndrome (González-Agüero, Ara, et al., 2011; Pitchford et al., 2018; Soler Marin & Xandri Graupera, 2011; Zemel et al., 2015). Sensitivity and specificity of adult cut-points for overweight and obesity for young adults with Down syndrome in the PANDs study are presented in Chapter 5.

When analysing changes in BMI category across the two Down syndrome NOW time periods (2004/2009 and 2004/2011) reported BMI at each time point was classified for each participant using cut-points specific to their age group (CDC, 2018; NHMRC, 2013b). This meant that different references were used for many participants at each of the two time-points which may have impacted on results.

In the Down syndrome NOW questionnaires reported BMI was the only proxy measure of body fatness. As discussed in 1.2, weight-to-height ratio can be a useful measure of central obesity in adolescents and young adults with Down syndrome (Real de Asua et al., 2014b) with a recent study involving adults without Down syndrome finding waist-to-height ratio to be the better predictor of total body and visceral fat mass (Swainson et al., 2017). Including waist circumference in future questionnaires along with height and weight and the date of recording would enable the waist-to height-ratio to be calculated and used in future research.

There were also limitations in the way questions were presented which are recommended for change in future questionnaires. One question was inadvertently left out of the Child Feeding Questionnaire however the internal consistency of the relevant factor (restriction) was still high. The question on fast food did not define or give examples of 'fast food' and thus was open to interpretation. The question on physical activity "on how many days was your son/daughter physically active for 60 minutes or more?" whilst addressing the Physical Activity and Sedentary Behaviour Guidelines for adolescents (Australian Government Department of Health, 2014) could not be analysed as to the Physical Activity and Sedentary Behaviour Guidelines for adults. There was also no indication of the intensity of physical activity as specified in the Guidelines. These limitations are addressed in Chapter 7 of this thesis when analysing the objective measurement of physical activity of adolescents and young adults with Down syndrome in the PANDs study. In the list of possible physical activities a common physical activity (bowling) was omitted and walking was not listed separately. Future lists of physical activity types should include these forms of activity.

In summary, the transition between adolescence and young adulthood is an important time of change for young people with intellectual disability including Down syndrome, and their families (H. Leonard et al., 2016). Using standard cut-points this study found an increasing proportion of overweight and obesity in adolescents and young adults with Down syndrome over time. Family members/carers reported concern about their young person's weight, particularly the weight of young females for whom the proportions of overweight and obesity were greater. Family members and carers also reported a high level of responsibility for their young person's food intake, however as only 10.1% of adolescents and young adults could prepare an adequate variety of meals without supervision, the need remains for family members/carers to ensure a healthy and varied diet. Almost 63% of adolescents and young adults did have some level of independent food preparation skills and these need to be encouraged and supported. Previously, when asked what makes a good life, young adults with Down syndrome expressed a desire for greater independence and autonomy with less parental control (M. Scott et al., 2013), however in this study, a higher reported BMI was related to behaviours associated with independence - increased fast food consumption (females), living out of the family home, not eating with others at the dining table and higher food preparation skills. As transition is an important time for the development of healthy behaviours of young people (Patton et al., 2011), these findings highlight the need for education and support for the development of healthy food related skills and behaviours in adolescents and young adults with Down syndrome.

Chapter 4 The Physical Activity, Nutrition and Down syndrome study

4.1 Overview

The Physical Activity, Nutrition and Down syndrome (PANDs) study was a cross-sectional study of the body composition, dietary intake and physical activity of a sample of adolescents and young adults with Down syndrome (aged 12-30 years) living in Western Australia. The research aims addressed by the PANDs study were to:

1. Describe the anthropometry and body composition of a sample of Australian adolescents and young adults with Down syndrome using standard BMI, percentage body fat, waist circumference and waist to height ratio cut-points.
2. Describe the performance of standard BMI, waist circumference and waist to height ratio cut-points for adolescents and young adults with Down syndrome including sensitivity and specificity of standard BMI cut-points.
3. Describe the dietary intake (food groups) and physical activity patterns of adolescents and young adults with Down syndrome.

This chapter will present an overview of the methodology for recruitment, ethics and consumer participation used in the study, with the following chapters presenting the specific objectives, methodology, results and discussion of each of the study components:
Chapter 5: Anthropometry and body composition of adolescents and young adults with Down syndrome
Chapter 6: Feasibility of assessing diet with a mobile food record for adolescents and young adults with Down syndrome
Chapter 7: Physical activity of adolescents and young adults with Down syndrome

4.2 Recruitment

Adolescents and young adults aged 12-30 years were identified from the Down syndrome NOW database held at the Telethon Kids Institute (formerly Telethon Institute for Child Health Research, Perth) (Foley et al., 2016). The inclusion criterion was residence within a 250 km of the Perth metropolitan area for travel purposes. There were no exclusion criteria. Families were contacted by mail and invited to participate. Participants and their family members were posted:

- Cover letter (Appendix G)
- Information sheet (Appendix H)
- Plain language information sheet (Appendix I)
- Consent form (Appendix J)
- Abridged version of the Down syndrome NOW 2011 questionnaire (see 3.2) along with instructions on how to complete it on paper or online (Appendix K), if the participant was not part of the 2011 Down syndrome NOW study wave.
- Reply paid return addressed envelope

For families where there were no contact details on the database, envelopes were addressed and posted by the Disability Services Commission (WA). To ensure the envelope had been received and to check for any questions, families were subsequently contacted by phone, either by the candidate or by a Disability Services Commission (WA) staff member.

Written consent was required from the family member/guardian and participants over the age of 18 years were also encouraged to also give consent if possible. Assent from all participants was required before proceeding with data collection.

4.3 Methodology

The design of this cross sectional study is shown in Figure 4.1. Once consent was received data collection for the PANDs study was conducted over two visits involving the candidate, the young person with Down syndrome and their family members/carers. The first visit was generally held at the young person's home at a time of their convenience to reduce transport barriers and to ensure the young person was in a comfortable environment. At the first visit, the study was explained to the young person and their family members/carers, equipment for capturing dietary intake and physical activity (Apple iPod and ActiGraph GT3X accelerometer) were demonstrated and practised and assent sought from the young person before proceeding with data collection. The DEXA scan was also discussed and an image of the scanner and what was involved was shown to participants and their family members/carers. If the participant's family had been posted an abridged version of the Down syndrome NOW 2011 questionnaire this was discussed and collected if completed on paper (otherwise collected at the second visit or it was posted back to the candidate). A folder was left with the participant with the Apple iPod and ActiGraph GT3X accelerometer, an instruction booklet for the Communicating Health and Technology (CHAT) app (mobile food record application specific to this study loaded onto the Apple iPod) and food diary (see Appendix L) and instructions on how to use the Actigraph activity monitor and activity diary (see Appendix M).

An appointment was set up for the second visit; although it was aimed to follow up a week after the initial visit this was not always possible due to the young person’s or their family member’s/carer’s commitments, and in these cases an appointment was arranged as soon as practical (within 1-4 weeks).

The venue for the second visit was generally either Curtin University (if assent for a DEXA scan was provided) or the young person’s home. At this visit, anthropometric measurements were taken (height, weight, waist circumference), equipment for capturing dietary and physical activity data was collected and dietary intake was discussed in more detail. A DEXA scan was conducted if assent was given by both the family member/carer and the young person with Down syndrome. At the conclusion of data collection participants were thanked for their participation, given a copy of a recipe book ‘Healthy Food Fast’, donated by the Health Department of Western Australia as a thank you gift, and invited to contact the candidate with any questions. Data collection commenced in 2013 and concluded in May 2015.

Following the second visit, data were downloaded from the devices and stored in secure databases at the Telethon Kids Institute and Curtin University in accordance with ethics requirements.

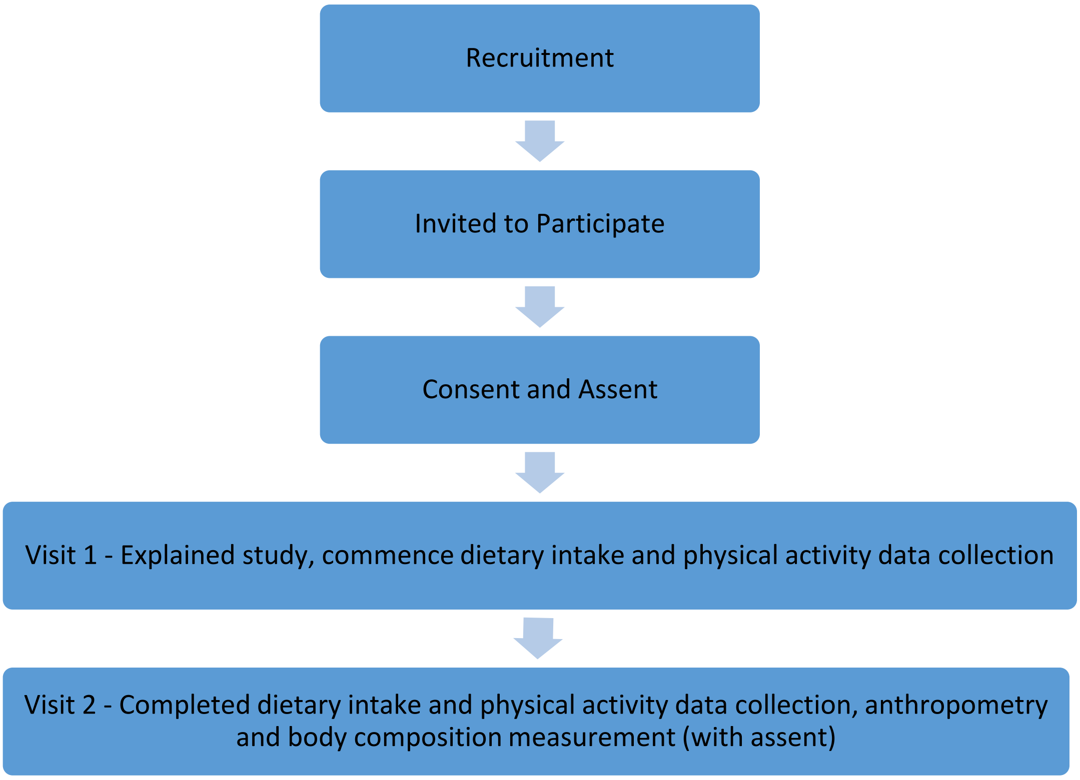


Figure 4.1 PANDs study design

4.3.1 Ethics, Approvals and Training

Approval for this study was granted by the Curtin University Human Ethics Research Committee (HR145/2011) (Appendix E). Approval was also obtained from the Disability Services Commission (WA). The Department of Education (WA) was also contacted about the study as some of the participants would be secondary school students and collecting data during the school day. The Department of Education (WA) confirmed that as the research was not considered to be conducted in schools, formal approval was not required, however it is was recommended that images and records of foods consumed during the school day be completed at home and that relevant Principals should be contacted either by the parents or by the candidate (with consent of the parent) with information about the accelerometer being worn by the student to measure physical activity.

Prior to conducting DEXA scans the candidate completed a Bone Densitometry Safety course and exam and received training and supervision on how to use the DEXA scanner. The candidate also participated in training on how to use the ActiGraph accelerometer (physical activity measurement), Apple iPod (dietary intake data collection) and anthropometric techniques (height, weight, waist circumference).

4.3.2 Consumer participation

During the planning stage, feedback was sought on the objectives and methodology of the PANDs study from a consumer reference group coordinated by the Telethon Kids Institute. The consumer reference group comprised of parents of young adults with Down syndrome and was established to advise on the Down syndrome NOW study (see 3.2.2). Down Syndrome WA was also consulted and the study was advertised in its newsletter. An update of the study was also featured in the Down Syndrome Australia journal *Voice* in 2015.

4.4 Results

Results specific to each part of the PANDs study are presented and discussed in separate chapters. Chapter 3 includes results from the abridged version of the Down syndrome NOW 2011 questionnaire, Chapter 5 presents the anthropometry and body composition results, Chapter 6 includes results from the dietary intake component, and Chapter 7 presents and discusses the physical activity results.

4.4.1 Participants

Of the 377 adolescents and young adults identified from the Down syndrome NOW database, consent was returned for 61 participants. Of these 61 participants, two participants withdrew from the study before any data was collected because they did not wish to participate and thus data was collected from 59 participants. This response was similar to that of a similar study where 1908 Irish adults with intellectual disability were invited to participate in a study of anthropometry and dietary intake and 131 participated (Hoey et al., 2017). All 59 participants provided anthropometric and dietary intake data, with 41 participating in the DEXA scan and 52 using the mobile food record app. Physical activity data was collected from 56 participants and the family member/carer of 21 participants who were not previously part of the 2011 Down syndrome NOW study completed a questionnaire (see Figure 4.2). Further detail on participation in the components of the PANDs study are discussed in Chapters 3, 5, 6 and 7.

Of the 59 participants, 32 (54.2%) were male, broadly consistent with the sex distribution of people born with Down syndrome in WA (S. Leonard et al., 2000). Most of the participants (78.0%) were young adults 18 years of age and older (see Table 4.1).

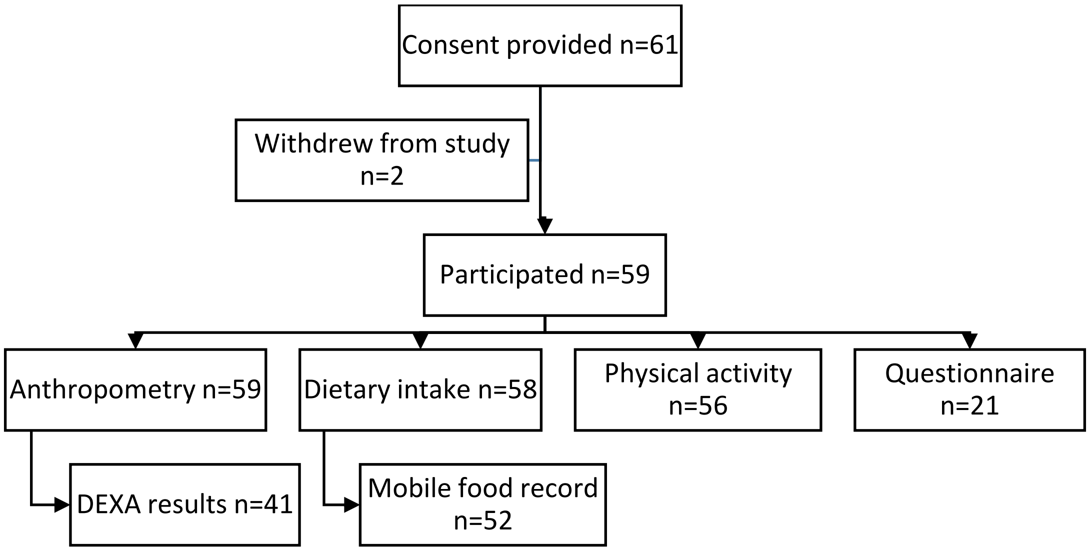


Figure 4.2 Participation in the PANDs study components

Table 4.1 PANDs participant characteristics

		Sex	
Age group	**Male (n)**	**Female (n)**	**Total (n)**
Adolescent <18 y	5	8	13
Young adult ≥18 y	27	19	46
Total	32	27	59

The objectives, methods and results of component of the PANDs study are discussed in separate chapters of this thesis. The Down syndrome NOW questionnaire data was included in Chapter 3. Anthropometric and body composition data including DEXA scan results are discussed in Chapter 5, and are also included in Chapters 6 and 7. Chapter 6 is a discussion of the feasibility of the mobile food record for adolescents and young adults with Down syndrome which was published in a peer-reviewed journal (Bathgate et al., 2017). Chapter 7 is a discussion of the accelerometer data and relationships with anthropometric and body composition measurements. Chapter 8 consolidates and discusses the main findings from all previous chapters, including recommendations for future research.

Preface to Chapter 5

Chapter 5 is a cross-sectional analysis of anthropometric and DEXA data collected as part of the Physical Activity, Nutrition and Down syndrome (PANDs) study as outlined in Chapter 4.

The candidate completed all data collection and analysis presented in this chapter.

Chapter 5 Anthropometry and body composition of adolescents and young adults with Down syndrome

5.1 Introduction

The anthropometry and body composition of adolescents and young adults with Down syndrome has been described in several studies using BMI, percentage body fat, waist circumference and waist-to-height ratio cut-points to identify proportions of overweight and obesity and predict metabolic risk (Izquierdo-Gomez et al., 2013; Parra et al., 2017; Real de Asua et al., 2014a; Soler Marin & Xandri Graupera, 2011) however analysis of percentage body fat using DEXA is lacking, particularly in young adults. Although it has been consistently reported that the proportion of adolescents and young adults with Down syndrome with a BMI categorised as overweight and obese is high, caution needs to be applied in the interpretation of BMI for adolescents and young adults with Down syndrome due to differences in height (Soler Marin & Xandri Graupera, 2011) and possibly body composition (González-Agüero, Ara, et al., 2011; Pitchford et al., 2018). Additionally, compared to those without Down syndrome, there is evidence that adolescents and young adults with Down syndrome have less lean mass (Baptista et al., 2005; González-Agüero, Ara, et al., 2011; Guijarro et al., 2008) and thus a greater proportion of those with a high body fat percentage may have a BMI in the healthy range.

When using BMI cut-points for overweight and obesity to identify those at risk, maximum sensitivity (proportion of true positives) and specificity (proportion of true negatives) is desired, however in practice there is often a trade-off between these two measures (Neovius, Linné, Barkeling, & Rossner, 2004). Maximising sensitivity at the expense of specificity to ensure all those at risk are identified will increase the proportion of false positives (Temple et al., 2010). Maximising specificity (to avoid categorising those who are healthy weight as overweight or obese) can also be desirable, however this will result in the misdiagnosis of true positives who are at risk (Neovius et al., 2004). The sensitivity and specificity of standard BMI percentile cut-points for overweight and obesity have been evaluated in studies involving adolescents and young adults with Down syndrome (Bandini et al., 2013; Hatch-Stein et al., 2016; Samur San-Matin et al., 2016) however there is a need to evaluate the sensitivity and specificity of the adult BMI cut-points as defined by the

NHMRC (2013b) specifically for this population so that accurate assessments of the risks associated with overweight and obesity can be made.

For adults with Down syndrome the use of standard waist circumference cut-points can lead to an underestimation of the proportion with abdominal obesity and the waist-to-height ratio has been proposed as a more effective predictor of risk for adults with Down syndrome (Real de Asua et al., 2014b). The waist-to-height ratio has been demonstrated to be useful in international research with adolescents adults with Down syndrome (Izquierdo-Gomez et al., 2016; Parra et al., 2017; Real de Asua et al., 2014b) however as these studies did not include measurement of visceral fat the relationship between waist-to-height ratio and abdominal obesity in adolescents and young adults with Down syndrome is unknown. In adults without Down syndrome (n=122) waist-to-height ratio has been shown to be a good predictor of both total percentage body fat and visceral fat (Swainson et al., 2017) however in adolescents and young adults with Down syndrome this relationship is unknown.

5.1.1 Aims and hypotheses

Therefore the aims of this study were to:

1. Describe the anthropometry and body composition of a sample of Australian adolescents and young adults with Down syndrome using standard BMI, percentage body fat, waist circumference and waist-to-height ratio cut-points.
2. Describe the performance of standard BMI, waist circumference and waist-to-height ratio cut-points for adolescents and young adults with Down syndrome including sensitivity and specificity of standard BMI cut-points.

From the literature review the following hypotheses were proposed:

1. A high proportion of adolescents and young adults with Down syndrome will be overweight and obese when applying standard BMI cut-points.
2. Standard BMI cut-points for overweight will have a high sensitivity and lower specificity in adolescents and young adults with Down syndrome, with the efficiency of the BMI cut-point for obesity being greater than that of the BMI cut-point for overweight.
3. The waist-to-height ratio may be a better indicator of abdominal obesity than waist circumference for young adults with Down syndrome.

5.2 Methodology

The recruitment, ethics and study design for the Physical Activity, Nutrition and Down syndrome (PANDs) study are described in 4.0. The following describes the specific methodology of the anthropometry and body composition component.

5.2.1 Data collection

Data collected for this study were height, weight, waist circumference, fat mass, lean mass and percentage body fat using anthropometric measurements and DEXA.

5.2.1.1 Anthropometric measurements

Height, weight and waist circumference were measured following standard procedures (Stewart, Marfell-Jones, Olds, & de Ridder, 2011) using a calibrated wall-fixed stadiometer, electronic digital scales and non-stretchable tape. Height and waist circumference were measured to the nearest 0.1 cm and weight to the nearest 0.1 kg with participants wearing light clothing and in bare feet. Three measurements for waist circumference were taken where possible (i.e. when the participants were comfortable with more than one measurement) with an average of all measurements used as the final measurement. All participants were measured in the presence of their family member/carer prior to the DEXA scan.

The CDC BMI percentile calculator for child and teen (CDC, 2018) was used to calculate the BMI percentile or each adolescent. Cut-points used for the anthropometric measurements of BMI, waist circumference and waist-to-height ratio are detailed in Table 5.1.

Table 5.1 Cut-points used for assessing anthropometry and body composition

Parameter	Reference	Cut-point Overweight	Cut-point Obesity
BMI			
Adolescent (≥12 y & <18 y)	CDC BMI percentile calculator for child and teen (CDC, 2018)	85th-95th percentile	>95th percentile
Young adult (≥18 y)	NHMRC definition (NHMRC, 2013b)	≥25 – 29.9 kg/m2	≥30 kg/m2
% Total body fat (DEXA)			
Adolescent (≥12 y & <18 y)	Body fat reference curves (McCarthy et al., 2006)	85th-95th percentile	>95th percentile
Young adult (≥18 y)	Cut-points for percentage body fat (20-29 y) (Pasco et al., 2014)	≥20.6 % males ≥36.0 % females	≥27.5 % males ≥43.4 % females
Parameter	**Reference**	**Increased metabolic risk**	**High metabolic risk**
Waist circumference Young adult (≥18 y)	NHMRC definition (NHMRC, 2013b)	≥94 cm males ≥80 cm females	≥102 cm males ≥88 cm females
Waist-to-height ratio			
Adolescent (≥12 y & <18 y)	Cut-points corresponding to percentage body fat cut-points (Nambiar et al., 2010)	≥0.46 males ≥0.45 females	≥0.48 males ≥0.47 females
Young adult (≥18 y)	Standard cut-point (Ashwell & Hsieh, 2005)	≥0.5	

5.2.1.2 Dual energy x-ray absorptiometry

Body composition was measured using a Lunar Prodigy (GE Medical Systems USA) situated in the School of Physiotherapy, Curtin University, Perth, WA. Before each total body scan, quality assurance and phantom spine scans were conducted by the candidate to ensure compliance. Participants received an effective dose of less than 0.5 µSv (0.005 mSV) of ionising radiation over the single 5-minute scan which is relatively low compared to other imaging techniques (50-820 µSv) and the amount of background radiation accumulated in 1-year (2400 µSv) (Albanese et al., 2003). The candidate conducted all scans and analysis.

Participants and their family member/carer were provided with written and visual information on how the Lunar Prodigy worked prior to arriving at Curtin University so an informed decision could be made as to whether to participate in the scan. Once at Curtin University the scan procedure was explained and demonstrated by the candidate and the participant's assent was obtained before conducting the scan. If assent was not provided the scan was not conducted. After height, weight and waist circumference were measured, participants were scanned once in a supine position in light metal-free clothing with all metal accessories (jewellery, glasses) removed. A Velcro strap was applied around the ankles to minimise leg movement and a pillow was placed under the head for comfort. At the conclusion of the scan participants were provided with a printed copy of the results for their records.

Each whole body scan was analysed using enCORE v15 SP1 software. Data provided for each participant were total mass, total fat mass, total lean mass, total percentage fat, android and gynoid regions fat and lean mass, android and gynoid regions percentage fat. Standard reference curves and cut-points for percentage body fat as derived for adolescents (McCarthy et al., 2006) and adults (Pasco et al., 2014) were used for the analysis of total percentage body fat (see Table 5.1).

5.2.2 Statistical analysis

Descriptive statistics, reported as means with standard deviations (SD) or proportions where appropriate were used to summarise participant characteristics, classification of weight status and metabolic risk. Independent samples t-tests with unequal variances were used to compare the means of age, height, weight, BMI, waist circumference and waist-to-height ratio by sex and the presence of DEXA results. Adolescent means were not compared due to small sample sizes.

Welch's ANOVA with a Games-Howell post hoc test was used to compare the means of age, height, weight, BMI, total body fat, percentage body fat, waist circumference and weight to height ratio of young adults in each of the standard BMI, percentage body fat and waist circumference categories as well as their tertiles. Means of participant age, height, weight, BMI, total body fat, percentage body fat and waist circumference for the two waist-to-height ratio categories and the 50th percentile were compared using independent sample t-tests with unequal variances. Although presented for the total group and individual sexes, means were not compared for individual sexes due to small sample sizes.

The relationships between BMI category and percentage body fat category, waist circumference category and waist-to-height category were tested using Pearson's chi-squared test of independence for the total group, but not for individual sexes due to small sample sizes.

Parameters involving sensitivity and specificity were calculated as described in similar studies of the anthropometry and body composition of adolescents and young adults with Down syndrome (Bandini et al., 2013; Temple et al., 2010). These variables were calculated for both males and females and the group as a whole: sensitivity of each BMI category (the proportion of true positives), specificity (the proportion of true negatives), positive predictive value (the proportion of true positives within each specific BMI category), negative predictive value (the proportion of true negatives within each BMI category) and efficiency of the overweight and obese BMI categories (the sum of true positives and true negatives divided by the total number of participants). The level of statistical significance was set at alpha=0.05 and all *P* values were estimated using two-tailed tests. All analyses were performed in SPSS (IBM Corp. Released 2016. IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp).

5.3 Results

5.3.1 Participants

Of the 59 participants who participated in the PANDs study, 13 were adolescents under 18 years of age and 46 were young adults 18 years of age or older. DEXA data were available for 41 participants, of whom 34 were young adults. The main reasons for DEXA data not being available for 18 participants were assent not being given either by participants and/or their family member/carer and the distance and travel time to participate in the scan (see Figure 5.1).

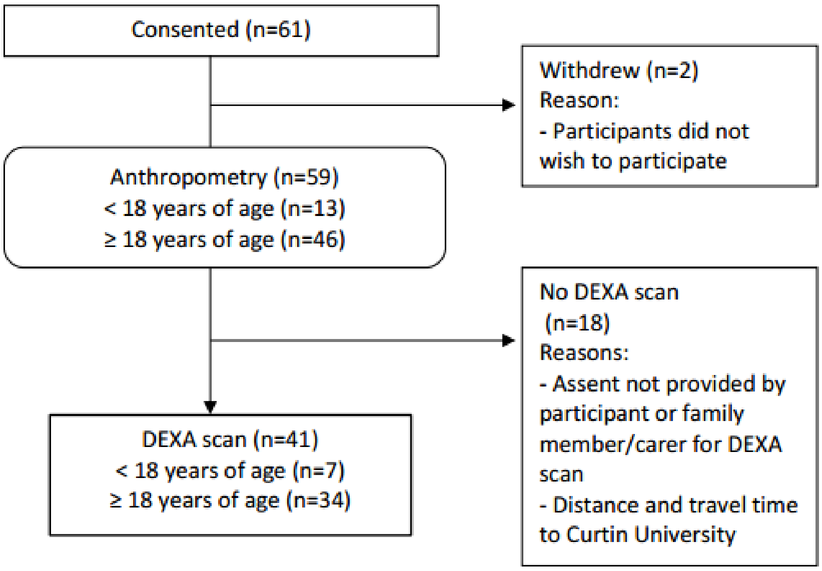


Figure 5.1. Anthropometry and body composition data collection flowchart

The anthropometric characteristics of all participants in the PANDs study (n=59) are shown in Table 5.2. Independent t-tests were not performed for adolescents due to the small sample sizes. The age range in the study was 13-30 years, with the mean age for adolescents being 15.5 years and 23.4 years for young adults. For young adults, males were taller than females (11.3, 95% CI 7.8, 14.9) with the mean height of young adult males being 158.4 cm and young adult females 147.1 cm. There were no differences in mean age, weight, BMI, waist circumference or waist-to-height ratio between young adult males and females.

Table 5.2 Characteristics of adolescent and young adult participants in the PANDs study

	Male Mean ± SD	Female Mean ± SD	Total Mean ± SD	Difference in means (95% CI) [male v. female]	*P* value^
Young adult n (%)	**27 (59%)**	**19 (41%)**	**46 (100%)**		
Age (y)	23.2 ± 3.7	23.6 ± 3.4	23.4 ± 3.5	-0.4 (-2.5, 1.7)	0.700
Height (cm)	158.4 ± 6.6	147.1 ± 5.3	153.8 ± 8.2	11.3 (7.8, 14.9)	<0.001[#]
Weight (kg)	68.5 ± 12.3	62.9 ± 15.8	66.2 ± 14.0	5.6 (-3.2, 14.4)	0.203
BMI (kg/m^2)	27.3 ± 4.7	29.0 ± 6.9	28.0 ± 5.7	-1.7 (-5.4, 2.1)	0.367
Waist circumference (cm)	85.2 ± 10.9	82.0 ± 21.5	83.8 ± 16.0	3.2 (-7.8, 14.3)	0.554
Waist-to-height ratio	0.54 ± 0.07	0.56 ± 0.15	0.55 ± 0.11	-0.02 (-0.10, 0.06)	0.593
Adolescent n (%)	**5 (38%)**	**8 (62%)**	**13 (100%)**		
Age (y)	14.8 ± 1.1	15.9 ± 1.6	15.5 ± 1.5		
Height (cm)	156.2 ± 3.5	142.6 ± 9.3	147.8 ± 10.1		
Weight (kg)	55.5 ± 8.6	57.5 ± 15.3	56.7 ± 12.7		
BMI (kg/m^2)	22.7 ± 2.8	27.8 ± 5.6	25.9 ± 5.3		
BMI percentile	73.2 ± 21.1	81.9 ± 26.8	78.5 ± 24.2		
Waist circumference (cm)	75.0 ± 7.0	74.5 ± 12.5	74.7 ± 10.4		
Waist-to-height ratio	0.48 ± 0.04	0.52 ± 0.07	0.51 ± 0.06		

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
[#]*P*<0.05

5.3.2 Classification of anthropometric and DEXA data

Using standard cut-points (CDC, 2018), 40.0% (2/5) of adolescent males and 75.0% (6/8) of adolescent females had a BMI classified as overweight or obese (see Table 5.3). Of the young adult participants, 66.6% (18/27) of males and 68.4% (13/19) of females had a BMI classified as overweight or obese. When applying standard waist circumference cut-points (NHMRC, 2013b), 22.2% (6/27) of young adult males and 47.4% (9/19) of young adult females had a waist circumference at increased or high risk of metabolic conditions, less than the percentages at risk when applying the waist-to-height ratio cut-point of 0.5 (63.0% for young adult males and 63.2% for young adult females).

Table 5.3 Classification of anthropometric data for adolescent and young adult participants in the PANDs study

Young adult	**Male n=27 (59%)**		**Female n=19 (41%)**		**Total n=46 (100%)**	
BMI*	**n**	**col %**	**n**	**col %**	**n**	**col %**
Healthy weight	9	33.3	6	31.6	15	32.6
Overweight	11	40.7	5	26.3	16	34.8
Obese	7	25.9	8	42.1	15	32.6
Waist circumference*						
No increased risk	21	77.8	10	52.6	31	67.4
Increased risk	4	14.8	4	21.1	8	17.4
High risk	2	7.4	5	26.3	7	15.2
Waist-to-height ratio**						
No increased risk	10	37.0	7	36.8	17	37.0
Increased risk	17	63.0	12	63.2	29	63.0
Adolescent	**Male n=5 (38%)**		**Female n=8 (62%)**		**Total n=13 (100%)**	
BMI***	**n**	**col %**	**n**	**col %**	**n**	**col %**
Healthy weight	3	60.0	2	25.0	5	38.5
Overweight	2	40.0	1	12.5	3	23.1
Obese	0	0	5	62.5	5	38.5
Waist-to-height ratio****						
Healthy weight	2	40.0	1	12.5	3	23.1
Overweight	1	20.0	1	12.5	2	15.4
Obese	2	40.0	6	75.0	8	61.5

col=column; *BMI and waist circumference of young adults classified using NHMRC cut-points (NHMRC, 2013b); **waist-to-height ratio of young adults classified as increased risk if ≥0.5 (Ashwell & Hsieh, 2005); ***BMI of adolescents classified using CDC BMI percentile calculator for child and teen (CDC, 2018); ****waist-to-height ratio classified using cut-points developed from data of Australian adolescents (Nambiar et al., 2010)

Tables 5.4 and 5.5 present the characteristics and classifications of BMI, percentage body fat, waist circumference and waist-to-height ratio for those adolescents (n=7) and young adults (n=34) with DEXA results. As shown in Table 5.5, all four adolescent females had a percentage body fat classified as obese and two of the three adolescent males had a percentage body fat classified as overweight or obese when applying standard body fat reference curve percentile cut-points (McCarthy et al., 2006). As the number of adolescents for whom DEXA data were available was low (n=7), further analysis has been conducted only on the results of young adults with DEXA results.

Young adult males with DEXA results were taller than young adult females (11.7, 95% CI 8.0, 15.3) with females having a higher percentage body fat (-10.1, 95% CI -16.2, -3.9) (see Table 5.4). Using standard BMI categories (NHMRC, 2013b), 68.4% (13/19) of young adult males and 80.0% (12/15) of young adult females had a BMI classified as overweight or obese. Interestingly, this pattern reversed when mean percentage body fat was classified using sex and age specific cut-points (Pasco et al., 2014) with 89.5% (17/19) of young adult males and 66.7% (10/15) of young adult females having a percentage body fat classified as overweight and obese (see Table 5.5). This was due to four males with a BMI classified as healthy weight having a percentage body fat classified as overweight and two females with a BMI classified as overweight having a percentage body fat classified as healthy weight.

In young adults, 31.6% (6/19) of males and 46.6% (7/15) of females had a waist circumference at increased or high metabolic risk when applying standard waist circumference cut-points, compared to 68.4% (13/19) of males and 66.7% (10/15) of females with a waist-to-height ratio at increased risk when applying the standard cut-point (see Table 5.5).

As shown in Table 5.6, there were no differences in age, height, weight, BMI and waist circumference for young adult participants with DEXA results compared to those without DEXA results. For young males waist circumference was lower for those without DEXA results (8.6, 95% CI 0.5, 16.7).

Table 5.4 Characteristics of adolescent and young adult participants with DEXA scan results

	Male Mean ± SD	Female Mean ± SD	Total Mean ± SD	Difference in means (95% CI) [male v. female]	*P* value^
Young adult n (%)	**19 (56%)**	**15 (44%)**	**34 (100%)**		
Age (y)	22.9 ± 3.7	23.2 ± 3.4	23.0 ± 3.5	-0.3 (-2.8, 2.2)	0.804
Height (cm)	159.4 ± 6.5	147.8 ± 4.0	154.3 ± 8.0	11.7 (8.0, 15.3)	<0.001[#]
Weight (kg)	71.0 ± 12.3	65.7 ± 16.2	68.6 ± 14.2	5.3 (-5.1, 15.6)	0.305
BMI (kg/m^2)	28.0 ± 5.0	30.0 ± 7.4	28.9 ± 6.1	-2.1 (-6.7, 2.5)	0.365
Total body fat (kg)	22.5 ± 9.5	28.2 ± 13.5	25.0 ± 11.6	-5.7 (-14.2, 2.8)	0.177
Total body fat (%)	30.0 ± 7.8	40.1 ± 9.4	34.5 ± 9.8	-10.1 (-16.2, -3.9)	0.002[#]
Waist circumference (cm)	87.7 ± 11.2	84.3 ± 23.3	86.2 ± 17.4	3.4 (-10.3, 17.1)	0.613
Waist-to-height ratio	0.55 ± 0.07	0.57 ± 0.16	0.56 ± 0.12	-0.02 (-0.12, 0.07)	0.640
Adolescent n (%)	**3 (43%)**	**4 (57%)**	**7 (100%)**		
Age (y)	15.0 ± 0.0	16.8 ± 0.5	16.0 ± 1.0		
Height (cm)	157.1 ± 3.8	147.5 ± 4.7	151.6 ± 6.5		
Weight (kg)	54.9 ± 7.8	67.2 ± 7.2	62.0 ± 9.4		
BMI (kg/m^2)	22.2 ± 2.3	30.9 ± 3.5	27.2 ± 5.4		
BMI percentile	68.0 ± 25.0	95 ± 5.0	83.0 ± 21.0		
Total body fat (kg)	13.3 ± 3.3	30.4 ± 5.6	23.1 ± 10.1		
Total body fat (%)	24.0 ± 4.0	44.7 ± 5.6	35.8 ± 12.0		
Waist circumference (cm)	73.8 ± 3.1	81.4 ± 4.5	78.1 ± 5.4		
Waist-to-height ratio	0.47 ± 0.02	0.56 ± 0.04	0.52 ± 0.06		

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
[#]$P<0.05$

Table 5.5 Classification of anthropometric and DEXA data of adolescent and young adult participants with DEXA scan results

	Male n=19 (55.9%)		Female n=15 (44.1%)		Total n=34 (100%)	
Young adult	**n**	**col %**	**n**	**col %**	**n**	**col %**
BMI#						
Healthy weight	6	31.6	3	20.0	9	26.5
Overweight	7	36.8	4	26.7	11	32.4
Obese	6	31.6	8	53.3	14	41.2
Percentage body fat##						
Healthy weight	2	10.5	5	33.3	7	20.6
Overweight	8	42.1	4	26.7	12	35.3
Obese	9	47.4	6	40.0	15	44.1
Waist circumference#						
No increased risk	13	68.4	8	53.3	21	61.8
Increased risk	4	21.1	2	13.3	6	17.6
High risk	2	10.5	5	33.3	7	20.6
Waist-to-height ratio###						
No increased risk	6	31.6	5	33.3	11	32.4
Increased risk	13	68.4	10	66.7	23	67.6
	Male n=3 (42.9%)		**Female n=4 (57.1%)**		**Total n=7 (100%)**	
Adolescent	**n**	**col %**	**n**	**col %**	**n**	**col %**
BMI*						
Healthy weight	2	66.7	0	0	2	28.6
Overweight	1	33.3	1	25.0	2	28.6
Obese	0	0	3	75.0	3	42.9
Percentage body fat**						
Healthy weight	1	33.3	0	0	1	14.3
Overweight	1	33.3	0	0	1	14.3
Obese	1	33.3	4	100	5	71.4
Waist-to-height ratio***						
Healthy weight	1	33.3	0	0	1	14.3
Overweight	1	33.3	0	0	1	14.3
Obese	1	33.3	4	100	5	71.4

col=column; #BMI and waist circumference of young adults classified using NHMRC cut-points (NHMRC, 2013b); ##percentage body fat classified using cut-points developed using age, sex and BMI (Pasco et al., 2014); ###waist-to-height ratio of young adults classified as increased risk if ≥0.5 (Ashwell & Hsieh, 2005)
*BMI of adolescents classified using CDC BMI percentile calculator for child and teen (CDC, 2018); **percentage body fat of adolescents classified using body fat reference curves (McCarthy et al., 2006); *** waist-to-height ratio classified using cut-points developed for Australian adolescents (Nambiar et al., 2010)

Table 5.6 Characteristics of young adult participants with and without DEXA results

	PANDs study with DEXA Mean ± SD	PANDs study without DEXA Mean ± SD	Difference in means (95% CI) [with v. without DEXA]	*P* value^
Male (n)	**19**	**8**		
Age (y)	22.9 ± 3.7	24.0 ± 3.8	-1.1 (-4.6, 2.3)	0.500
Height (cm)	159.4 ± 6.5	156.1 ± 6.6	3.4 (-2.6, 9.3)	0.245
Weight (kg)	71.0 ± 12.3	62.8 ± 10.9	8.2 (-2.0, 18.4)	0.108
BMI (kg/m^2)	28.0 ± 5.0	25.7 ± 3.6	2.3 (-1.3, 5.9)	0.201
Waist circumference (cm)	87.7 ± 11.2	79.1 ± 8.1	8.6 (0.5, 16.7)	0.039$^{\#}$
Waist-to-height-ratio	0.55 ± 0.07	0.51 ± 0.05	0.04 (-0.01, 0.09)	0.088
Female (n)	**15**	**4**		
Age (y)	23.2 ± 3.4	25.3 ± 3.3	-2.1 (-6.9, 2.8)	0.325
Height (cm)	147.8 ± 4.0	144.6 ± 9.1	3.2 (-10.9, 17.2)	0.540
Weight (kg)	65.7 ± 16.2	52.6 ± 9.5	13.1 (-1.4, 27.6)	0.072
BMI (kg/m^2)	30.0 ± 7.4	25.0 ± 2.8	5.0 (-0.02, 10.1)	0.051
Waist circumference (cm)	84.3 ± 23.3	73.0 ± 9.2	11.3 (-5.0, 27.6)	0.158
Waist-to-height-ratio	0.57 ± 0.16	0.50 ± 0.04	0.07 (-0.03, 0.17)	0.151

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
$^{\#}P<0.05$

Tables 5.7 to 5.13 show differences in the means of age, height, weight, BMI, total body fat (kg), total percentage body fat, waist circumference and waist-to-height ratio, grouped according to standard BMI categories (Table 5.7), percentage body fat categories (Table 5.8) and tertiles (Table 5.9), waist circumference risk categories (Table 5.10) and tertiles (Table 5.11) and waist-to-height ratio risk categories (Table 5.12) and 50th percentile (Table 5.13). Summaries of the differences in means as described below can be seen in Table 5.14. Differences in the means between groups are compared for the total group but not for individual sexes due to small sample sizes.

Across all BMI, percentage body fat, waist circumference and waist-to-height ratio categories and tertiles, there were no differences in the means of age. There were also no differences in the mean of height except for when using body fat percentiles where young adults with a percentage body fat in the lowest tertile were taller than young adults with a percentage body fat in the highest tertile (*P*=0.40).

Across the three BMI categories (Table 5.7), there were no differences in the means of weight, total percentage body fat and waist circumference between participants with a BMI in the healthy weight and overweight categories, however there were differences in these means between participants with a BMI in the obese category and those with a BMI in the healthy weight and overweight categories. For total body fat (kg) and waist-to-height ratio there were differences in the means across all three BMI categories (*P*<0.001).

Table 5.8 shows the means of age and anthropometric measurements by percentage body fat category (healthy weight, overweight and obese). For weight and total body fat (kg) there were differences in the means across all three percentage body fat categories (*P*<0.001). There were no differences in the means of BMI, waist circumference and waist-to-height ratio between participants in the healthy weight category and the overweight category, however there were differences in these means between participants with a percentage body fat in the obese category and those with a percentage body fat in the healthy weight and overweight categories.

When using percentage body fat tertiles, there were differences in the means for weight, waist circumference and waist-to-height ratio between participants with a percentage body fat in the lowest and highest tertiles and between participants with a percentage body fat in the middle and highest tertiles but not between participants with a percentage body fat in the lowest and middle tertiles (see Table 5.9). For BMI and total body fat (kg) there were differences in the means across all three tertiles (*P*<0.001).

For all participants, the means of total body fat (kg) and percentage body fat were different for participants in all three waist circumference risk groups (no increased risk, increased risk, and high risk) (*P*<0.001). For weight, BMI, and waist-to-height-ratio there were differences in the means between participants with a waist circumference in the 'no increased risk' and 'increased risk' groups and 'no increased risk' and 'high risk' groups, but not between the 'increased risk' and 'high risk' groups (see Table 5.10).

When using waist circumference tertiles (Table 5.11) there were differences in the means of weight and waist-to-height ratio between all three tertiles (*P*<0.001). For BMI, total body fat (kg), percentage body fat there were differences in the means between participants with a waist circumference in the lowest and highest tertiles and middle and highest tertiles, but not between lowest tertile and middle tertiles.

For both the waist-to-height ratio categories (no increased risk, increased risk) and the two waist-to-height 50^{th} percentiles groups (Tables 5.12 and 5.13) there were differences in the means of weight, BMI, total body fat (kg), total percentage body fat and waist circumference for all young adults.

Table 5.14 presents the summaries of differences in the means between BMI, percentage body fat, waist circumference and waist-to-height ratio for young adults in the PANDs study. Blue shaded cells with ticks are those where there is difference in the means, a cross indicates where there is no difference in the means. Superscripted characters show the level of significance.

Table 5.7 Differences in the means of age, anthropometric and DEXA measurements by BMI category

	BMI category*					
Total	**Healthy weight n=9 (27%)**	**Overweight n=11 (32%)**	**Obese n=14 (41%)**	**Total n=34 (100%)**	$F_{2,31}$	***P* value^**
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	22.4 ± 4.3	23.5 ± 3.4	23.0 ± 3.2	23.0 ±3.5	0.19	0.825
Height (cm)	156.5 ± 10.3	155.4 ± 7.4	152.0 ± 6.7	154.3 ± 8.0	1.04	0.375
Weight (kg)	55.8 ± 9.7[a]	64.8 ± 7.7[a]	80.0 ± 11.9[b]	68.6 ± 14.2	14.32	<0.001[#]
Total body fat (kg)	14.3 ± 3.0[a]	19.6 ± 4.2[b]	36.1 ± 9.3[c]	25.0 ± 11.6	33.02	<0.001[#]
Total body fat (%)	25.8 ± 5.7[a]	30.0 ± 6.2[a]	43.5 ± 6.2[b]	34.5 ± 9.8	27.31	<0.001[#]
Waist circumference (cm)	73.6 ± 9.5[a]	80.2 ± 8.0[a]	99.1 ± 18.5[b]	86.2 ± 17.4	9.14	0.002[#]
Waist-to-height ratio	0.47 ± 0.04[a]	0.52 ± 0.04[b]	0.65 ± 0.13[c]	0.56 ± 0.12	12.74	<0.001[#]
Male	**n=6 (32%)**	**n=7 (37%)**	**n=6 (32%)**	**n=19 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	21.5 ± 4.1	22.7 ± 3.9	24.5 ± 2.8	22.9 ± 3.7		
Height (cm)	162.0 ± 7.2	159.8 ± 5.2	156.4 ± 6.9	159.4 ± 6.5		
Weight (kg)	61.2 ± 5.0	68.9 ± 6.1	83.2 ± 13.2	71.0 ± 12.3		
Total body fat (kg)	14.6 ± 2.4	19.4 ± 4.3	34.0 ± 7.1	22.5 ± 9.5		
Total body fat (%)	23.5 ± 3.1	27.5 ± 5.0	39.5 ± 3.4	30.0 ± 7.8		
Waist circumference (cm)	79.0 ± 5.2	84.4 ± 6.9	100.3 ± 8.1	87.7 ± 11.2		
Waist-to-height ratio	0.49 ± 0.03	0.53 ± 0.04	0.64 ± 0.04	0.55 ± 0.07		
Female	**n=3 (20%)**	**n=4 (27%)**	**n=8 (53%)**	**n=15 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	24.3 ± 4.9	25.0 ± 2.2	21.9 ± 3.1	23.2 ± 3.4		
Height (cm)	145.3 ± 3.7	147.8 ± 2.8	148.7 ± 4.6	147.8 ± 4.0		
Weight (kg)	44.9 ± 6.7	57.6 ± 4.0	77.5 ± 11.0	65.7 ± 16.2		
Total body fat (kg)	13.8 ± 4.5	20.0 ± 4.8	37.7 ± 10.9	28.2 ± 13.5		
Total body fat (%)	30.4 ± 7.7	34.4 ± 6.1	46.6 ± 6.1	40.1 ± 9.4		
Waist circumference (cm)	62.8 ± 5.5	72.9 ± 2.1	98.2 ± 24.2	84.3 ± 23.3		
Waist-to-height ratio	0.43 ± 0.03	0.50 ± 0.02	0.66 ± 0.18	0.57 ± 0.16		

SD=standard deviation; *BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Welch's ANOVA *P* value; [a, b, c] means sharing the same superscript do not differ significantly by a Games-Howell post hoc test
[#]*P*<0.05

Table 5.8 Differences in the means of age, anthropometric and DEXA measurements by percentage body fat category

	Percentage body fat category*					
Total	**Healthy weight n=7 (21%)**	**Overweight n=12 (35%)**	**Obese n=15 (44%)**	**Total n=34 (100%)**	$F_{2,31}$	***P* value^**
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	23.6 ± 4.3	22.8 ± 3.7	22.9 ± 3.2	23.0 ± 3.5	0.07	0.929
Height (cm)	149.6 ± 6.9	156.9 ± 8.2	154.4 ± 7.8	154.3 ± 8.0	2.14	0.148
Weight (kg)	51.9 ± 8.0[a]	63.8 ± 4.8[b]	80.4 ± 10.9[c]	68.6 ± 14.2	23.50	<0.001[#]
BMI	23.1 ± 2.3[a]	26.0 ± 2.8[a]	33.9 ± 5.5[b]	28.9 ± 6.1	20.26	<0.001[#]
Total body fat (kg)	13.9 ± 3.1[a]	19.3 ± 5.1[b]	34.7 ± 10.1[c]	25.0 ± 11.6	25.87	<0.001[#]
Waist circumference (cm)	69.6 ± 8.4[a]	79.2 ± 4.5[a]	99.6 ± 17.1[b]	86.2 ± 17.4	14.63	<0.001[#]
Waist-to-height ratio	0.46 ± 0.04[a]	0.51 ± 0.04[a]	0.65 ± 0.13[b]	0.56 ± 0.12	11.93	0.001[#]
Male	**n=2 (11%)**	**n=8 (42%)**	**n=9 (47%)**	**n=19 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	19.5 ± 2.1	23.3 ± 4.4	23.3 ± 3.1	22.9 ± 3.7		
Height (cm)	159.0 ± 1.6	160.8 ± 7.1	158.3 ± 6.8	159.4 ± 6.5		
Weight (kg)	60.1 ± 2.1	63.5 ± 5.4	80.0 ± 11.7	71.0 ± 12.3		
BMI	23.8 ± 0.4	24.6 ± 1.8	32.0 ± 4.3	28.0 ± 5.0		
Total body fat (kg)	12.0 ± 0.05	16.1 ± 1.8	30.5 ± 7.8	22.5 ± 9.5		
Waist circumference (cm)	77.4 ± 9.3	80.0 ± 4.0	96.8 ± 8.7	87.7 ± 11.2		
Waist-to-height ratio	0.49 ± 0.05	0.50 ± 0.03	0.61 ± 0.06	0.55 ± 0.07		
Female	**n=5 (33%)**	**n=4 (27%)**	**n=6 (40%)**	**n=15 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	25.2 ± 3.8	22.0 ± 2.2	22.3 ± 3.4	23.2 ± 3.4		
Height (cm)	145.8 ± 2.9	149.1 ± 2.5	148.5 ± 5.3	147.8 ± 4.0		
Weight (kg)	48.6 ± 7.0	64.3 ± 3.8	80.9 ± 10.8	65.7 ± 16.2		
BMI	22.8 ± 2.8	28.9 ± 1.7	36.8 ± 6.1	30.0 ± 7.4		
Total body fat (kg)	14.7 ± 3.5	25.8 ± 2.2	41.1 ± 10.5	28.2 ± 13.5		
Waist circumference (cm)	66.5 ± 6.4	77.4 ± 5.5	103.9 ± 25.7	84.3 ± 23.3		
Waist-to-height ratio	0.46 ± 0.04	0.52 ± 0.04	0.70 ± 0.19	0.57 ± 0.16		

SD=standard deviation* percentage body fat classified using cut-points developed using age, sex and BMI (Pasco et al., 2014); ^Welch's ANOVA *P* value; [a, b, c] means sharing the same superscript do not differ significantly by a Games-Howell post hoc test; [#]P<0.05

Table 5.9 Differences in the means of age, anthropometric and DEXA measurements by percentage body fat tertiles

	Percentage body fat tertiles					
Total cut-points 27.6%, 39.6%	**Lowest tertile n=11**	**Middle tertile n=12**	**Highest tertile n=11**	**Total n=34**	$F_{2,31}$	***P* value^**
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	22.4 ± 4.1	23.8 ± 3.6	22.9 ± 3.0	23.0 ± 3.5	0.39	0.684
Height (cm)	159.3 ± 7.1[a]	152.3 ± 7.6[a,c]	151.4 ± 7.5[b,c]	154.3 ± 8.0	3.79	0.040[#]
Weight (kg)	61.1 ± 7.4[a]	64.9 ± 13.1[a]	80.3 ± 13.8[b]	68.6 ± 14.2	8.04	0.003[#]
BMI	24.0 ± 2.0[a]	27.7 ± 4.0[b]	35.0 ± 5.8[c]	28.9 ± 6.1	18.91	<0.001[#]
Total body fat (kg)	14.8 ± 2.8[a]	22.5 ± 5.5[b]	37.9 ± 9.8[c]	25.0 ± 11.6	32.77	<0.001[#]
Waist circumference (cm)	78.1 ± 6.6[a]	80.2 ± 12.5[a]	100.9 ± 20.6[b]	86.2 ± 17.4	5.91	0.011[#]
Waist-to-height ratio	0.49 ± 0.04[a]	0.53 ± 0.07[a]	0.67 ± 0.15[b]	0.56 ± 0.12	8.03	0.003[#]
Male cut-points 25.8%, 34.8%	**n=6**	**n=7**	**n=6**	**n=19**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	22.7 ± 4.1	22.6 ± 4.2	23.5 ± 3.2	22.9 ± 3.7		
Height (cm)	161.9 ± 6.3	159.6 ± 6.4	156.8 ± 6.7	159.4 ± 6.5		
Weight (kg)	63.5 ± 4.5	68.3 ± 9.3	81.6 ± 14.5	71.0 ± 12.3		
BMI	24.2 ± 1.0	26.8 ± 3.8	33.1 ± 4.6	28.0 ± 5.0		
Total body fat (kg)	14.2 ± 2.1	20.0 ± 4.4	33.7 ± 7.5	22.5 ± 9.5		
Waist circumference (cm)	79.0 ± 5.3	85.1 ± 7.9	99.5 ± 8.9	87.7 ± 11.2		
Waist-to-height ratio	0.49 ± 0.03	0.53 ± 0.05	0.63 ± 0.05	0.55 ± 0.07		
Female cut-points 36.0%, 45.7%	**n=5**	**n=5**	**n=5**	**n=15**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	25.2 ± 3.8	22.0 ± 1.9	22.4 ± 3.8	23.2 ± 3.4		
Height (cm)	145.8 ± 2.9	149.1 ± 2.1	148.4 ± 5.9	147.8 ± 4.0		
Weight (kg)	48.6 ± 7.0	66.0 ± 5.1	82.4 ± 11.2	65.7 ± 16.2		
BMI	22.8 ± 2.8	29.7 ± 2.3	37.6 ± 6.5	30.0 ± 7.4		
Total body fat (kg)	14.7 ± 3.5	27.1 ± 3.6	42.8 ± 10.8	28.2 ± 13.5		
Waist circumference (cm)	66.5 ± 6.4	78.5 ± 5.4	108.1 ± 26.3	84.3 ± 23.3		
Waist-to-height ratio	0.46 ± 0.04	0.53 ± 0.04	0.73 ± 0.20	0.57 ± 0.16		

SD=standard deviation; ^Welch's ANOVA *P* value; [a, b, c] means sharing the same superscript do not differ significantly by a Games-Howell post hoc test
[#]$P<0.05$

Table 5.10 Differences in the means of age, anthropometric and DEXA measurements by waist circumference category

Waist circumference category*						
Total	**No increased risk n=21 (62%)**	**Increased risk n=6 (18%)**	**High risk n=7 (20%)**	**Total n=34 (100%)**	$F_{2,31}$	***P* value^**
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	23.0 ± 3.9	24.3 ± 2.1	22.0 ± 3.2	23.0 ± 3.5	1.32	0.300
Height (cm)	154.7 ± 8.5	155.5 ± 7.0	152.1 ± 8.1	154.3 ± 8.0	0.35	0.713
Weight (kg)	60.6 ± 8.9^{a}	76.1 ± 5.8^{b}	86.5 ± 12.5^{b}	68.6 ± 14.2	19.61	<0.001$^{\#}$
BMI	25.3 ± 3.0^{a}	31.5 ± 2.3^{b}	37.5 ± 5.9^{b}	28.9 ± 6.1	23.67	<0.001$^{\#}$
Total body fat (kg)	18.1 ± 5.5^{a}	28.6 ± 4.5^{b}	42.6 ± 9.1^{c}	25.0 ± 11.6	27.39	<0.001$^{\#}$
Total body fat (%)	29.3 ± 7.1^{a}	36.9 ± 5.4^{b}	47.8 ± 5.5^{c}	34.5 ± 9.8	24.12	<0.001$^{\#}$
Waist-to-height ratio	0.50 ± 0.05^{a}	0.59 ± 0.02^{b}	0.72 ± 0.16^{b}	0.56 ± 0.12	21.73	<0.001$^{\#}$
Male	**n=13 (68%)**	**n=4 (21%)**	**n=2 (11%)**	**n=19 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	22.4 ± 4.1	25.5 ± 1.3	21.0 ± 0.0	22.9 ± 3.7		
Height (cm)	159.2 ± 7.3	159.2 ± 5.2	161.3 ± 3.9	159.4 ± 6.5		
Weight (kg)	64.5 ± 6.0	79.2 ± 3.2	96.6 ± 12.0	71.0 ± 12.3		
BMI	25.5 ± 2.6	31.4 ± 2.8	37.3 ± 6.4	28.0 ± 5.0		
Total body fat (kg)	17.8 ± 5.2	28.1 ± 5.2	42.1 ± 6.1	22.5 ± 9.5		
Total body fat (%)	26.7 ± 6.4	34.7 ± 4.9	42.1 ± 0.14	30.0 ± 7.8		
Waist-to-height ratio	0.52 ± 0.06	0.60 ± 0.02	0.69 ± 0.02	0.55 ± 0.07		
Female	**n=8 (53%)**	**n=2 (13%)**	**n=5 (33%)**	**n=15 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	24.0 ± 3.6	22.0 ± 0.0	22.4 ± 3.8	23.2 ± 3.4		
Height (cm)	147.3 ± 3.3	148.2 ± 1.1	148.4 ± 5.9	147.8 ± 4.0		
Weight (kg)	54.2 ± 9.6	69.9 ± 4.5	82.4 ± 11.2	65.7 ± 16.2		
BMI	24.9 ± 3.6	31.8 ± 1.6	37.6 ± 6.5	30.0 ± 7.4		
Total body fat (kg)	18.7 ± 6.3	29.8 ± 4.0	42.8 ± 10.8	28.2 ± 13.5		
Total body fat (%)	33.6 ± 6.5	41.4 ± 3.5	50.0 ± 4.7	40.1 ± 9.4		
Waist-to-height ratio	0.47 ± 0.04	0.57 ± 0.01	0.73 ± 0.20	0.57 ± 0.16		

SD=standard deviation; *waist circumference classified using NHMRC cut-points (NHMRC, 2013b)
^Welch's ANOVA *P* value; $^{a, b, c}$ means sharing the same superscript do not differ significantly by a Games-Howell post hoc test; $^{\#}P<0.05$

Table 5.11 Differences in the means of age, anthropometric and DEXA measurements by waist circumference tertiles

	Waist circumference tertiles					
Total cut-points 78.1 cm, 93.6 cm	**Lowest tertile n=11**	**Middle tertile n=12**	**Highest tertile n=11**	**Total n=34**	$F_{2,31}$	***P* value^**
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	23.4 ± 4.3	22.5 ± 3.3	23.3 ± 3.1	23.0 ± 3.5	0.21	0.810
Height (cm)	150.0 ± 5.7	157.8 ± 8.8	154.7 ± 7.7	154.3 ± 8.0	3.33	0.056
Weight (kg)	55.7 ± 8.7[a]	66.6 ± 5.5[b]	83.8 ± 10.5[c]	68.6 ± 14.2	22.66	<0.001[#]
BMI	24.6 ± 3.2[a]	26.9 ± 3.4[a]	35.3 ± 5.7[b]	28.9 ± 6.1	14.12	<0.001[#]
Total body fat (kg)	17.3 ± 5.8[a]	20.8 ± 6.5[a]	37.3 ± 10.6[b]	25.0 ± 11.6	14.76	<0.001[#]
Total body fat (%)	30.6 ± 7.7[a]	30.2 ± 8.0[a]	43.0 ± 8.3[b]	34.5 ± 9.8	8.64	0.002[#]
Waist-to-height ratio	0.47 ± 0.04[a]	0.54 ± 0.05[b]	0.68 ± 0.14[c]	0.56 ± 0.12	14.51	<0.001[#]
Male cut-points 81.9 cm, 93.7 cm	**n=6**	**n=7**	**n=6**	**n=19**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	22.5 ± 5.2	22.3 ± 3.3	24.0 ± 2.5	22.9 ± 3.7		
Height (cm)	159.3 ± 5.4	159.2 ± 9.1	159.9 ± 4.5	159.4 ± 6.5		
Weight (kg)	61.4 ± 4.7	67.1 ± 6.0	85.0 ± 10.7	71.0 ± 12.3		
BMI	24.2 ± 1.4	26.6 ± 3.0	33.4 ± 4.7	28.0 ± 5.0		
Total body fat (kg)	14.9 ± 1.8	20.2 ± 6.1	32.7 ± 8.7	22.5 ± 9.5		
Total body fat (%)	24.0 ± 3.2	29.1 ± 7.7	37.2 ± 5.4	30.0 ± 7.8		
Waist-to-height ratio	0.48 ± 0.03	0.54 ± 0.06	0.63 ± 0.05	0.55 ± 0.07		
Female cut-points 72.5 cm, 91.2 cm	**n=5**	**n=5**	**n=5**	**n=15**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Age (y)	24.2 ± 3.6	23.0 ± 3.3	22.4 ± 3.8	23.2 ± 3.4		
Height (cm)	147.1 ± 3.7	147.8 ± 2.3	148.4 ± 5.9	147.8 ± 4.0		
Weight (kg)	50.3 ± 9.0	64.4 ± 7.6	82.4 ± 11.2	65.7 ± 16.2		
BMI	23.1 ± 3.2	29.4 ± 2.8	37.6 ± 6.5	30.0 ± 7.4		
Total body fat (kg)	16.4 ± 5.2	25.5 ± 6.5	42.8 ± 10.8	28.2 ± 13.5		
Total body fat (%)	32.0 ± 6.3	38.2 ± 6.2	50.0 ± 4.7	40.1 ± 9.4		
Waist-to-height ratio	0.45 ± 0.03	0.54 ± 0.03	0.73 ± 0.2	0.57 ± 0.16		

SD=standard deviation; ^Welch's ANOVA *P* value

[a, b, c] means sharing the same superscript do not differ significantly by a Games-Howell post hoc test; [#]$P<0.05$

Table 5.12 Differences in the means of age, anthropometric and DEXA measurements by waist-to-height ratio category

	Waist-to-height ratio category*				
Total	**No increased risk n=11 (32%)**	**Increased risk n=23 (68%)**	**Total n=34 (100%)**	**Difference in means (95% CI) [increased risk v. no increased risk]**	***P* value^**
	Mean ± SD	**Mean ± SD**	**Mean ± SD**		
Age (y)	23.4 ± 4.3	22.9 ± 3.2	23.0 ± 3.5	0.5 (-2.6, 3.6)	0.739
Height (cm)	155.7 ± 9.8	153.6 ± 7.1	154.3 ± 8.0	2.1 (-4.9, 9.2)	0.528
Weight (kg)	57.3 ± 9.7	74.1 ± 12.8	68.6 ± 14.2	-16.7 (-24.9, -8.6)	<0.001#
BMI	23.5 ± 2.2	31.5 ± 5.7	28.9 ± 6.1	-8.0 (-10.8, -5.2)	<0.001#
Total body fat (kg)	15.7 ± 3.6	29.5 ± 11.5	25.0 ± 11.6	-13.7 (-19.1, -8.4)	<0.001#
Total body fat (%)	27.5 ± 6.3	37.8 ± 9.5	34.5 ± 9.8	-10.4 (-16.0, -4.8)	0.001#
Waist circumference (cm)	71.9 ± 7.3	93.1 ± 16.7	86.2 ± 17.4	-21.1 (-29.5, -12.7)	<0.001#
Male	**n=6 (32%)**	**n=13 (68%)**	**n=19 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**		
Age (y)	22.7 ± 5.0	23.0 ± 3.1	22.9 ± 3.7		
Height (cm)	162.9 ± 6.8	157.8 ± 5.9	159.4 ± 6.5		
Weight (kg)	63.2 ± 5.5	74.6 ± 13.1	71.0 ± 12.3		
BMI	23.8 ± 1.3	29.9 ± 4.9	28.0 ± 5.0		
Total body fat (kg)	15.2 ± 2.0	25.9 ± 9.7	22.5 ± 9.5		
Total body fat (%)	23.6 ± 2.9	33.0 ± 7.6	30.0 ± 7.8		
Waist circumference (cm)	76.8 ± 4.1	92.8 ± 9.6	87.7 ± 11.2		
Female	**n=5 (33%)**	**n=10 (67%)**	**n=15 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**		
Age (y)	24.2 ± 3.6	22.7 ± 3.4	23.2 ± 3.4		
Height (cm)	147.1 ± 3.7	148.1 ± 4.3	147.8 ± 4.0		
Weight (kg)	50.3 ± 9.0	73.4 ± 13.1	65.7 ± 16.2		
BMI	23.1 ± 3.2	33.5 ± 6.4	30.0 ± 7.4		
Total body fat (kg)	16.4 ± 5.2	34.1 ± 12.4	28.2 ± 13.5		
Total body fat (%)	32.0 ± 6.3	44.1 ± 8.1	40.1 ± 9.4		
Waist circumference (cm)	66.2 ± 6.1	93.4 ± 23.6	84.3 ± 23.3		

SD=standard deviation; CI=confidence interval; *no increased risk <0.5, increased risk ≥0.5 (Ashwell & Hsieh, 2005)
^Two-tailed, independent samples t-test *P* value; #*P*<0.05

Table 5.13 Differences in the means of age, anthropometric and DEXA measurements by the waist-to-height ratio 50^{th} percentile

	Waist-to-height ratio 50^{th} percentile				
Total cut-point 0.53 cm	**<50^{th} percentile n=16 (47%)**	**≥50^{th} percentile n=18 (53%)**	**Total n=34**	**Difference in means (95% CI) [<50^{th} percentile v. ≥50^{th} percentile]**	***P* value^**
	Mean ± SD	**Mean ± SD**	**Mean ± SD**		
Age (y)	23.0 ± 4.1	23.1 ± 3.1	23.0 ± 3.5	-0.06 (-2.6, 2.5)	0.965
Height (cm)	155.1 ± 9.3	153.6 ± 6.8	154.3 ± 8.0	1.5 (-4.3, 7.3)	0.600
Weight (kg)	59.4 ± 9.7	76.8 ± 12.5	68.6 ± 14.2	-17.4 (-25.1, -9.6)	<0.001[#]
BMI	24.6 ± 2.8	32.7 ± 5.8	28.9 ± 6.1	-8.1 (-11.2, -4.9)	<0.001[#]
Total body fat (kg)	17.3 ± 5.2	31.9 ± 11.5	25.0 ± 11.6	-14.6 (-20.8, -8.4)	<0.001[#]
Total body fat (%)	28.8 ± 7.2	39.5 ± 9.2	34.5 ± 9.8	-10.7 (-16.5, -5.0)	0.001[#]
Waist circumference (cm)	74.1 ± 7.3	97.0 ± 16.7	86.2 ± 17.4	-22.9 (-31.9, -14.0)	<0.001[#]
Male cut-point 0.53 cm	**n=10 (53%)**	**n=9 (47%)**	**n=19 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**		
Age (y)	21.9 ± 4.3	24.0 ± 2.7	22.9 ± 3.7		
Height (cm)	161.2 ± 6.4	157.4 ± 6.2	159.4 ± 6.5		
Weight (kg)	63.5 ± 6.5	79.2 ± 12.2	71.0 ± 12.3		
BMI	24.4 ± 1.7	31.9 ± 4.4	28.0 ± 5.0		
Total body fat (kg)	15.8 ± 3.5	30.0 ± 8.4	22.5 ± 9.5		
Total body fat (%)	24.2 ± 3.6	36.4 ± 5.7	30.0 ± 7.8		
Waist circumference (cm)	79.3 ± 4.5	97.1 ± 8.3	87.7 ± 11.2		
Female cut-point 0.52 cm	**n=7 (47%)**	**n=8 (53%)**	**n=15 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**		
Age (y)	24.0 ± 3.9	22.5 ± 3.0	23.2 ± 3.4		
Height (cm)	147.3 ± 3.5	148.1 ± 4.6	147.8 ± 4.0		
Weight (kg)	53.3 ± 10.0	76.5 ± 12.2	65.7 ± 16.2		
BMI	24.4 ± 3.7	34.9 ± 6.2	30.0 ± 7.4		
Total body fat (kg)	17.8 ± 6.2	37.3 ± 11.3	28.2 ± 13.5		
Total body fat (%)	32.5 ± 6.2	46.7 ± 5.9	40.1 ± 9.4		
Waist circumference (cm)	68.8 ± 6.7	98.0 ± 24.4	84.3 ± 23.3		

SD=standard deviation; CI=confidence interval; ^Two-tailed, independent samples t-test *P* value; $P<0.05$

Table 5.14 Summary of differences in the means between BMI, percentage body fat, waist circumference and waist-to-height ratio for young adults in the PANDs study

	Age (years)	Height (cm)	Weight (kg)	BMI (kg/m²)	Total body fat (kg)	Total body fat (%)	Waist circumference (cm)	Waist-to-height ratio
BMI								
Healthy weight and overweight	X	X	X		√***	X	X	√***
Healthy weight and obese	X	X	√***		√***	√***	√**	√***
Overweight and obese	X	X	√***		√***	√***	√**	√***
Percentage body fat								
Healthy weight and overweight	X	X	√***	X	√***		X	X
Healthy weight and obese	X	X	√***	√***	√***		√***	√**
Overweight and obese	X	X	√***	√***	√***		√***	√**
Waist circumference								
No increased risk and increased risk	X	X	√***	√***	√***	√***		√***
No increased risk and high risk	X	X	√***	√***	√***	√***		√***
Increased risk and high risk	X	X	X	X	√***	√***		X
Waist-to-height ratio								
No increased risk and increased risk	X	X	√^^^	√^^^	√^^^	√^^	√^^^	

X=no difference in the means; √=difference in the means

, * significantly different by Welch's ANOVA at *P*<0.01 and *P*<0.001 respectively

^^, ^^^significantly different by two tailed, independent samples t-test at *P*<0.01 and *P*<0.001, respectively

5.3.3 Sensitivity and specificity of BMI cut-points

Table 5.15 shows the relationship between standard adult BMI cut-points (NHMRC, 2013b) and percentage body fat cut-points. Table 5.16 details the sensitivity and specificity of the standard BMI cut-points for adult participants using standard percentage body fat cut-points (Pasco et al., 2014) as the gold standard.

For the healthy weight BMI cut-point, sensitivity was high for males (100%), with both males in the healthy weight percentage body fat category being true positives. However the positive predictive value was low (33.3%), as four males in the healthy weight BMI category had a percentage body fat in the overweight category. Sensitivity of the healthy weight BMI cut-point was lower in females (60.0%), however there was a higher positive predictive value (100%) with all females within the healthy weight BMI category having a percentage body fat in the healthy weight category. Specificity and negative predictive value were high for both sexes, contributing to an overall efficiency of 82.4% for the BMI healthy weight cut-point.

Sensitivity and predictive value of the overweight BMI cut-point were low for both males and females. Half the males in the overweight percentage body fat category (4/8) had a BMI in the healthy weight category and half the females in the overweight percentage body fat category (2/4), had a BMI in the obese category. The overall efficiency of the BMI overweight cut-point was 67.6%, lower than the efficiencies of both the healthy weight and obese BMI cut-points.

Sensitivity (80.0%) and specificity (89.5%) were high overall for the obese BMI cut-point, with 100% sensitivity in females and 100% specificity in males. Positive and negative predictive values were also high overall (85.7% and 85.0%, respectively) contributing to an overall efficiency of 85.3% for the obese BMI cut-point.

Table 5.15 Relationship between BMI and percentage body fat categories

	Percentage body fat category**					
BMI category*	**Healthy weight**	**Overweight**	**Obese**	**Total**	χ^2	***P* value^**
Male						
Healthy weight (n)	2	4	0	6		
% within body fat category	100	50.0	0.0	31.6		
% within BMI category	33.3	66.7	0.0	100		
Overweight (n)	0	4	3	7		
% within body fat category	0.0	50.0	33.3	36.8		
% within BMI category	0.0	57.1	42.9	100		
Obese (n)	0	0	6	6		
% within body fat category	0.0	0.0	66.7	31.6		
% within BMI category	0.0	0.0	100	100		
Total (n)	2	8	9	19		
% within body fat category	100	100	100	100		
% within BMI category	10.5	42.1	47.4	100		
Female						
Healthy weight (n)	3	0	0	3		
% within body fat category	60.0	0.0	0.0	20		
% within BMI category	100	0.0	0.0	100		
Overweight (n)	2	2	0	4		
% within body fat category	40.0	50.0	0.0	26.7		
% within BMI category	50.0	50.0	0.0	100		
Obese (n)	0	2	6	8		
% within body fat category	0.0	50.0	100	53.3		
% within BMI category	0.0	25.0	75.0	100		
Total (n)	5	4	6	15		
% within body fat category	100	100	100	100		
% within BMI category	33.3	26.7	40.0	100		
Total					21.55	<0.001[#]
Healthy weight (n)	5	4	0	9		
% within body fat category	71.4	33.3	0.0	26.5		
% within BMI category	55.6	44.4	0.0	100		
Overweight (n)	2	6	3	11		
% within body fat category	28.6	50.0	20.0	32.4		
% within BMI category	18.2	54.5	27.3	100		
Obese (n)	0	2	12	14		
% within body fat category	0.0	16.7	80.0	41.2		
% within BMI category	0.0	14.3	85.7	100		
Total (n)	7	12	15	34		
% within body fat category	100	100	100	100		
% within BMI category	20.6	35.3	44.1	100		

*BMI of young adults classified using NHMRC cut-points (NHMRC, 2013b)
**percentage body fat classified using cut-points developed using age, sex and BMI (Pasco et al., 2014)
^Two-tailed Pearson's chi-squared test of independence *P* value
[#]P<0.05

Table 5.16 Sensitivity and specificity of standard BMI cut-points for healthy weight, overweight and obesity* based on percentage body fat cut-points**

	Male (n=19)	Female (n=15)	Total (n=34)
Healthy weight BMI<25	**%**	**%**	**%**
Sensitivity	100	60.0	71.4
Specificity	76.5	100	85.2
Positive predictive value	33.3	100	55.6
Negative predictive value	100	83.3	92.0
Efficiency	78.9	86.7	82.4
Overweight BMI ≥25 <30			
Sensitivity	50.0	50.0	50.0
Specificity	72.7	81.8	77.3
Positive predictive value	57.1	50.0	54.5
Negative predictive value	66.7	81.8	73.9
Efficiency	63.2	73.3	67.6
Obese BMI ≥30			
Sensitivity	66.7	100	80.0
Specificity	100	77.8	89.5
Positive predictive value	100	75.0	85.7
Negative predictive value	76.9	100	85.0
Efficiency	84.2	86.7	85.3

*BMI of young adults classified using NHMRC cut-points (NHMRC, 2013b); **percentage body fat classified using cut-points developed using age, sex and BMI (Pasco et al., 2014)

As seen in Table 5.17 percentage body fat tertile cut-points were higher than the cut-points for percentage body fat proposed by Pasco et al. (2014) and there was a relationship between BMI categories and percentage body fat tertiles for the total group ($P<0.001$). For males and females respectively, the sensitivity of the BMI obese category against the highest tertile (83.3%, 100%) was higher than the sensitivity of the BMI overweight category against the middle tertile (57.1%, 40.0%) and the sensitivity of the BMI healthy weight category against the lowest tertile (66.7%, 60.0%).

Table 5.17 Relationship between standard BMI categories* and percentage body fat tertiles

	BMI category					
Percentage body fat tertiles	**Healthy weight**	**Overweight**	**Obese**	**Total**	χ^2	***P* value^**
Male cut-points 25.8%, 34.8%						
Lowest tertile (n)	4	2	0	6		
% within body fat tertile	66.7	33.3	0.0	100		
% within BMI category	66.7	28.6	0.0	31.6		
Middle tertile(n)	2	4	1	7		
% within body fat tertile	28.6	57.1	14.3	100		
% within BMI category	33.3	57.1	16.7	36.8		
Highest tertile (n)	0	1	5	6		
% within body fat tertile	0.0	16.7	83.3	100		
% within BMI category	0.0	14.3	83.3	31.6		
Total (n)	6	7	6	19		
% within body fat tertile	31.6	36.8	31.6	100		
% within BMI category	100	100	100	100		
Female cut-points 36.0%, 45.7%						
Lowest tertile (n)	3	2	0	5		
% within body fat tertile	60.0	40.0	0.0	100		
% within BMI category	100	50.0	0.0	33.3		
Middle tertile(n)	0	2	3	5		
% within body fat tertile	0.0	40.0	60.0	100		
% within BMI category	0.0	50.0	37.5	33.3		
Highest tertile (n)	0	0	5	5		
% within body fat tertile	0.0	0.0	100	100		
% within BMI category	0.0	0.0	62.5	33.3		
Total (n)	3	4	8	15		
% within body fat tertile	20.0	26.7	53.3	100		
% within BMI category	100	100	100	100		
Total cut-points 27.6%, 39.6%					23.45	<0.001#
Lowest tertile (n)	7	4	0	11		
% within body fat tertile	63.6	36.4	0.0	100		
% within BMI category	77.8	36.4	0.0	32.4		
Middle tertile(n)	2	6	4	12		
% within body fat tertile	16.7	50.0	33.3	100		
% within BMI category	22.2	54.5	28.6	35.3		
Highest tertile (n)	0	1	10	11		
% within body fat tertile	0.0	9.1	90.9	100		
% within BMI category	0.0	9.1	71.4	32.4		
Total (n)	9	11	14	34		
% within body fat tertile	26.5	32.4	41.2	100		
% within BMI category	100	100	100	100		

*BMI of young adults classified using NHMRC cut-points (NHMRC, 2013b)
^Two-tailed Pearson's chi-squared test of independence *P* value
#$P<0.05$

Table 5.18 details the relationship between standard BMI categories and waist circumference risk categories (NHMRC, 2013b). All male (6/6) and female (3/3) participants with a BMI in the healthy weight category had a waist circumference which put them in the 'not increased risk' category (high predictive value). Of the males and females with a BMI in the overweight category sensitivity was low with all females (4/4) and almost all males (6/7) with a BMI in the overweight category being false positives with waist circumferences in the 'not increased' category. All male (2/2) and female (5/5) participants with a waist circumference categorised in the 'high risk' category had BMI in the obese category (high sensitivity), however not all male (2/6) and female (5/8) participants who had a BMI in the obese category had a waist circumference which placed them in the 'high risk' category (lower predictive value).

When using tertiles rather than standard waist circumference categories (see Table 5.19), there continued to be a relationship between waist circumference and BMI category with 100% (3/3) of female and 50.0% (3/6) of male participants with a BMI in the healthy weight category in the lowest waist circumference tertile and 71.4% (10/14) of participants with a BMI in the obese category in the highest waist circumference tertile. Both male (81.9 cm, 93.7 cm) and one female (72.5 cm) tertile cut-points were lower than the standard waist circumference cut-points for males (94 cm, 102 cm) and females (80 cm, 88 cm) (NHMRC, 2013b).

Table 5.18 Relationship between BMI and waist circumference categories

	BMI category*					
Waist circumference category*	**Healthy weight**	**Overweight**	**Obese**	**Total**	χ^2	***P* value^**
Male						
Not increased risk (n)	6	6	1	13		
% within waist category	46.2	46.2	7.7	100		
% within BMI category	100	85.7	16.7	68.4		
Increased risk (n)	0	1	3	4		
% within waist category	0.0	25.0	75.0	100		
% within BMI category	0.0	14.3	50.0	21.1		
High risk (n)	0	0	2	2		
% within waist category	0.0	0.0	100	100		
% within BMI category	0.0	0.0	33.3	10.5		
Total (n)	6	7	6	19		
% within waist category	31.6	36.8	31.6	100		
% within BMI category	100	100	100	100		
Female						
Not increased risk (n)	3	4	1	8		
% within waist category	37.5	50.0	12.5	100		
% within BMI category	100	100	12.5	53.3		
Increased risk (n)	0	0	2	2		
% within waist category	0.0	0.0	100	100		
% within BMI category	0.0	0.0	25.0	13.3		
High risk (n)	0	0	5	5		
% within waist category	0.0	0.0	100	100		
% within BMI category	0.0	0.0	62.5	33.3		
Total (n)	3	4	8	15		
% within waist category	20.0	26.7	53.3	100		
% within BMI category	100	100	100	100		
Total					23.39	<0.001[#]
Not increased risk (n)	9	10	2	21		
% within waist category	42.9	47.6	9.5	100		
% within BMI category	100	90.9	14.3	61.8		
Increased risk (n)	0	1	5	6		
% within waist category	0.0	16.7	83.3	100		
% within BMI category	0.0	9.1	35.7	17.6		
High risk (n)	0	0	7	7		
% within waist category	0.0	0.0	100	100		
% within BMI category	0.0	0.0	50.0	20.6		
Total (n)	9	11	14	34		
% within waist category	26.5	32.4	41.2	100		
% within BMI category	100	100	100	100		

*BMI and waist circumference of young adults classified using NHMRC cut-points (NHMRC, 2013b)
^Two-tailed Pearson's chi-squared test of independence *P* value
[#]$P<0.05$

Table 5.19 Relationship between BMI categories and waist circumference tertiles

	BMI category*					
Waist circumference tertiles	**Healthy Weight**	**overweight**	**Obese**	**Total**	χ^2	***P* value^**
Male cut-points 81.9 cm, 93.7 cm						
Lowest tertile (n)	3	3	0	6		
% within Waist tertile	50.0	50.0	0.0	100		
% within BMI category	50.0	42.9	0.0	31.6		
Middle tertile(n)	3	3	1	7		
% within waist tertile	42.9	42.9	14.3	100		
% within BMI category	50.0	42.9	16.7	36.8		
Highest tertile (n)	0	1	5	6		
% within waist tertile	0.0	16.7	83.3	100		
% within BMI category	0.0	14.3	83.3	31.6		
Total (n)	6	7	6	19		
% within waist tertile	31.6	36.8	31.6	100		
% within BMI category	100	100	100	100		
Female cut-points 72.5 cm, 91.2 cm						
Lowest tertile (n)	3	2	0	5		
% within waist tertile	60.0	40.0	0.0	100		
% within BMI category	100	50	0.0	33.3		
Middle tertile(n)	0	2	3	5		
% within waist tertile	0.0	40.0	60.0	100		
% within BMI category	0.0	50.0	37.5	33.3		
Highest tertile (n)	0	0	5	5		
% within waist tertile	0.0	0.0	100	100		
% within BMI category	0.0	0.0	62.5	33.3		
Total (n)	3	4	8	15		
% within waist tertile	20.0	26.7	53.3	100		
% within BMI category	100	100	100	100		
Total cut-points 78.1 cm, 93.6 cm					17.49	0.002#
Lowest tertile (n)	5	5	1	11		
% within waist tertile	45.5	45.5	9.1	100		
% within BMI category	55.6	45.5	7.1	32.4		
Middle tertile(n)	4	5	3	12		
% within waist tertile	33.3	41.7	25.0	100		
% within BMI category	44.4	45.5	21.4	35.3		
Highest tertile (n)	0	1	10	11		
% within waist tertile	0.0	9.1	90.9	100		
% within BMI category	0.0	9.1	71.4	32.4		
Total (n)	9	11	14	34		
% within waist tertile	26.5	32.4	41.2	100		
% within BMI category	100	100	100	100		

*BMI of young adults classified using NHMRC cut-points (NHMRC, 2013b)
^Two-tailed Pearson's chi-squared test of independence *P* value
#P<0.05

Table 5.20 shows the relationship between standard BMI categories and the waist-to-height ratio. All participants with a BMI in the obese category (14/14) had a waist-to-height ratio ≥0.5, placing them in the increased risk category (high predictive value). All females (3/3) and 66.7% (4/6) of males with a BMI in the healthy weight category had a waist-to-height ratio that placed them in the 'no increased risk' category. Of the female participants with a BMI in the overweight category, half (2/4) had a waist-to-height ratio in the 'no increased risk' category and half (2/4) had a waist-to-height ratio in the 'increased risk' category. Of the male participants with a BMI in the overweight category, 71.4% (5/7) had a waist-to-height ratio in the 'increased risk' category and 28.6% (2/7) had a waist-to-height ratio in the 'no increased risk' category.

As shown in Table 5.21 the 50th percentile cut-point for waist-to-height ratio was 0.53 in males and 0.52 in females, higher than the 0.50 reference value (Ashwell & Hsieh, 2005). When using the 50% tertile instead of the waist-to-height cut-point, 100% of both males (6/6) and females (3/3) with a BMI in the healthy weight category had a waist-to-height ratio that placed them in the 'no increased risk' category. Additionally, 100% of males (6/6) and 87.5% (7/8) of females with a BMI in the obese category had a waist-to-height ratio in the 'increased risk' waist-to-height category.

Table 5.20 Relationship between standard BMI and waist-to-height ratio categories

	BMI category*					
Waist-to-height ratio category**	**Healthy weight**	**Overweight**	**Obese**	**Total**	χ^2	***P* value^**
Male						
No increased risk (n)	4	2	0	6		
% within waist height category	66.7	33.3	0.0	100		
% within BMI category	66.7	28.6	0.0	31.6		
Increased risk (n)	2	5	6	13		
% within waist height category	15.4	38.5	46.2	100		
% within BMI category	33.3	71.4	100	68.4		
Total (n)	6	7	6	19		
% within waist height category	31.6	36.8	31.6	100		
% within BMI category	100	100	100	100		
Female						
No increased risk (n)	3	2	0	5		
% within waist height category	60.0	40.0	0.0	100		
% within BMI category	100	50.0	0.0	33.3		
Increased risk (n)	0	2	8	10		
% within waist height category	0.0	20	80.0	100		
% within BMI category	0.0	50	100	66.7		
Total (n)	3	4	8	15		
% within waist height category	20.0	26.7	53.3	100		
% within BMI category	100	100	100	100		
Total					15.26	<0.001[#]
No increased risk (n)	7	4	0	11		
% within waist height category	63.6	36.4	0.0	100		
% within BMI category	77.8	36.4	0.0	32.4		
Increased risk (n)	2	7	14	23		
% within waist height category	8.7	30.4	60.9	100		
% within BMI category	22.2	63.6	100	67.6		
Total (n)	9	11	14	34		
% within waist height category	26.5	32.4	41.2	100		
% within BMI category	100	100	100	100		

*BMI of young adults classified using NHMRC cut-points (NHMRC, 2013b)
**waist-to-height ratio of young adults classified as increased risk if <0.5 (Ashwell & Hsieh, 2005)
^Two-tailed Pearson's chi-squared test of independence *P* value
[#]*P*<0.05

Table 5.21 Relationship between standard BMI categories* and waist-to-height ratio 50th percentile

	BMI category					
Waist-to-height ratio 50th percentile	**Healthy weight**	**Overweight**	**Obese**	**Total**	χ^2	***P* value^**
Male cut-point 0.53 cm						
<50th percentile (n)	6	4	0	10		
% within percentile group	60	40.0	0.0	100		
% within BMI category	100	57.1	0.0	52.6		
≥ 50th percentile (n)	0	3	6	9		
% within percentile group	0.0	33.3	66.7	100		
% within BMI category	0.0	42.9	100	47.4		
Total (n)	6	7	6	19		
% within percentile group	31.6	36.8	31.6	100		
% within BMI category	100	100	100	100		
Female cut-point 0.52 cm						
<50th percentile (n)	3	3	1	7		
% within percentile group	42.9	42.9	14.3	100		
% within BMI category	100	75.0	12.5	46.7		
≥ 50th percentile (n)	0	1	7	8		
% within percentile group	0.0	12.5	87.5	100		
% within BMI category	0.0	25.0	87.5	53.3		
Total (n)	3	4	8	15		
% within percentile group	20.0	26.7	53.3	100		
% within BMI category	100	100	100	100		
Total cut-point 0.53 cm					16.49	<0.001#
<50th percentile (n)	8	7	1	16		
% within percentile group	50.0	43.8	6.3	100		
% within BMI category	88.9	63.6	7.1	47.1		
≥ 50th percentile (n)	1	4	13	18		
% within percentile group	5.6	22.2	72.2	100		
% within BMI category	11.1	36.4	92.9	52.9		
Total (n)	9	11	14	34		
% within percentile group	26.5	32.4	41.2	100		
% within BMI category	100	100	100	100		

*BMI of young adults classified using NHMRC cut-points (NHMRC, 2013b)
^Two-tailed Pearson's chi-squared test of independence *P* value
#$P<0.05$

5.4 Discussion

The aims of this study were to describe the body composition and performance of standard BMI, waist circumference and waist-to-height ratio cut-points for a sample of Australian adolescents and young adults with Down syndrome. Although the proportions of overweight and obesity in adolescents and young adults with Down syndrome in this study were high, lower sensitivity of the BMI overweight cut-point for adults indicated that Down syndrome specific BMI cut-points may be required. Limitations observed with the use of standard waist circumference cut-points suggested that the waist-to-height ratio may be a more useful measure of abdominal obesity in adolescents and young adults with Down syndrome.

Compared to adolescents aged 12-15 years and young adults aged 18-24 years in the in the 2014-15 National Health Survey (Australian Bureau of Statistics, 2015b), adolescent males in the PANDs study were 3.0 kg lighter and 9.8 cm shorter, adolescent females were 0.9 kg heavier and 17.9 cm shorter, young adult males were 13.1 kg lighter and 20.0 cm shorter and young adult females were 4.4 kg lighter and 17.7 cm shorter. As a consequence, mean BMIs for participants in the PANDs study were higher than those of adolescents and young adults in the 2014-15 National Health Survey (Australian Bureau of Statistics, 2015b) and 40.0% (2/5) of adolescent males, 75.0% (6/8) of adolescent females, 66.6% (18/27) of young adult males and 67.4% (31/46) of young adult females had a BMI classified as overweight or as obese.

In the PANDs study young adult females who participated in DEXA had a greater percentage of body fat compared to young adult males, with the percentage body fat of 66.7% (10/15) of females and 89.5% (17/19) of males classified as overweight or as obese using age and sex specific percentage body fat cut-points (Pasco et al., 2014). These proportions of overweight and obesity in young adults with Down syndrome were higher than percentages reported for young adults aged 20-29 years without Down syndrome (Pasco et al., 2014) however as the PANDs study sample size was small and these percentage body fat cut-points were developed using a population-based sample of adults without Down syndrome, further research is required to validate their use for young adults with Down syndrome.

As judged by DEXA BMI was ineffective in discriminating between young adult participants in the healthy and overweight BMI categories but was able to discriminate between participants in the healthy weight and obese categories, and overweight and obese categories. Sensitivity of the overweight BMI cut-point was 50.0% for both young adult males and females, with the cut-point underestimating the proportion of males and overestimating the proportion of females who were overweight. Sensitivity was higher for the obese BMI cut-point with all young adult females and two-thirds of young adult males correctly classified as obese. Although specificity was higher than sensitivity for the overweight BMI cut-point, specificity and overall efficiency was greater still for the obese BMI cut-point (85.3%) indicating it performed better than the cut-point for overweight (67.6%).

Waist circumference of young adult males in the PANDs study was smaller than the waist circumference of young adults males in the 2014-15 National Health Survey (Australian Bureau of Statistics, 2015b) with both waist circumference tertile cut-points being below the standard waist circumference cut-points for males (NHMRC, 2013b) possibly due to the difference in height. Conversely, despite the shorter height also observed in young adult females in the PANDs study, mean waist circumference was greater than the mean waist circumferences of young adult females in the 2014-15 National Health Survey (Australian Bureau of Statistics, 2015b). This may be due to differences in body composition with greater truncal fat and lean masses observed in adolescent females with Down syndrome (González-Agüero, Ara, et al., 2011). Consequently when applying the standard Australian waist circumference cut-points for metabolic risk (NHMRC, 2013b), a smaller proportion of young adult males (6/27) and a greater proportion of young adult females (9/19) in the PANDs study had waist circumferences classified as ‘increased’ or ‘high risk’ compared to young adults in the 2014-15 National Health Survey (Australian Bureau of Statistics, 2015b). Although standard waist circumference cut-points (NHMRC, 2013b) for adult males discriminated between the means of weight, BMI and total body fat, this was not observed for adult females. These findings suggest that standard waist circumference cut-points may not be suitable for adults with Down syndrome and lower cut-points may be required.

When applying the waist-to-height cut-point for young adults (Ashwell & Hsieh, 2005) 63.0% of young adult males and 63.2% of young adult females in the PANDs study had a waist-to-height ratio that represented an increased metabolic risk. Unlike waist circumference, the waist-to-height ratio cut-point (Ashwell & Hsieh, 2005) discriminated between the means of BMI, total body fat (kg), total percentage body fat and waist circumference for both young adult males and females, indicating it may be a better predictor of metabolic risk for young adults with Down syndrome.

In previous studies involving adolescents and young adults with Down syndrome, the sensitivity of the CDC BMI-for-age growth chart 85th percentile cut-point has been high (Bandini et al., 2013; Hatch-Stein et al., 2016) with Hatch-Stein et al. (2016) also reporting high specificity. In the PANDs study the sensitivity of the NHMRC BMI cut-point for overweight (67.6%) was lower than previously reported for the CDC BMI-for-age growth chart 85th percentile cut-point (Bandini et al., 2013; Hatch-Stein et al., 2016) with specificity (77.3%) similar to that as reported by Hatch-Stein et al. (2016), indicating a lower proportion of true positives and a higher proportion of true negatives. As the purpose of classifying weight status in this instance was to identify those in need of intervention (Temple et al., 2010), a higher sensitivity Down syndrome specific cut-point for overweight may be required. In contrast to the BMI cut-point for overweight, sensitivity and specificity of the NHMRC BMI obesity cut-point was high in the PANDs study (80.0% and 89.5%, respectively), similar to the findings of Bandini et al. (2013), and should be used in future studies.

As discussed previously, the differences in height and possible differences in body composition observed in young people with Down syndrome indicate that waist circumference may not be the best predictor of metabolic risk for adults with Down syndrome and either Down syndrome specific cut-points and/or waist-height-ratio should be included in future studies. The proportion of young adults with Down syndrome with a waist-to-height ratio classified as ‘increased risk’ (63.0%, 29/46) was lower than the percentage reported in an earlier Spanish study (Real de Asua et al., 2014a), however mean age in the Spanish study was older (36 ± 11 years), and as the proportion of adults with Down syndrome classified as overweight and obese increases with age (Havercamp et al., 2017), a greater proportion at risk may be expected. As the number of studies using waist-to-height ratio with groups with Down syndrome is limited, further research is required.

There were several strengths and limitations of this study. This is the first study which has evaluated the performance of standard BMI cut-points in an Australian sample of young adults with Down syndrome. Although not all participants in the PANDs study participated in the DEXA scan, there was no noteworthy difference in the age, weight, height, BMI and height to waist ratio between those who did and did not participate in the scan. The waist circumference of young adult males who did not participate in the scan was smaller than the waist circumference of young adult males who did participate however the 95% confidence interval was very large. The present study is limited by the sample size, with only 59 adolescents and young adults participating and 34 participants with DEXA results, however the sample size is similar to that of similar Australian and international studies of anthropometry and body composition (see Table 1.1). The DEXA scan did not include measurement of visceral fat which would have been useful to assess the value of waist-to-height ratio as a marker of metabolic risk. Unfortunately, an insufficient number of adolescents participated in the DEXA scan to be able to statistically test the performance of the cut-points specific to this age group. Additionally, no control group was included in the study which would have been useful for comparison.

In conclusion, although the proportion of young adults with Down syndrome classified as overweight and obese using both BMI and percentage body fat was high, the low sensitivity of the BMI cut-point for overweight in adults suggests that Down syndrome specific cut-points for overweight are required so that the risks associated with overweight and obesity can be accurately assessed. Nevertheless, the high sensitivity of the BMI obese cut-point for adults, coupled with higher proportions of obesity in young adults with Down syndrome does support a higher metabolic risk. Compared to waist circumference, the waist-to-height ratio appears to be a more appropriate indicator of abdominal obesity for adults with Down syndrome and should be included in future studies of anthropometry and body composition. Longitudinal research investigating the relationship between waist-to-height ratio and health outcomes of young adults with Down syndrome is recommended.

Preface to Chapter 6

Chapter 6 is a transcript of the journal article co-authored by the candidate and available from http://www.mdpi.com/2072-6643/9/3/273.

Bathgate, K., J. Sherriff, H. Leonard, S. Dhaliwal, E. Delp, C. Boushey, and D. Kerr. 2017. "Feasibility of assessing diet with a mobile food record for adolescents and young adults with Down syndrome." *Nutrients* 9 (3):273. doi.10.3390/nu9030273.

As part of the PANDs study participants were asked to record usual food intake using a mobile food record (mFR). This journal article is a discussion of the feasibility of the mFR for adolescents and young adults with Down syndrome in comparison with a similarly aged cohort without Down syndrome from the Connecting Health and Technology Study (CHAT) (Kerr et al., 2016). The CHAT study "aimed to evaluate the effectiveness of tailored dietary feedback and weekly text messaging to improve dietary intake of fruit, vegetables and junk food over 6 months among a population-based sample of men and women (aged 18-30 years)" (Kerr et al., 2016). As discussed by Kerr et al. (2016) fruit, vegetables and junk food were selected as the food groups of interest as in the 2011-12 Australian Health Survey, young adults were reported to have consumed inadequate serves of fruit and vegetables and a high proportion of energy from discretionary foods (Australian Bureau of Statistics, 2014). Young adults were also reported to have consumed a high amount of sugar-sweetened beverages (Australian Bureau of Statistics, 2014).

Included in this Chapter are initial results of the mean number of food group serves reported (fruit, vegetables, energy-dense nutrient-poor [EDNP] foods, sugar sweetened beverages [SSB]) by participants in both studies. Serves of fruit (150 g), vegetables (75 g), EDNP foods (600 kJ) and SSB (600 kJ) were classified according to the Australian Guide to Healthy Eating (NHMRC, 2013a). Adolescents and young adults with Down syndrome were reported to have consumed a higher mean number of serves of fruit (2.2 ± 1.8 vs. 1.0 ± 0.9) and vegetables (2.4 ± 1.3 vs. 1.9 ± 1.0) compared to adolescents and young adults with Down syndrome, however there was no evident difference in the mean number of serves of energy-dense nutrient-poor foods and sugar sweetened beverages reported for the groups as a whole.

The candidate was not involved in any part of the CHAT study. The candidate collected and analysed all PANDs study data, performed all statistical analysis using data from the CHAT study and wrote the first draft of the journal article prior to input from co-authors. The candidate did receive assistance with image analysis in the PANDs study from a student in the Masters of Dietetics degree. In the PANDs study, all images were eligible to be included in the analysis, including those where the fiducial marker was missing.

Tables of analyses and discussion of the relationships between measures of body fatness (BMI, percentage body fat, waist circumference, waist-to-height ratio) and reported serves of vegetables, fruit, energy-dense nutrient-poor foods and sugar sweetened beverages follow in a supplement to Chapter 6.

Chapter 6 Feasibility of assessing diet with a mobile food record for adolescents and young adults with Down syndrome

6.1 Abstract

Technology-based methods for assessing diet in those with disability remains largely unexplored. The aim was to assess the feasibility of assessing diet with an image-based mobile food record application (mFR) in 51 adolescents and young adults with Down syndrome (PANDs). Adherence was also assessed with the instruction to include a fiducial marker object in the before and after eating images. The PANDs sample completed a four-day mFR and results were compared with a sample of young adults from the Connecting Health and Technology study (CHAT n=244). Compared to the CHAT sample, PANDs participants reported more fruit (2.2 ± 1.8 versus 1.0 ± 0.9 serves respectively) and vegetables (2.4 ± 1.3 versus 1.9 ± 1.0 serves, respectively), but no differences in energy-dense nutrient-poor (EDNP) foods and beverages were observed. Compared to CHAT, PANDs participants captured fewer images with the mFR (4.9 ± 2.3 versus 4.0 ± 1.5 images, respectively). Adherence to the instruction to include the fiducial marker in images was lower for PANDs compared with the CHAT sample (90.3% versus 96.5%). Due to the quality of information captured in images and the high acceptability of the fiducial marker, the mFR shows great promise as a feasible method of assessing diet in adolescents and young adults with Down syndrome.

6.2 Introduction

In Western Australia (WA), the prevalence of intellectual disability is 17 in 1000 live births, with Down syndrome being the most common biomedical cause accounting for 6.2% of all cases (Bourke et al., 2016). Down syndrome is associated with varying levels of intellectual disability as well as an increased risk of cardiac, gastrointestinal and endocrine disorders, orthopaedic conditions, hearing and sight impairments, dementia and obesity (Roizen & Patterson, 2003). Due to advancing medical and social advancements, life expectancy for people with Down syndrome is increasing (Glasson et al., 2016), highlighting the importance of addressing chronic disease risk factors such as sub-optimal dietary intake (Humphries et al., 2009). In the 2011–2013 Australian Health Survey, over a quarter of adolescents aged 12-17 years and over a third of young adults aged 18-24 years were overweight or obese (Australian Bureau of Statistics, 2013c). Published data on the prevalence of overweight and obesity in adolescents and young adults with Down syndrome indicate even higher levels of overweight and obesity (Basil et al., 2016; Hsieh et al., 2014; Krause et al., 2016; Stancliffe et al., 2011). In a large (n=197) population-based Western Australian study, 57.4% of adolescents and young adults with Down syndrome aged 16-30 years were perceived by their parents and carers to be overweight or obese (Pikora et al., 2014).

There are limited data on what young adults with intellectual disabilities are eating due to the challenges of assessing diet in this population (Humphries et al., 2009; Ptomey et al., 2013; Ptomey, Willis, et al., 2015). Acceptable dietary assessment methods for people with intellectual disabilities present additional challenges due to difficulties with memory, cognition, literacy and communication (Humphries et al., 2009). Previous studies with adolescents and young adults with Down syndrome have utilised a variety of dietary assessment methods (Fujiura et al., 1997; Grammatikopoulou et al., 2008; Nordstrøm et al., 2015; Soler Marin & Xandri Graupera, 2011). In almost all these studies, parents and carers completed the questionnaires on behalf of the young person with Down syndrome (Fujiura et al., 1997; Grammatikopoulou et al., 2008; Soler Marin & Xandri Graupera, 2011), with few studies involving the young people themselves in data collection (Nordstrøm et al., 2015). For adolescents and young adults, their growing independence outside the home can limit the acceptability of proxy-reported dietary intake (Humphries et al., 2009); thus, for adolescents and young adults with Down syndrome, mobile technologies may improve participation in dietary intake research.

Mobile devices such as mobile telephones are used by people with intellectual disabilities (Tanis et al., 2012). Although early research suggested that the use of mobile phones by people with intellectual disabilities was less than by people without intellectual disabilities (Bryen, Carey, & Friedman, 2007), more recent research has found increasing use of mobile phones by adults with intellectual disabilities (Tanis et al., 2012). Studies investigating the use of mobile devices such as iPods and iPads demonstrate people with intellectual and developmental disabilities can manipulate these devices and they enjoy using them (Kagohara et al., 2013; Ptomey, Sullivan, et al., 2015; Stephenson & Limbrick, 2015). The use of image-based dietary assessment has several advantages over written food records (Boushey, Spoden, Zhu, Delp, & Kerr, 2017). Images taken in real time can provide accurate information on the type and amount of food and beverages consumed whilst potentially reducing the recording burden associated with written food records for participants

(Boushey et al., 2009; Boushey et al., 2017). An image-based dietary assessment system known as Technology-Assisted Dietary Assessment or TADA (Ahmad et al., 2016; Bosch, Zhu, Khanna, Boushey, & Delp, 2011; Zhu, Bosch, Khanna, Boushey, & Delp, 2015; Zhu et al., 2010) uses the camera on a mobile device to capture before and after images of food and beverages consumed. Referred to as the mobile food record (mFR) app, the participant is instructed take a before and after image of all food and beverages and to include a reference device known as a fiducial marker (a checkerboard pattern of known shape, size and colour) to assist with food identification and portion size estimation (Xu, Zhu, Khanna, Boushey, & Delp, 2012; Zhu et al., 2010). Although trialled with children (Aflague et al., 2015), adolescents (Schap, Zhu, Delp, & Boushey, 2014) and young adults without disabilities (Kerr et al., 2016), it has not been trialled with people with intellectual disabilities. The aim of this research was to assess the feasibility of assessing diet with an image-based mobile food record application in adolescents and young adults with Down syndrome. A second objective was to assess the acceptability of the use of the fiducial marker in this population.

6.3 Materials and methods

6.3.1 Study design

This study was a cross-sectional analysis of food and beverage intake captured using the mobile food record from two studies—the Physical Activity, Nutrition and Down syndrome (PANDs) study and the Connecting Health and Technology (CHAT) study previously published (Kerr et al., 2016; Kerr et al., 2012). The PANDs study was a cross-sectional study of body composition, dietary intake and physical activity of adolescents and young adults with Down syndrome. Approval for both studies was granted by the Curtin University Human Ethics Research Committee (HR145/2011, HR181/2011) and the CHAT trial was registered (Australian Clinical Trials Registry Registration number ACTRN12612000250831). Approval for the PANDs study was also obtained from the Disability Services Commission (WA).

6.3.2 Participant recruitment

6.3.2.1 PANDs study

Participants with Down syndrome aged 12-30 years living within a 250 km radius of Perth, Western Australia, were recruited from the Down syndrome NOW (Needs, Opinions, Wishes) database (Foley et al., 2016) and contacted by mail. Informed consent was obtained from a parent/guardian and where possible, from the participant providing the individual was at least 18 years of age. If the latter consent was not possible then assent from the young person was obtained before proceeding. Assent was also required from children younger than 18 years of age. There were no exclusion criteria.

6.3.2.2 CHAT study

Young adults (18-30 years) living in the Perth metropolitan area were recruited via the Federal Electoral Roll and contacted by mail. Details of the study protocol and outcomes have been previously published (Kerr et al., 2016; Kerr et al., 2012). Participants were excluded if they were unable to attend the study site over the six-month study period, were following a restrictive diet, participating in extreme exercise, studying nutrition at University, or were pregnant or breastfeeding or if they had any serious illnesses. Of the 247 recruited, three participants were excluded for this analysis due to incomplete (less than one image-pair per day) mobile food records.

6.3.3 Data collection

Participants in both studies completed a four-day mobile food record (mFR) using an Apple iPod Touch. Height and weight were measured for participants in both studies following standard procedures (Stewart et al., 2011). In both studies, participants underwent the same training on how to use the mFR app for the collection of dietary information. The training session included information on how to: connect to Wi-Fi for sending images; take a practice image of plastic food replicas; and sending the before and after image pair to the back-end server. Participants were instructed to record their food and beverage intake using the mFR app for four consecutive days (including one weekend day) with the investigator-supplied iPod Touch (iOS6, Apple Inc., Cupertino, CA, USA) loaded with the mFR app. When taking an image, participants in both studies were instructed to include a reference device known as a fiducial marker to assist with food identification and portion size estimation. They were instructed to record food and beverage items not captured using the iPod notes section or in a small booklet provided that also contained visual and written instructions on using the mFR app. For both studies, on returning the iPod one week later, a dietitian confirmed the contents of the images and probed for any forgotten recordings with participants.

6.3.3.1 PANDs study

Participants in the PANDs study along with their family members/carers were visited by the research dietitian in their own home or a venue of their choosing and trained in the use of the iPod and the mFR app. The training consisted of physical and verbal instruction in the use of the iPod and mFR app, including the capturing of practice food and beverage images, firstly with the participants followed by their family members/carers. Family members/carers were reassured that connection to Wi-Fi was not essential and images could be uploaded securely once the device was returned. Participants were encouraged to carry the iPod with them at all times however the iPods could not be taken to schools and some family members and carers were hesitant about the iPod going to work, day activities or social occasions. Therefore if the participant with Down syndrome took food and beverages with them to school, work or other activities, it was recommended that images of the food and beverages were captured at home beforehand or notes made in the booklet. The PANDs study dietitian reviewed the images and also took a diet history to capture usual diet and daily activities involving both the participant and the family members/carers who accompanied them. This was done to confirm the contents of the images that were consumed or prompt identification of any missing foods or beverages not captured using the mFR app or recorded in the paper booklet. Participants in the PANDs study received a recipe book donated by the Health Department of WA. Figure 6.1 shows the data collection flow for the PANDs study; data flow for the CHAT study has been previously described (Kerr et al., 2016; Kerr et al., 2012).

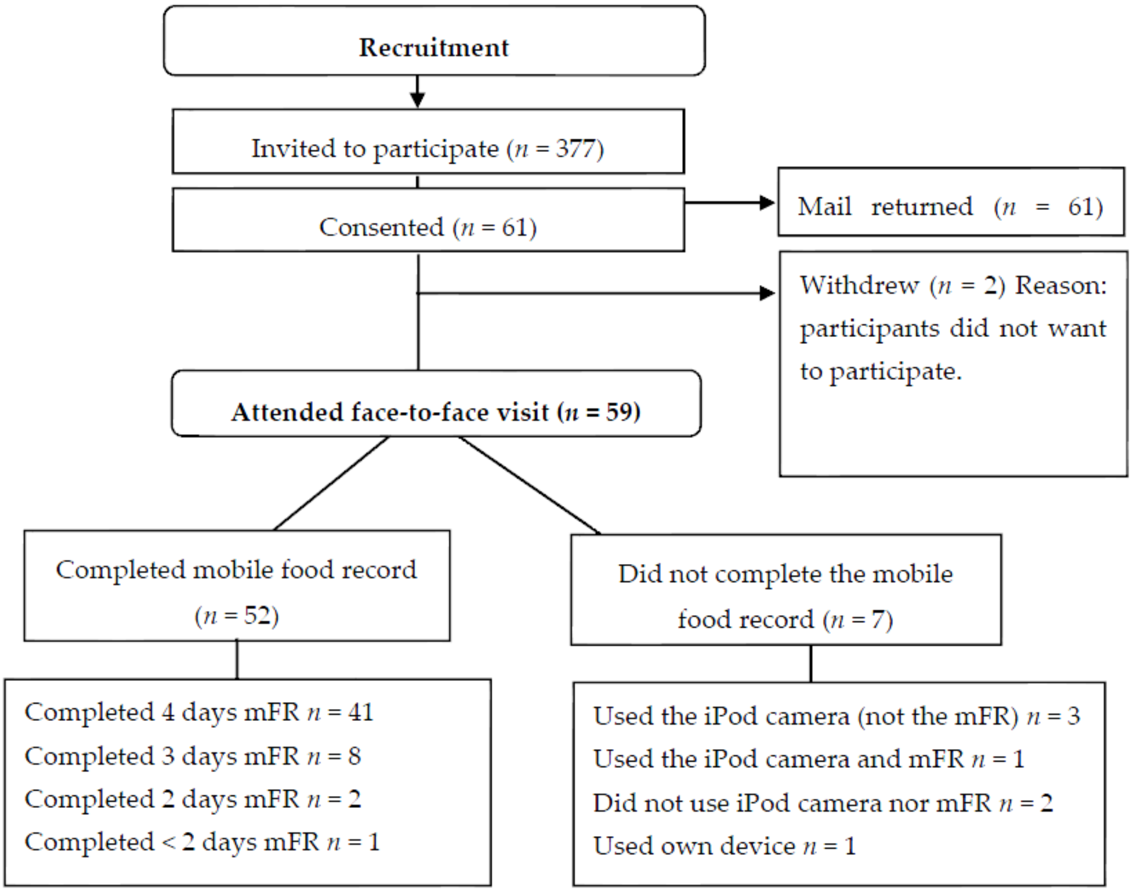


Figure 6.1 Data collection flowchart for the PANDs study

6.3.4 Image analysis in the PANDs study

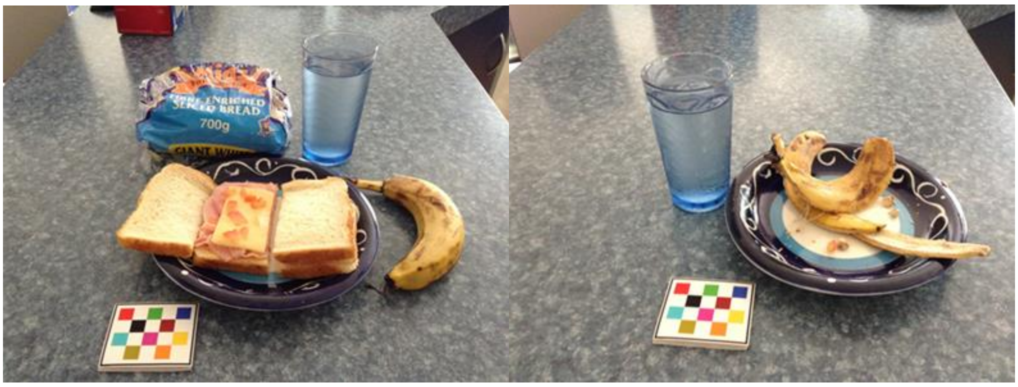
Food and beverage images from the mFR and fiducial marker inclusion in the images were assessed by two trained analysts. An example of a before and after image is shown in Figure 6.2. Each before and after image was recorded as an image pair. To be included in the food and beverage analysis (Table 6.1), a minimum of two full days' food record needed to be completed (either using the mFR app, iPod camera without using the mFR app or written food record). The procedure for the analysis of the mFR was the same for both studies. The research dietitian assessed the mFR food and beverage images and used a quality scoring of food items by food group serves sizes according to the Australian Guide to Healthy Eating (AGHE) (NHMRC 2013). A purpose-built Microsoft Access data table was developed for food and beverages data entry with linked categories for food group, food type and serving size. For each participant, an average serve per day was calculated for fruits, vegetables, sugar sweetened beverages (SSB), energy-dense, nutrient-poor (EDNP) foods and alcohol.

Acceptability of the fiducial marker was determined by analysing the presence or absence of the fiducial marker in all images captured using the mFR. The fiducial marker was either recorded as present, partially present, absent or OOPS. Partially present was where only part of the fiducial marker was visible in the image, with the rest of the marker either outside the image or obscured in some way. OOPS referred to when the participant or their family member/carer had not taken an after image of the food or beverage consumed. They were instructed to capture an image of the word OOPS (which was written on the reverse of the fiducial marker) to replace the after image. The mFR app had an inbuilt reminder prompting participants if they had forgotten to take an after image. If participants ignored this reminder and proceeded with taking their next before image, this image was captured in place of an after image. This situation occurred with some of the PANDs participants.

Table 6.1 Characteristics of participants in the (Physical Activity, Nutrition and Down syndrome) (PANDs 1) and Connecting Health and Technology (CHAT) studies who completed a food record using the mobile food record (mFR) app.

	PANDs Study						CHAT Study					
	Male *n* = 31 (53%)		**Female** *n* = 27 (47%)		**Persons [2]** *n* = 58 (100%)		**Male** *n* = 82 (34%)		**Female** *n* = 162 (66%)		**Persons** *n* = 244 (100%)	
Characteristics	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**	**Mean**	**SD**
Age (year)	21.7 ***	4.6	21.3 ***	4.7	21.5 ***	4.6	24.7 ***	3.4	24.1 ***	3.4	24.3 ***	3.4
Height (cm)	158.0 ***	6.3	145.8 ***	6.8	152.3 ***	9.0	178.3 ***	7.3	165.0 ***	6.8	169.5 ***	9.4
Weight (kg)	65.9 ***	12.7	61.3	15.5	63.8 **	14.2	78.7 ***	15.3	65.6	15.6	70.0 **	16.7
BMI	26.4	4.7	28.6 ***	6.5	27.4 ***	5.7	24.7	4.4	24.1 ***	5.8	24.3 ***	5.4
Food group serves												
Fruit daily serves (150 g)	2.3 ***	1.9	2.0 ***	1.6	2.2 ***	1.8	1.1 ***	1.3	0.9 ***	0.7	1.0 ***	0.9
Vegetable daily serves (75g)	2.4 *	1.5	2.4 **	1.1	2.4 ***	1.3	1.9 *	1.0	1.9 **	1.0	1.9 ***	1.0
EDNP [3] daily serves (600 kJ)	3.2	1.7	2.4 *	1.2	2.8	1.5	3.3	2.0	3.1 *	1.5	3.2	1.7
SSB [4] daily serves (600 kJ)	0.5	0.7	0.4	0.4	0.4	0.6	0.5	0.7	0.5	0.6	0.5	0.6

[1] For PANDs data includes participants who completed the food record using either the mFR app, the iPod camera, a written food record or a combination for a minimum of two days; [2] Statistical comparisons are between studies for males, females and persons; [3] Total energy-dense nutrient-poor (EDNP) food group serves includes junk foods, sugar-sweetened beverages (SSB) and alcohol; [4] sugar-sweetened beverages; *, **, *** Significantly different by independent sample t-test at $p < 0.05$, $p < 0.01$ and $p < 0.001$ respectively, SD= standard deviation



(a) (b)

Figure 6.2 Example of the image capture by a PANDs participant using the mFR. (a) Before eating image; (b) After eating image. The image also shows the inclusion of the fiducial marker in the images. The loaf of bread was included in the image to help with identification of the type of bread consumed, only what was on the plate was analysed

6.3.5 Statistical Analysis

The statistical package used for all analysis was SPSS Statistics v. 24 (IBM Corp, Armonk, NY, USA 2016). Descriptive statistics were used to describe and compare participant characteristics, food group serves and mFR images. Differences in the mean of food group serves, number of image pairs, height, weight and body mass index (BMI) in both studies were compared in total and by gender using independent t-tests. Statistical significance was set at ($p < 0.05$).

6.4 Results

In the PANDs study, of the 377 adolescents and young adults who were invited to participate, consent was provided for 61 participants (Figure 6.1). Two participants withdrew from the study as they chose not to participate, resulting in a 15.6% response fraction. Of the 59 participants, 52 completed the study using the mFR app, six did not use the mFR app and one participant used a combination of the mFR app and images taken using the iPod camera. Another participant who used the mFR app did not complete two full days of recording and their data have been excluded from the results, with 51 participants using the mFR app for a minimum of two days.

The physical characteristics of all participants in both studies are shown in Table 6.1. Participants in the PANDs study were younger on average than participants in the CHAT sample (21.5 ± 4.6 years vs. 24.3 ± 3.4 years, $p < 0.001$); however, this was expected as the target cohort age was younger (12–30 years compared to 18–30 years). Participants in the PANDs study had a higher mean BMI, especially among females, and a lower mean height compared to participants in the CHAT sample ($p < 0.001$).

When comparing food group intake between all participants of the two studies (including PANDs participants who did not use the mFR app), there was no difference in the mean number of daily serves of sugar-sweetened beverages reported; however, participants in the PANDs study reported a higher number of serves of fruit (2.2 ± 1.8 vs. 1.0 ± 0.9) and vegetables (2.4 ± 1.3 vs. 1.9 ± 1.0) compared with participants in the CHAT study (see Table 6.1). Women in the PANDs study reported fewer daily serves of EDNP foods than female participants in the CHAT sample (2.4 ± 1.2 vs. 3.1 ± 1.5, $p=0.015$). This outcome was not seen in males or in the groups as a whole. Comparing adults in the PANDs study (n=45) to those in the CHAT sample, there continued to be a higher mean number of serves of fruit reported by both genders and a lower mean number of serves of EDNP foods reported by women in the PANDs study; however, a significant difference in the mean number of serves of vegetables reported was not observed in females.

Table 6.2 shows the use of the mFR app and the inclusion of the fiducial marker in the images. In those participants who used the mFR app there was a difference in the mean number of image pairs from the participants in the PANDS study compared to participants in the CHAT sample (4.0 ± 1.5 vs. 4.9 ± 2.3, $p < 0.01$) and differences in the inclusion of the fiducial marker in the images (see Table 6.2). There was less inclusion of the fiducial marker in before images for the PANDs study with 6.7% of images missing the fiducial marker, compared to 2.1% of images in the CHAT sample. In the PANDs study there were also 11 more before images compared to the after images (see Table 6.2). This was due to an after image not being captured and a before image of the next meal or snack being captured in its place.

Table 6.2 Use of the mobile food record (mFR) app and inclusion of the fiducial marker in images taken by participants in the Physical Activity and Down syndrome (PANDs) and Connecting Health and Technology (CHAT) studies.

	PANDs Study (n=51)		CHAT Study (n=244)	
	N before Images (%)	**N after Images (%)**	**N before Images (%)**	**N after Images (%)**
Fiducial marker present	692 (90.3%)	671 (88.9%)	4768 (96.6%)	4528 (91.8%)
Fiducial marker partially present	23 (3.0%)	24 (3.2%)	12 (0.2%)	17 (0.3%)
Fiducial marker missing	51 (6.7%)	58 (7.7%)	105 (2.1%)	110 (2.2%)
OOPS [1]	0	2 (0.0%)	50 (1.0%)	280 (5.7%)
Total	766 (100%)	755 (100%) [2]	4935 (100%)	4935 (100%)

1 OOPS. Participants were instructed to include an image of the OOPS on the alternate side of the fiducial marker when they had forgotten to take an after image; 2 Difference in totals was due to a before image of the next meal or snack being captured in place of an after image

6.5 Discussion

In this study, adolescents and young adults with Down syndrome were able to capture images of their diet using a mobile food record, with 86% (51 of 59) of participants collecting dietary intake for at least two full days. Fewer image pairs were captured using the mFR app by participants with Down syndrome and their families/carers compared to participants without Down syndrome. Nevertheless, the acceptability of the fiducial marker among participants with Down syndrome was high with the marker fully present in 88.9%–90.3% of images captured using the mFR app. This use of the fiducial marker is higher than previous research using a poorly constructed fiducial marker with adolescents (n=18) without disability (Casperson et al., 2015). This higher rate in the present study may have been assisted by the in-built technology of the mFR version used in this study that prompts the user to include the marker if not detected (Xu et al., 2012; Zhu et al., 2010). The mFR app used in the current study appears to be a feasible dietary assessment method for adolescents and young adults with Down syndrome.

For the seven participants and their families who did not use the mFR app, the most popular method of data collection was the capturing of images using the iPod camera or another mobile device camera, with two families providing written food records in place of images. This could be due to some participants being less familiar with the iPod device or reluctance to use the mFR app to take images in public or at work. This is consistent with findings in a study with young adults with intellectual disabilities where diet was captured with an image-assisted recall method (Ptomey et al. 2013). This finding also highlights the importance of the initial training for young people with Down syndrome and their families/carers in using the mFR app and suggests that improvements such as video instructions preloaded onto the iPod could be of assistance in future studies.

Participants in the PANDs study reported a significantly greater number of servings of fruit and vegetables compared to participants in the CHAT study. Similar findings were also observed in two studies of adults with Down syndrome (both n=51) where, compared to controls, adults with Down syndrome reported a greater mean intake of fruit and vegetables (Parra et al., 2017; Real de Asua et al., 2014a). Earlier research with overweight and obese adolescents (n=61) in WA found low average intakes of fruit (0.7 serves) and vegetables (1.2 serves) (K. L. Smith, Straker, Kerr, & Smith, 2015); however, these low intakes were not observed in the PANDs study. These observed differences could be due to family members having more positive influences on fruit and vegetable intake for the PANDs participants, compared to other adolescents and young adults. However, there were no differences in the consumption of energy-dense nutrient-poor foods and sugar-sweetened beverages between the PANDs and CHAT study participants, except for a lower consumption of EDNP foods in females with Down syndrome.

The strengths and limitations of the CHAT study have been discussed previously (Kerr et al., 2016). The PANDs study sample was representative of the gender distribution of people with Down syndrome in WA, with 56.6% of infants born from 1980–1996 being male (S. Leonard et al., 2000), similar to 53% of the PANDs study sample being male. As with previous studies using iPads with adolescents and young adults with intellectual disabilities (Ptomey et al., 2013; Ptomey, Sullivan, et al., 2015; Ptomey, Willis, et al., 2015), the PANDs study involved the young person with Down syndrome as much as possible in the collection of food intake data, with participants trained and encouraged to use the mFR app themselves. The mFR app also has several advantages over simply using a mobile device camera. The mFR app allows images to be uploaded to a secure server and not stored on the device. This ensured the images could not be accidentally deleted even if the mFR was deleted. The mFR images also include a time and date stamp. The requirement (including built-in prompting) to take both a before and after image ensured that any uneaten portion was captured and could be taken into account during analysis. In addition, the mFR app indicated if the fiducial marker was not in the image, prompting another image to be taken, and immediate feedback through the use of a colour border indicated if the angle of the photograph was optimal (green) or not (red) for analysis.

The PANDs study had several limitations. The number of images taken by the participants with Down syndrome rather than the family members or carers was not recorded. Previous studies using the mFR app have demonstrated the importance of user feedback (Boushey et al., 2015; Daugherty et al., 2012) but this was not undertaken in the PANDs study. User feedback may have been helpful in identifying issues, such as identifying the reasons for the 11 extra before images taken by PANDs participants. It is recommended future studies in participants with Down syndrome include user feedback, to better inform the assessment of diet using the mFR app. Additionally, the measurement error from unrecorded foods and beverages or changes to usual dietary patterns could have influenced the results (Labonté et al., 2016; Subar et al., 2015).

There may have been a social desirability bias in those who participated in the PANDs and CHAT studies but this was not assessed in either study (Hébert, 2016). The families of participants who volunteered to participate in the PANDs study may have been more interested in nutrition, and families who declined the invitation were not surveyed as to their reason for refusal. Families who lived further than 250 km from the Perth metropolitan region were not invited due to travel constraints, and these selection biases (Hammer, Prel, & Blettner, 2009) may have impacted the results.

In both the CHAT and PANDs studies, the identification of food and beverages and the estimation of portion size was undertaken by different trained analysts and therefore there may be differences in estimation. Using the camera function on a mobile device such as an iPod may have been more familiar to PANDs study participants if they had previously used these devices. Compared to using the iPod camera, the mFR app required additional steps in taking the image (e.g., turning the iPod horizontally to capture the image) and buttons on the screen had written instructions (e.g., 'snap it') (Ahmad et al., 2016). The need to read instructions was compensated for, however, by the buttons always being in the same place on the screen, and participants with Down syndrome and their family members/carers receiving training on how to use the app and device, and written and visual instructions being left with participants and families. This training could have been enhanced by the development of a step-by-step video loaded on the iPod to which participants and their families could refer. The mFR application was also accidentally deleted from the iPod by one participant. In the current study, the mFR application was provided on the study iPod. With advances in technology, there is now the capability to install the mFR application on the participants' own devices which may improve the acceptability in future studies.

6.6 Conclusions

The mFR is a feasible app for adolescents and adults with Down syndrome. The mFR app was used by most participants and their families in the PANDs study to record foods and beverages consumed, providing detailed visual information and reducing the burden of traditional food intake data collection. In future studies, the development of video instructions, accessible on the iPod, could better assist participants with Down syndrome in using the mFR app, further enabling young people with Down syndrome to be involved in the collection of their own dietary intake data. Future studies should also evaluate the ease of use of the mFR app by adolescents and young adults with Down syndrome and suggest ways to improve the usability if required.

Supplement to Chapter 6

These data and discussion form a supplement to the data in Chapter 6, which is a study of the feasibility of the mFR for adolescents and young adults with Down syndrome.

The aim of this further analysis was to:

Describe the reported dietary intake (fruit, vegetable and discretionary food groups) of adolescents and young adults with Down syndrome and the relationships with BMI, percentage body fat, waist circumference and waist-to-height ratio.

From the literature review the following hypotheses were proposed:

1. Adolescents and young adults with Down syndrome will report less than the recommended number of serves of fruit and vegetables.
2. There will be a negative relationship between reported fruit and vegetable serves and measured BMI.
3. There will be a positive relationship between the reported serves of energy-dense nutrient-poor foods, sugar-sweetened beverage and measured BMI.

6.7 Statistical analysis

Descriptive statistics, reported as means with standard deviations (SD) or proportions where appropriate were used to summarise the number food serves reported. Independent t-tests with unequal variances were used to compare mean number of reported food group serves between sexes and means of reported food group serves by waist-to-height category. Spearman's rank correlation was used to test for the relationships between mean number of reported food group serves and BMI, percentage body fat, waist circumference and waist-to-height ratio. Correlation strengths were determined using the guidelines of 0.00-0.25 = little or no relationship, 0.25 to 0.50 = fair relationship, 0.50 to 0.75 = moderate to good relationship and >0.75 = good to excellent relationship (Portney & Watkins, 2009). Welch's ANOVA with a Games-Howell's post hoc test was used to test for differences in the mean number of reported food group serves by BMI and percentage body fat categories. Waist circumference categories were not included due to limitations identified in Chapter 5. Analyses of the relationships between reported food group serves, anthropometric and DEXA parameters were conducted with young adults only due to the small sample size of adolescents. Similarly, analysis of the differences in reported food group serves by anthropometric and percentage body fat categories were not analysed by sex due to the small sample sizes. The level of statistical significance was set at alpha=0.05 and all *P* values were estimated using two-tailed tests. All analyses were performed in SPSS (IBM Corp. Released 2016. IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp).

6.8 Results

Table 6.3 shows the mean number of reported vegetable, fruit, energy-dense nutrient-poor food and sugar-sweetened beverage serves reported for participants in the PANDs study who completed a food record (using either a mFr, other device or written record) for a minimum of 2 days. Tables 6.4 and 6.5 show the relationships between reported food group serves and BMI, as a continuous and for young adults, as categorical variables using standard cut-points (NHMRC, 2013b). Tables 6.6 and 6.7 show the relationships between reported food group serves and percentage body fat as continuous and for young adults, as categorical variables using standard cut-points (Pasco et al., 2014). Table 6.8 shows the relationship between reported food group serves and waist circumference as a continuous variable. Tables 6.9 and 6.10 present the relationships between reported food group serves and waist-height-ratio as a continuous and categorical variable using the standard cut-point (Ashwell & Hsieh, 2005).

Participants in the PANDS study reported 2.4 ± 1.3 vegetable serves and 2.2 ± 1.8 fruit serves daily. Males reported 0.8 additional energy-dense nutrient-poor food serves than females (CI 0.1, 1.6). There were no differences in the reported mean number of vegetable, fruit and sugar-sweetened beverage serves between sexes (see Table 6.3).

As shown in Tables 6.4, 6.6, 6.8 and 6.9 there were no relationships between the mean of reported vegetable and energy-dense nutrient-poor food serves and BMI, percentage body fat, waist circumference and waist-to-height ratio, either as continuous or categorical variables. In female young adults there was a negative moderate to good relationship between the mean number of reported fruit serves and BMI (*P*=0.002), waist circumference (*P*=0.012) and waist-to-height ratio (*P*=0.020). In young adults there was a positive relationship between reported sugar-sweetened beverage serves and percentage body fat (*P*=0.029).

Young women with a BMI classified as healthy weight reported 2.4 serves of fruit per day more than young women with a BMI classified as obese, however the difference could not be analysed due to small sample size (n=19).

Table 6.3 Reported mean food group serves for adolescents and young adults

	Male n=31	**Female n=27**	**Total n=58**		
Food Group serves	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**	**Difference in means (95% CI) [male v. female]**	***P* value^**
Vegetable serves (150 g)	2.4 ± 1.5	2.4 ± 1.1	2.4 ± 1.3	-0.0 (-0.7, 0.7)	0.989
Fruit serves (75 g)	2.3 ± 1.9	2.0 ± 1.6	2.2 ± 1.8	0.3 (-0.6, 1.2)	0.528
EDNP serves (600 kJ)	3.2 ± 1.7	2.4 ± 1.2	2.8 ± 1.5	0.8 (0.1, 1.6)	0.032#
SSB serves (600 kJ)	0.5 ± 0.7	0.4 ± 0.4	0.4 ± 0.6	0.1 (-0.2, 0.4)	0.610

SD=standard deviation; CI=confidence interval; EDNP=energy-dense nutrient-poor; SSB=sugar-sweetened beverage

^Two-tailed, independent samples t-test *P* value

#*P*<0.05

Table 6.4 Relationships between reported food group serves and BMI for young adults

Young adult	**Male n=26**		**Female n=19**		**Total n=45**	
	rho	***P* value**	**rho**	***P* value**	**rho**	***P* value**
Vegetable serves (150 g)	-0.081	0.694	-0.262	0.278	-0.156	0.307
Fruit serves (75 g)	0.098	0.635	-0.652	0.002#	-0.224	0.138
EDNP serves (600 kJ)	-0.167	0.414	-0.144	0.556	-0.178	0.241
SSB serves (600 kJ)	0.194	0.343	0.308	0.199	0.232	0.125

EDNP=energy-dense nutrient-poor; SSB=sugar-sweetened beverage; rho=Spearman's rank correlation coefficient

#*P*<0.05

Table 6.5 Differences in the means of reported food group serves and BMI category for young adults

	BMI category*					
Total	**Healthy weight n=15 (33%)**	**Overweight n=17 (38%)**	**Obese n=13 (29%)**	**Total n=45 (100%)**	$F_{2,42}$	***P* value^**
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Vegetable serves (150 g)	2.5 ± 1.2	2.4 ± 1.2	2.3 ± 1.7	2.4 ± 1.4	0.09	0.914
Fruit serves (75 g)	2.6 ± 1.9	2.2 ± 1.9	1.6 ± 1.6	2.2 ± 1.8	1.13	0.338
EDNP serves (600 kJ)	3.3 ± 1.7	2.8 ± 1.6	2.5 ± 1.5	2.9 ± 1.6	0.90	0.420
SSB serves (600 kJ)	0.4 ± 0.5	0.5 ± 0.8	0.7 ± 0.6	0.5 ± 0.6	0.93	0.408
Male	**n=9 (35%)**	**n=11 (42%)**	**n=6 (23%)**	**n=26 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Vegetable serves (150 g)	2.5 ± 1.4	2.3 ± 1.2	2.8 ± 2.4	2.4 ± 1.5		
Fruit serves (75 g)	2.1 ± 1.9	2.6 ± 2.1	2.4 ± 2.0	2.4 ± 1.9		
EDNP serves (600 kJ)	4.1 ± 1.5	2.9 ± 1.8	3.3 ± 1.8	3.4 ± 1.7		
SSB serves (600 kJ)	0.4 ± 0.6	0.6 ± 0.9	0.7 ± 0.8	0.5 ± 0.8		
Female	**n=6 (32%)**	**n=6 (32%)**	**n=7 (37%)**	**n=19 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Vegetable serves (150 g)	2.6 ± 0.95	2.5 ± 1.4	1.9 ± 0.90	2.3 ± 1.1		
Fruit serves (75 g)	3.4 ± 1.5	1.3 ± 1.1	1.0 ± 0.60	1.9 ± 15		
EDNP serves (600 kJ)	2.3 ± 1.4	2.8 ± 1.0	1.8 ± 0.8	2.3 ± 1.1		
SSB serves (600 kJ)	0.5 ± 0.3	0.3 ± 0.3	0.7 ± 0.4	0.5 ± 0.4		

SD=standard deviation; EDNP=energy-dense nutrient-poor; SSB=sugar-sweetened beverage; *BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Welch's ANOVA P value; #*P*<0.05

Table 6.6 Relationship between reported food group serves and percentage body fat for young adults with DEXA results

Young adult	**Male n=18**		**Female n=15**		**Total n=33**	
	rho	***P* value**	**rho**	***P* value**	**rho**	***P* value**
Vegetable serves (150 g)	-0.164	0.515	-0.341	0.213	-0.199	0.266
Fruit serves (75 g)	0.070	0.781	-0.359	0.188	-0.127	0.483
EDNP serves (600 kJ)	0.024	0.925	-0.215	0.442	-0.238	0.182
SSB serves (600 kJ)	0.330	0.181	0.382	0.160	0.380	0.029#

EDNP=energy-dense nutrient-poor; SSB=sugar-sweetened beverage; rho=Spearman's rank correlation coefficient
#*P*<0.05

Table 6.7 Differences in the means of reported food group serves and percentage body fat category for young adults

	Percentage body fat category*					
Total	**Healthy weight n=7 (21%)**	**Overweight n=12 (36%)**	**Obese n=14 (42%)**	**Total n=33 (100%)**	$F_{2,30}$	***P* value^**
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Vegetable serves (150 g)	2.5 ± 0.9	2.3 ± 1.1	2.1 ± 1.8	2.3 ± 1.4	0.18	0.839
Fruit serves (75 g)	1.8 ± 1.1	1.9 ± 1.5	1.7 ± 1.6	1.8 ± 1.4	0.04	0.963
EDNP serves (600 kJ)	2.8 ± 0.9	2.6 ± 1.2	3.0 ± 1.9	2.8 ± 1.5	0.19	0.833
SSB serves (600 kJ)	0.2 ± 0.2	0.4 ± 0.5	0.8 ± 0.8	0.5 ± 0.6	3.09	0.068
Male	**n=2 (11%)**	**n=8 (44%)**	**n=8 (44%)**	**n=18 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Vegetable serves (150 g)	2.0 ± 1.5	2.3 ± 0.8	2.4 ± 2.3	2.3 ± 1.6		
Fruit serves (75 g)	1.4 ± 0.8	2.0 ± 1.7	2.2 ± 1.9	2.1 ± 1.7		
EDNP serves (600 kJ)	3.9 ± 1.1	2.7 ± 1.3	3.9 ± 2.1	3.3 ± 1.7		
SSB serves (600 kJ)	0.06 ± 0.09	0.3 ± 0.5	0.9 ± 1.0	0.5 ± 0.8		
Female	**n=5 (33%)**	**n=4 (27%)**	**n=6 (40%)**	**n=15 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**		
Vegetable serves (150 g)	2.6 ± 0.7	2.2 ± 1.7	1.8 ± 1.0	2.2 ± 1.1		
Fruit serves (75 g)	2.0 ± 1.2	1.5 ± 1.4	1.0 ± 0.6	1.5 ± 1.1		
EDNP serves (600 kJ)	2.3 ± 0.4	2.5 ± 1.3	1.8 ± 0.9	2.2 ± 0.9		
SSB serves (600 kJ)	0.3 ± 0.2	0.5 ± 0.5	0.6 ± 0.4	0.5 ± 0.4		

SD=standard deviation; EDNP=energy-dense nutrient-poor; SSB=sugar-sweetened beverage; *percentage body fat classified using cut-points developed using age, sex and BMI (Pasco et al., 2014); ^Welch's ANOVA P value; #*P*<0.05

Table 6.8 Relationship between reported food group serves and waist circumference for young adults

Young adult	**Male n=26**		**Female n=19**		**Total n=45**	
	rho	***P* value**	**rho**	***P* value**	**rho**	***P* value**
Vegetable serves (150 g)	-0.114	0.578	-0.283	0.240	-0.217	0.152
Fruit serves (75 g)	0.063	0.760	-0.564	0.012[#]	-0.182	0.231
EDNP serves (600 kJ)	-0.012	0.955	-0.196	0.422	-0.033	0.831
SSB serves (600 kJ)	0.193	0.346	0.390	0.099	0.197	0.194

EDNP=energy-dense nutrient-poor; SSB=sugar-sweetened beverage; rho=Spearman's rank correlation coefficient
[#]$P<0.05$

Table 6.9 Relationship between reported food group serves and waist-to-height ratio for young adults

Young adult	**Male n=26**		**Female n=19**		**Total n=45**	
	Rho	***P* value**	**rho**	***P* value**	**rho**	***P* value**
Vegetable serves (150 g)	-0.091	0.659	-0.195	0.423	-0.161	0.290
Fruit serves (75 g)	0.081	0.693	-0.528	0.020[#]	-0.181	0.234
EDNP serves (600 kJ)	-0.138	0.501	-0.190	0.436	-0.144	0.346
SSB serves (600 kJ)	0.178	0.384	0.355	0.136	0.238	0.116

EDNP=energy-dense nutrient-poor; SSB=sugar-sweetened beverage; rho=Spearman's rank correlation coefficient
[#]$P<0.05$

Table 6.10 Differences in the means of reported food group serves and waist-to-height ratio category for young adults

	Waist-to-height ratio category*				
Total	**No increased risk n=17 (38%)**	**Increased risk n=28 (62%)**	**Total n=45 (100%)**	**Difference in means (95% CI) [no increased risk v. increased risk]**	***P* value^**
	Mean ± SD	**Mean ± SD**	**Mean ± SD**		
Vegetable serves (150 g)	2.5 ± 1.3	2.3 ± 1.4	2.4 ± 1.4	0.2 (-0.6, 1.0)	0.613
Fruit serves (75 g)	2.6 ± 1.8	1.9 ± 1.7	2.2 ± 1.8	0.7 (-0.4, 1.9)	0.185
EDNP serves (600 kJ)	3.1 ± 1.7	2.8 ± 1.6	2.9 ± 1.6	0.4 (-0.6, 1.4)	0.453
SSB serves (600 kJ)	0.4 ± 0.4	0.6 ± 0.7	0.5 ± 0.6	-0.3 (-0.6, 0.07)	0.122
Male	**n=10 (38%)**	**n=16 (62%)**	**n=26 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**		
Vegetable serves (150 g)	2.6 ± 1.3	2.3 ± 1.7	2.4 ± 1.5		
Fruit serves (75 g)	2.5 ± 2.0	2.3 ± 2.0	2.4 ± 1.9		
EDNP serves (600 kJ)	3.6 ± 1.8	3.3 ± 1.8	3.4 ± 1.7		
SSB serves (600 kJ)	0.3 ± 0.5	0.7 ± 0.9	0.5 ± 0.8		
Female	**n=5 (33%)**	**n=10 (67%)**	**n=19 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**		
Vegetable serves (150 g)	2.3 ± 1.3	2.3 ± 1.0	2.3 ± 1.1		
Fruit serves (75 g)	2.8 ± 1.7	1.3 ± 1.1	1.9 ± 15		
EDNP serves (600 kJ)	2.6 ± 1.4	2.1 ± 1.0	2.3 ± 1.1		
SSB serves (600 kJ)	0.4 ± 0.2	0.6 ± 0.4	0.5 ± 0.4		

SD=standard deviation; CI=confidence interval; EDNP=energy-dense nutrient-poor; SSB=sugar-sweetened beverage
*no increased risk <0.5, increased risk ≥0.5 (Ashwell & Hsieh, 2005);
^Two-tailed, independent samples t-test *P* value
[#] $P<0.05$

6.9 Discussion

Although participants reported fruit serves that met the Eat for Health guideline (NHMRC, 2013a), the number of vegetable serves reported was below the NHMRC recommendations of 5-6 serves per day and promotion of fruit and vegetables in adolescents and young adults with Down syndrome is recommended. Previous international studies involving adolescents and adults with Down syndrome have also reported numbers of fruit and vegetable serves that did not meet national recommendations (Braunschweig et al., 2004; Goluch-Koniuszy & Kunowski, 2013). In Polish adolescents (n=24), 3-day food records showed percentage intakes of fruit and vegetables much lower than daily allowances (Goluch-Koniuszy & Kunowski, 2013), and in adults over the age of 30 years (n=48), food frequency data revealed inadequate daily intake of vegetables (1.0 serve) and fruit (2.8 serves) compared to USA guidelines (Braunschweig et al., 2004). Fruit and vegetables serves below NHMRC guidelines have also been reported in Australian adolescents (n=61) (K. L. Smith et al., 2015) and young adults (Nour et al., 2017) without Down syndrome. Using 3-day food records, K. L. Smith et al. (2015) reported 0.7 serves fruit serves and 1.2 vegetable serves daily, and data from the 2011-12 National Nutrition and Physical Activity Survey (NNPAS) (n=2397) revealed young adults consumed 0.9 fruit serves and 2.7 vegetables serves daily (Nour et al., 2017). As family members/carers reported in the 2011 Down syndrome NOW study that most adolescents and young adults needed support to prepare an adequate variety of meals, this support may have resulted in higher reporting of fruit and vegetables for adolescents and young adults with Down syndrome, however further research is required to confirm this theory. Further discussion of the relationship between food group serve, anthropometry and body composition is in Chapter 8.

Preface to Chapter 7

Chapter 7 is a cross-sectional analysis of physical activity data collected as part of the Physical Activity, Nutrition and Down syndrome (PANDs) study as outlined in Chapter 4.

The candidate completed all data collection and analysis presented in this chapter.

Chapter 7 Sedentary behaviour and physical activity levels of adolescents and young adults with Down syndrome

7.1 Introduction

The Australian Physical Activity Guidelines recommended that adolescents spend at least 60 minutes per day engaged in moderate to vigorous physical activity and young adults should accumulate ≥150 minutes of MVPA per week (Australian Government Department of Health, 2014). As discussed in 2.3.2.1.1, objective studies of physical activity levels have reported that adolescents and young adults with Down syndrome are insufficiently active, with between zero and 43% reported to have met Physical Activity Guidelines (see Table 2.1) (Matute-Llorente et al., 2013; Nordstrøm et al., 2013; Shields et al., 2009). Although differences in accelerometers, minimum wear protocols, epochs, cut-points and definitions of physical activity guidelines make comparisons difficult, males with Down syndrome have been consistently reported to be more physically active than females (Izquierdo-Gomez et al., 2014; Nordstrøm et al., 2013) and in most studies there was reported a decrease in physical activity with age (Esposito et al., 2012; Izquierdo-Gomez et al., 2014; Phillips & Holland, 2011; Shields et al., 2009).

Studies describing the physical activity patterns of adolescents with Down syndrome have reported no differences in physical activity levels between weekdays and weekends or between school time and after-school time (Izquierdo-Gomez et al., 2014; Shields et al., 2009), however patterns have not been described for young adults. Exposure variation analysis (EVA) has been defined as "the reduction of exposure data recorded as a function of time" (Mathiassen & Winkel, 1991, p. 1460), with exposure data being physical activity data in the context of this research. Exposure variation analysis has been applied in studies of adults without Down syndrome to describe physical activity patterns using the percentage of time spent in different length bouts of sedentary behaviour and physical activity (McVeigh, Winkler, Howie, et al., 2016; Straker et al., 2014). To date, EVA has not been applied in a study of adolescents and young adults with Down syndrome.

Previous research involving adolescents and young adults with Down syndrome has analysed physical activity using a combination of counts-per-minute, time spent in sedentary, light, moderate and vigorous physical activity, number of steps and time spent both in total MVPA and 10 minute bouts (Esposito et al., 2012; Nordstrøm et al., 2013; Pitchford et al., 2018; Shields et al., 2009; Shields et al., 2017; Ulrich, Burghardt, Lloyd, Tiernan, & Hornyak, 2011). In Canadian adults without Down syndrome, total time and time spent in prolonged bouts of sedentary behaviour (≥20 minutes) have been positively associated with insulin and diastolic blood pressure levels (Carson et al., 2014). Additionally, in adults without Down syndrome, a higher number of breaks from sedentary behaviour has been associated with lower BMI, waist circumference measurements and lower blood glucose and triglyceride levels (Carson et al., 2014; Healy et al., 2008; Healy, Matthews, Dunstan, Winkler, & Owen, 2011). Although number of breaks from sedentary behaviour has been investigated in older adults with intellectual disability (Oviedo, Travier, & Guerra-Balic, 2017), data on prolonged sedentary bouts and the number of breaks from sedentary behaviour have not yet been described specifically for adolescents and young adults with Down syndrome.

Although there have been no strong univariate relationships reported between BMI, waist circumference and objectively measured physical activity in adolescents and young adults with Down syndrome (Esposito et al., 2012; Izquierdo-Gomez, Martínez-Gómez, et al., 2015; Nordstrøm et al., 2013; Pitchford et al., 2018; Shields et al., 2009), significant relationships between percentage body fat and time spent in vigorous activity have recently been reported for adolescents with Down syndrome (n=22), with time spent in MVPA found to be a significant predictor of total percentage body fat (Pitchford et al., 2018). DEXA has been used in one previous study of physical activity and body fatness in adolescents with Down syndrome (Pitchford et al., 2018) and there is a need for research using DEXA in young adults. Waist circumference as an indicator of central obesity has been included in two studies of physical activity in adolescents with Down syndrome (Izquierdo-Gomez, Martínez-Gómez, et al., 2015; Shields et al., 2017), however as discussed in Chapter 5, the waist-to-height ratio may be a better indicator of central obesity in young people with Down syndrome, and this measure also needs to be included in future research.

7.1.1. Aim, objectives and hypotheses

The aim of this study was to:

> Describe the sedentary behaviour and physical activity levels of adolescents and young adults with Down syndrome and relationships with anthropometric and DEXA variables.

To address this aim the objectives of this study were to:

1. Describe the sedentary behaviour and physical activity levels of adolescents and young adults with Down syndrome.
2. Estimate the proportions of adolescents and young adults with Down syndrome who met Australia's Physical Activity Guidelines.
3. Investigate the relationship between sedentary behaviour and physical activity levels and anthropometric and DEXA variables in young adults with Down syndrome.

From the literature review the following hypotheses were proposed:

1. Few adolescents and young adults with Down syndrome will meet Australia's Physical Activity Guidelines.
2. There will be no relationship between physical activity level and anthropometric variables, however there may be a relationship with percentage body fat as assessed using DEXA.

7.2 Methodology

The recruitment, ethics and study design for the Physical Activity, Nutrition and Down syndrome (PANDS) study are described in Chapter 4.0. The following describes the specific methodology for the physical activity component.

7.2.1 Data collection

At the first visit with participants in the PANDS study and their family members/carers, participants were provided with an ActiGraph GT3X accelerometer (ActiGraph, LLC, Pensacola, FL, USA) attached to an adjustable elastic waist strap (see Figure 7.1). The ActiGraph wGT3X accelerometer has been used in previous studies involving adolescents and young adults with Down syndrome (Castro-Piñero et al., 2014; Izquierdo-Gomez et al., 2014; Izquierdo-Gomez et al., 2017; Izquierdo-Gomez, Martínez-Gómez, et al., 2015; Izquierdo-Gomez, Veiga, Villagra, & Diaz-Cueto, 2015; Nordstrøm et al., 2013) as well as girls with Rett syndrome (J. Downs et al., 2015), adults with multiple sclerosis (Sandroff et al., 2014) and adults and children with intellectual disability (McGarty, Penpraze, & Melville, 2016; Oviedo et al., 2017).

Figure 7.1 ActiGraph wGT3X accelerometer on a waist strap

At this first visit, participants and their family member/carer were shown how to wear the accelerometer and the elastic strap was adjusted for fit. Participants were instructed to wear the accelerometer on their right hip from when they awoke in the morning to when they went to bed at night for seven consecutive days, removing it for sleeping, showering/bathing, swimming or any other water-based activity. Participants and their family/members carers were provided with written instructions and a diary for recording when the accelerometer was put on and taken off and the reasons for removal (e.g. going to bed, having a shower) (see Appendix M).

At the second visit the ActiGraph wGT3X accelerometer was returned and any difficulties encountered were discussed. The activity diary was also discussed with the participant and their family member/carer. With the assent of both the participant and their family member/carer and whilst wearing the ActiGraph wGT3X accelerometer, the participant's feet were videoed during a short 5-10 minute walk so the number of steps per minute could be calculated from the video. All data were downloaded and stored securely. Height, weight, waist circumference and percentage body fat measurements used in this chapter are those described in Chapter 5.

7.2.2 Data reduction

Accelerometer data were downloaded as 60 second epochs and waking wear time was analysed using an algorithm previously validated for young adults without Down syndrome (McVeigh, Winkler, Healy, et al., 2016). A single non-wear rule was applied to all of the data. All minutes in continuous periods of ≥90 min of zero cpm, allowing for <3 min with counts 1–50 cpm, were classed as non-wear.

Physical activity heat-maps such as the one in Figure 7.2 and the physical activity diaries were visually inspected to determine participant data valid for inclusion. Data were valid if the accelerometer was worn for a minimum of 8 hours per day for 3 out of 7 days (Izquierdo-Gomez et al., 2014; Izquierdo-Gomez et al., 2017), or for a minimum of 10 hours per day for 4 of the 7 days (Esposito et al., 2012; Matute-Llorente et al., 2013; Nordstrøm et al., 2013; Shields et al., 2017). Figure 7.2 is an example of the accelerometer data heat-map of one participant; calendar dates are across the x axis and time of day using a 24-hour clock are on the y axis. The colours represent the intensity of activity, from low activity (blue) to high activity (red). Grey bands are indicative of non-wear or sleep time. This heat map shows that the participant wore the accelerometer for six consecutive days from approximately 7am in the morning to between 8pm and 11pm at night. Most of the activity recorded was low intensity with bursts of middle and high intensity physical activity.

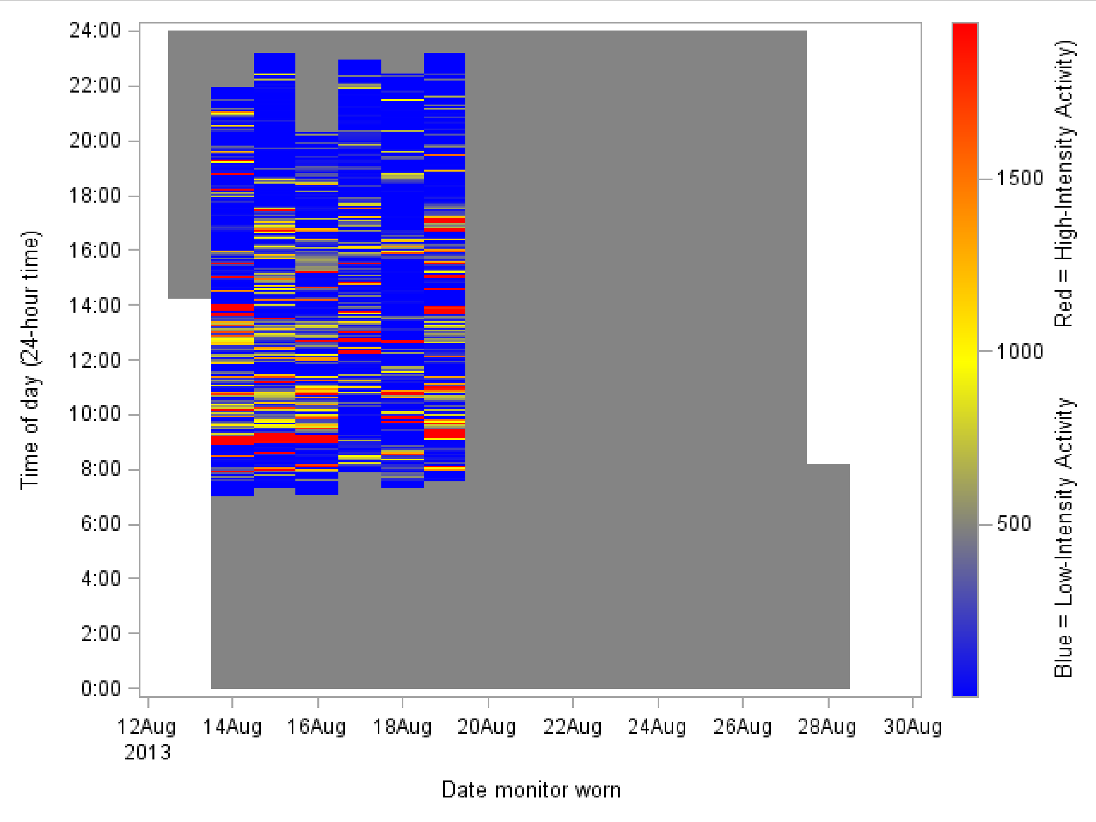


Figure 7.2 Physical activity heat-map

Standard cut-points were used to classify sedentary behaviour (<100 cpm) (Matthews et al., 2008), light (100-1951 cpm), moderate (1952-5724 cpm) and vigorous activity intensity (>5724 cpm) (S. P. Freedson, Melanson, & Sirard, 1998) to enable comparisons with populations without Down syndrome. Down syndrome specific cut-points as developed by

Agiovlasitis et al. (2011) were not used as these were developed using a uni-axial accelerometer and 30 second epochs. Whilst the Down syndrome specific cut-points proposed by Peiris et al. (2017) were developed using a tri-axial accelerometer and 60 second epochs, the accelerometer was a different brand (RT3) and therefore these cut-points may not be applicable.

Previous objective research of the physical activity of adolescents and young adults with Down syndrome has specified various minimum wear times, the more common being 10 hours per day for 4 out of 7 days (Esposito et al., 2012; Matute-Llorente et al., 2013; Nordstrøm et al., 2013) and 8 hours per day for 3 out of 7 days (Izquierdo-Gomez et al., 2014; Izquierdo-Gomez et al., 2017). For comparison, both these minimum wear times were used. For participants with a minimum of 8 hours of wear per day for 3 out of 7 days (Group A), and those with a minimum of 10 hours of wear per day for 4 out of 7 days (Group B), average wear time, number of minutes spent in each intensity, counts per minute and step count were analysed for each day and per average day. Prolonged sedentary bouts of ≥20 and ≥30 minutes, the number of breaks from sedentary behaviour and ≥10 minute MVPA bouts, both strict and modified, were analysed for an average day for each participant. Breaks in sedentary behaviour were the count of occasions where counts-per-minute increased above 100 cpm. Modified 10 minute MVPA bouts allowed for 2 minutes below the cut-point as described by McVeigh, Winkler, Howie, et al. (2016).

7.2.3 Statistical analysis

Descriptive statistics, reported as means with standard deviations (SD) or proportions where appropriate were used to summarise the number of days the accelerometer was worn, participant characteristics and the number of participants meeting physical activity guidelines. Differences in the characteristics of participants and non-participants (adolescents and young adults in the PANDs study who did not wear the accelerometer) were analysed using independent samples t-tests with unequal variances and Pearson’s chi-squared test of independence. Differences in participant characteristics and the mean amount of time spent in sedentary behaviour and physical activity, number of steps, number of breaks and bouts of sedentary behaviour and MVPA by sex and age group were analysed using independent samples t-tests with unequal variances.

Relationships between measures of sedentary behaviour and physical activity, anthropometric and DEXA variables as continuous variables were tested using Spearman’s correlation. Correlation strength was determined using the guidelines of 0.00-0.25 = little or no relationship, 0.25 to 0.50 = fair relationship, 0.50 to 0.75 = moderate to good relationship and >0.75 = good to excellent relationship (Portney & Watkins, 2009). Welch's ANOVA with a Games-Howell's post hoc test and independent sample t-tests with unequal variances were used to test for differences between BMI categories, percentage body fat and waist-to-height categories for young adults. Analyses of the relationship between physical activity, sedentary behaviour, anthropometric and DEXA variables in adolescents were not conducted due to the small sample sizes.

Exposure Variation Analysis (EVA) was used to analyse the percentage of total time spent at each intensity across different bouts of time. These bouts were 0 to <5 minutes, 5 to <10 minutes, 10 to <20 minutes, 20 to <30 minutes, 30 to <60 minutes and ≥60 minutes (McVeigh, Winkler, Howie, et al., 2016; Straker et al., 2014). The level of statistical significance was set at alpha=0.05 and all *P* values were estimated using two-tailed tests. All analyses were performed in SPSS (IBM Corp. Released 2016. IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp).

7.3 Results

7.3.1 Participants

Of the 59 participants in the PANDs study, 56 wore the accelerometer to collect physical activity data. Of these participants, 31 returned the completed physical activity diary and 49 (87.5%) wore the accelerometer for at least 7 days (see Table 7.1). Forty seven (83.9%) participants wore the accelerometer for a minimum of 8 hours per day for 3 days and 27 (42%) participants wore the accelerometer for a minimum of 8 hours on 7 or more days. Forty one (73.2%) participants wore the accelerometer for a minimum of 10 hours per day for 4 days, and 14 (25%) participants wore the accelerometer for a minimum of 10 hours on 7 or more days (see Table 7.1). Twelve participants and their family member/carer assented to their steps being videoed.

The characteristics of participants in Group A and Group B are shown in Table 7.2. Apart from height (13.0, 95% CI 9.2, 16.7) there were no differences between the characteristics of males and females in either group. There were also no differences in the means of age, height, weight, waist circumference and waist-to-height ratio between participants in

Group A (n=47) and non-participants (n=12), nor between participants in Group B (n=41) and non-participants (n=18) (see Table 7.3). When comparing the anthropometric characteristics of participants in Group B (stricter protocol) with the participants in Group A that were not included in Group B (n=6), there were no differences in age, height, weight, waist circumference or waist to height ratio (see Table 7.4). In group A, 75% (24/32) of males in the PANDs study were participants, whereas in Group B, 59.4% (19/32) of males were participants (see Table 7.5). There were no relationships between the proportions of adolescents and young adults and participation in either group (see Table 7.6).

Table 7.1 Number of days the accelerometer was worn by participants

	Participant n (%)		
Number of days	**Total**	**Group A**	**Group B**
0	0	2 (3.6)	5 (8.9)
1	0	3 (5.4)	3 (5.4)
2	0	4 (7.1)	4 (7.1)
3	0	3 (5.4)	3 (5.4)
4	2 (3.6)	3 (5.4)	8 (14.3)
5	1 (1.8)	5 (8.9)	7 (12.5)
6	4 (7.1)	9 (16.1)	12 (21.4)
≥7	49 (87.5)	27 (48.2)	14 (25.0)
Total	56 (100)	56 (100)	56 (100)

Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days. Shading indicates those participants who wore the accelerometer for the minimum number of days for Group A and Group B.

Table 7.2 Characteristics of participants in Group A and Group B by sex

Group A	**Male n=24 Mean ± SD**	**Female n=23 Mean ± SD**	**Total n=47 Mean ± SD**	**Difference in means (95% CI) [male v. female]**	***P value^***
Age (y)	22.0 ± 5.0	21.3 ± 4.7	21.6 ± 4.8	0.7 (-2.2, 3.6)	0.625
Height (cm)	159.1 ± 5.9	146.1 ± 6.8	152.7 ± 9.1	13.0 (9.2, 16.7)	<0.001#
Weight (kg)	67.2 ± 14.3	61.1 ± 16.1	64.2 ± 15.3	6.1 (-2.9, 15.0)	0.178
BMI (kg/m^2)	26.5 ± 5.3	28.4 ± 6.8	27.4 ± 6.1	-1.9 (-5.5, 1.7)	0.283
Waist circumference (cm)	83.5 ± 11.9	80.1 ± 20.7	81.9 ± 16.7	3.4 (-6.7, 13.4)	0.497
Waist-to-height ratio	0.52 ± 0.07	0.55 ± 0.14	0.54 ± 0.11	-0.02 (-0.09, 0.04)	0.457
Group B	**Male n=19 Mean ± SD**	**Female n=22 Mean ± SD**	**Total n=41 Mean ± SD**	**Difference in means (95% CI) [male v. female]**	***P value^***
Age (y)	22.5 ± 4.9	21.1 ± 4. 7	21.7 ± 4.8	1.4 (-1.7, 4.4)	0.366
Height (cm)	159.1 ± 4.4	146.3 ± 6.9	152.2 ± 8.7	12.8 (9.2, 16.5)	<0.001#
Weight (kg)	66.6 ± 12.2	59.4 ± 14.1	62.7 ± 13.6	7.2 (-1.1, 15.5)	0.087
BMI (kg/m^2)	26.3 ± 4.4	27.5 ± 5.4	26.9 ± 4.9	-1.2 (-4.3, 1.8)	0.421
Waist circumference (cm)	83.2 ± 11.0	76.7 ± 13.0	79.7 ± 12.4	6.5 (-1.1, 14.0)	0.093
Waist-to-height ratio	0.52 ± 0.07	0.52 ± 0.08	0.52 ± 0.07	-0.00 (-0.05, 0.04)	0.934

SD=standard deviation; CI=confidence interval; Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days

^Two-tailed, independent samples t-test *P* value

#*P*<0.05

Table 7.3 Characteristics of participants in Group A and Group B compared to non-participants

Group A	**Participants n=47 Mean ± SD**	**Non-participants n=12 Mean ± SD**	**Total n=59 Mean ± SD**	**Difference in means (95% CI) [participants v. non-participants**	***P* value^**
Age (y)	21.6 ± 4.8	21.8 ± 3.7	21.6 ± 4.6	-0.1 (-2.8, 2.5)	0.919
Height (cm)	152.7 ± 9.1	151.2 ± 8.6	152.4 ± 8.9	1.5 (-4.5, 7.4)	0.610
Weight (kg)	64.2 ± 15.3	63.7 ± 8.6	64.1 ± 14.2	0.5 (-6.3, 7.3)	0.879
BMI (kg/m^2)	27.4 ± 6.1	27.9 ± 3.5	27.5 ± 5.6	-0.4 (-3.2, 2.3)	0.753
Waist circumference (cm)	81.9 ± 16.7	81.7 ± 8.8	81.8 ± 15.3	0.2 (-7.0, 7.3)	0.962
Waist-to-height ratio	0.54 ± 0.11	0.54 ± 0.06	0.54 ± 0.10	-0.01 (-0.05, 0.04)	0.812
Group B	**Participants n=41 Mean ± SD**	**Non-participants n=18 Mean ± SD**	**Total n=59 Mean ± SD**	**Difference in means (95% CI) [participants v. non-participants**	***P* value^**
Age (y)	21.7 ± 4.8	21.4 ± 4.2	21.6 ± 4.6	0.3 (-2.2, 2.8)	0.819
Height (cm)	152.2 ± 8.7	153.0 ± 9.6	152.4 ± 8.9	-0.8 (-6.2, 4.6)	0.759
Weight (kg)	62.7 ± 13.6	67.3 ± 15.3	64.1 ± 14.2	-4.6 (-13.1, 4.0)	0.284
BMI (kg/m^2)	26.9 ± 4.9	28.9 ± 7.0	27.5 ± 5.6	-1.9 (-5.7, 1.8)	0.296
Waist circumference (cm)	79.7 ± 12.4	86.6 ± 20.2	81.8 ± 15.3	-6.9 (-17.5, 3.7)	0.191
Waist-to-height ratio	0.52 ± 0.07	0.57 ± 0.14	0.54 ± 0.10	-0.04 (-0.12, 0.03)	0.226

SD=standard deviation; CI=confidence interval for the difference in means by participation; Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days

^Two-tailed, independent samples t-test *P* value

$^{\#}P<0.05$

Table 7.4 Characteristics of participants compared to non-participants in Group B

Characteristic	Group B participants n=41 Mean ± SD	Non-participants in Group B n=6 Mean ± SD	Total Group A n=47 Mean ± SD	Difference in means (95% CI) [participants v. non-participants	*P* value^
Age (y)	21.7 ± 4.8	20.8 ± 5.4	21.6 ± 4.8	0.9 (-4.7, 6.5)	0.712
Height (cm)	152.2 ± 8.7	156.5 ± 11.5	152.7 ± 9.1	-4.3 (-16.3, 7.7)	0.415
Weight (kg)	62.7 ± 13.6	74.5 ± 23.3	64.2 ± 15.3	-11.7 (-36.1, 12.6)	0.278
BMI (kg/m^2)	26.9 ± 4.9	30.9 ± 11.4	27.4 ± 6.1	-3.9 (-15.9, 8.0)	0.441
Waist circumference (cm)	79.7 ± 12.4	96.5 ± 32.2	81.9 ± 16.7	-16.8 (-50.5, 17.0)	0.260
Waist-to-height ratio	0.52 ± 0.07	0.62 ± 0.24	0.54 ± 0.11	-0.1 (-0.35, -0.16)	0.368

SD=standard deviation; CI=confidence interval for the difference in means by participation; Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days
^Two-tailed, independent samples t-test *P* value
$^{\#}P<0.05$

Table 7.5 Relationship between participation in Group A, Group B and sex

	Participants	Non-participants	Total	χ^2	*P* value^
Group A				0.94	0.333
Male (n)	24	8	32		
% within sex category	75.0	25.0	100		
% within participation category	51.1	66.7	54.2		
Female (n)	23	4	27		
% within sex category	85.2	14.8	100		
% within participation category	48.9	33.3	45.8		
Total (n)	47	12	59		
% within sex category	79.7	20.3	100		
% within participation category	100	100	100		
Group B				3.38	0.066
Male (n)	19	13	32		
% within sex category	59.4	40.6	100		
% within participation category	46.3	72.2	54.2		
Female (n)	22	5	27		
% within sex category	81.5	18.5	100		
% within participation category	53.7	27.8	45.8		
Total	41	18	59		
% within sex category	69.5	30.5	100		
% within participation category	100	100	100		

Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days
^Two-tailed Pearson's chi-squared test of independence *P* value
$^{\#}P<0.05$

Table 7.6 Relationship between participation in Group A, Group B and age group

	Participants	Non-participants	Total	χ^2	*P* value^
Group A				1.65	0.200
Adolescent (n)	12	1	13		
% within age group	92.3	7.7	100		
% within participation category	25.5	8.3	22.0		
Young adult (n)	35	11	46		
% within age group	76.1	23.9	100		
% within participation category	74.5	91.7	78.0		
Total	47	12	59		
% within age group	79.7	20.3	100		
% within participation category	100	100	100		
Group B				0.43	0.510
Adolescent (n)	10	3	13		
% within age group	76.9	23.1	100		
% within participation category	24.4	16.7	22.0		
Young adult (n)	31	15	46		
% within age group	67.4	32.6	100		
% within participation category	75.6	83.3	78.0		
Total	41	18	59		
% within age group	69.5	30.5	100		
% within participation category	100	100	100		

Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days
^Two-tailed Pearson's chi-squared test of independence *P* value
#*P*<0.05

7.3.2. Physical activity and sedentary behaviour

Tables 7.7 to 7.10 present the mean wear time, minutes of sedentary behaviour, light, moderate, vigorous and MVPA, counts per minute, number of steps, number of breaks from sedentary behaviour and time spent in bouts of sedentary behaviour and MVPA for participants in Group A and Group B by age group and sex. Participants in Group A wore the accelerometer for a mean of 743.4 minutes (12 hours, 24 minutes) per day and participants in Group B wore the accelerometer for a mean of 786.0 minutes (13 hours, 6 minutes) per day. There were no differences in mean wear time between adolescents and young adults and between males and females. Participants in Group A spent a mean of 439.5 ± 79.1 minutes (7 hours 20 minutes) in sedentary behaviour and 27.2 ± 21.7 minutes in MVPA (see Table 7.7). Participants in Group B spent a mean of 466.9 ± 74.8 minutes (7 hours 47 minutes) in sedentary behaviour and 27.1 ± 18.9 minutes in MVPA (see Table 7.8).

For both groups there was no significant difference in any of the physical activity variables between adolescents and young adults with Down syndrome (see Tables 7.7 and 7.8). As shown in Table 7.9, males in Group A spent less time in sedentary behaviour compared to females (-46.6, 95% CI -91.4, -1.8), however the confidence interval was large and the difference was not observed in Group B.

Tables 7.11, 7.12 and Figures 7.3, 7.4 show the EVA results for Groups A and B. For both groups, the greatest percentages of total wear time was spent in small bouts (0 to <5 minutes, 5 to <10 minutes) of light and sedentary behaviour. For participants in Group A, 20.1% of total wear time was spent in bouts of 0 to <5 minutes of light activity and 15.6% of total wear time was spent in bouts of 0 to < 5 minutes of sedentary behaviour. There was no time spent in bouts of light, moderate or vigorous activity in either group.

Table 7.7 Mean daily wear time, time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks by age group for participants in Group A

Group A	**Adolescent n=12 Mean ± SD**	**Young adult n=35 Mean ± SD**	**Total n=47 Mean ± SD**	**Difference in means (95% CI) [adolescent v. young adult]**	***P* value^**
Wear (min/day)	736.0 ± 67.3	745.9 ± 85.0	743.4 ± 80.3	-10.0 (-59.9, 39.9)	0.684
Sedentary (min/day)	424.6 ± 74.4	444.6 ± 81.1	439.5 ± 79.1	-20.0 (-73.1, 33.0)	0.441
Light (min/day)	273.8 ± 48.7	277.8 ± 66.1	276.8 ± 61.6	-3.9 (-40.8, 33.0)	0.829
Moderate (min/day)	35.1 ± 27.2	20.6 ± 14.5	24.3 ± 19.3	14.5 (-3.3, 32.2)	0.102
Vigorous (min/day)	2.5 ± 4.5	3.0 ± 5.6	2.8 ± 5.3	-0.5 (-3.8, 2.8)	0.773
MVPA (min/day)	37.6 ± 29.1	23.6 ± 17.6	27.2 ± 21.7	14.0 (-5.1, 33.1)	0.139
cpm/day	398.3 ± 194.5	328.3 ± 136.5	346.2 ± 154.2	70.0 (-59.5, 199.5)	0.267
Steps (n/day)	6845 ± 2748	6084 ± 2588	6278 ± 2621	761 (-1141, 2663)	0.412
Number of breaks (n/day)	85.2 ± 10.8	90.2 ± 15.8	89.0 ± 14.7	-5.0 (-13.4, 3.4)	0.232
Sedentary bouts ≥20 min	114.2 ± 65.8	125.7 ± 71.6	122.8 ± 69.7	-11.5 (-58.4, 35.4)	0.614
Sedentary bouts ≥30 min	66.7 ± 52.1	70.3 ± 51.9	69.4 ± 51.4	-3.6 (-40.0, 32.8)	0.839
Strict MVPA bouts ≥10 min	10.0 ± 12.0	5.6 ± 7.9	6.8 ± 9.2	4.3 (-3.6, 12.3)	0.260
Modified MVPA bouts ≥10 min	18.5 ± 22.4	9.7 ± 11.4	11.9 ± 15.2	8.7 (-5.8, 23.3)	0.217

SD=standard deviation; MVPA=moderate vigorous physical activity; cpm=counts per minute; CI=confidence interval; Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days

^Two-tailed, independent samples t-test *P* value

#*P*<0.05

Table 7.8 Mean daily wear time, time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks by age group for participants in Group B

	Adolescent n=10 Mean ± SD	Young adult n=31 Mean ± SD	Total n=41 Mean ± SD	Difference in means (95% CI) [adolescent v. young adult]	*P* value^
Wear (min/day)	765.5 ± 58.0	792.6 ± 62.2	786.0 ± 61.6	-27.2 (-72.6, 18.3)	0.224
Sedentary (min/day)	451.6 ± 49.7	471.9 ± 81.4	466.9 ± 74.8	-20.3 (-64.5, 23.9)	0.354
Light (min/day)	279.6 ± 50.3	295.9 ± 70.1	291.9 ± 65.6	-16.3 (-58.5, 25.9)	0.430
Moderate (min/day)	31.6 ± 18.5	22.0 ± 14.7	24.3 ± 16.0	9.6 (-4.3, 23.5)	0.159
Vigorous (min/day)	2.7 ± 4.9	2.8 ± 5.6	2.8 ± 5.3	-0.2 (-4.0, 3.7)	0.932
MVPA (min/day)	34.3 ± 21.3	24.8 ± 17.7	27.1 ± 18.9	9.4 (-6.7, 25.5)	0.228
cpm/day	372.7 ± 143.4	320.7 ± 118.1	333.4 ± 124.9	52.1 (-55.9, 160.1)	0.317
Steps (n/day)	6832 ± 2015	6434 ± 2623	6531 ± 2471	398 (-1256, 2052)	0.621
Number of breaks (n/day)	89.0 ± 11.4	96.6 ± 13.9	94.7 ± 13.6	-7.6 (-16.8, 1.6)	0.101
Sedentary bouts ≥20 min	117.4 ± 61.8	131.6 ± 82.5	128.1 ± 77.5	-14.2 (-65.3, 36.9)	0.569
Sedentary bouts ≥30 min	66.0 ± 51.7	74.6 ± 60.1	72.5 ± 57.6	-8.6 (-49.8, 32.7)	0.667
Strict MVPA bouts ≥10 min	11.3 ± 14.5	5.4 ± 7.7	6.9 ± 9.9	5.8 (-4.7, 16.4)	0.248
Modified MVPA bouts ≥10 min	15.8 ± 17.8	10.0 ± 11.6	11.4 ± 13.3	5.7 (-7.4, 18.8)	0.358

SD=standard deviation; MVPA=moderate vigorous physical activity; cpm=counts per minute; CI=confidence interval; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days
^Two-tailed, independent samples t-test *P* value
[#]$P<0.05$

Table 7.9 Mean daily wear time, time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks by sex for participants in Group A

	Male n=24 Mean ± SD	**Female n=23 Mean ± SD**	**Total n=47 Mean ± SD**	**Difference in means (95% CI) [male v. female]**	***P* value^**
Wear (min/day)	729.3 ± 74.3	758.1 ± 85.2	743.4 ± 80.3	-28.9 (-76.0, 18.2)	0.223
Sedentary (min/day)	416.7 ± 79.0	463.3 ± 73.5	439.5 ± 79.1	-46.6 (-91.4, -1.8)	0.042[#]
Light (min/day)	283.3 ± 69.1	270.0 ± 53.4	276.8 ± 61.6	13.3 (-22.9, 49.5)	0.463
Moderate (min/day)	26.6 ± 22.6	22.0 ± 15.2	24.3 ± 19.3	4.6 (-6.8, 15.9)	0.421
Vigorous (min/day)	2.8 ± 5.1	2.9 ± 5.5	2.8 ± 5.3	-0.2 (-3.3, 3.0)	0.918
MVPA (min/day)	29.3 ± 24.2	24.9 ± 18.9	27.2 ± 21.7	4.4 (-8.3, 17.1)	0.490
cpm/day	366.6 ± 165.0	324.9 ± 142.5	346.2 ± 154.2	41.7 (-48.8, 132.2)	0.358
Steps (n/day)	6370 ± 3203	6182 ± 1902	6278 ± 2621	189 (-1359, 1737)	0.806
Number of breaks (n/day)	86.6 ± 13.9	91.4 ± 15.4	89.0 ± 14.7	-4.9 (-13.5, 3.8)	0.261
Sedentary bouts ≥20 min	115.1 ± 65.6	130.8 ± 74.2	122.8 ± 69.7	-15.6 (-56.9, 25.6)	0.450
Sedentary bouts ≥30 min	64.3 ± 44.9	74.7 ± 58.0	69.4 ± 51.4	-10.4 (-41.0, 20.2)	0.497
Strict MVPA bouts ≥10 min	6.9 ± 8.6	6.6 ± 10.0	6.8 ± 9.2	0.2 (-5.3, 5.7)	0.932
Modified MVPA bouts ≥10 min	13.7 ± 16.3	10.1 ± 14.1	11.9 ± 15.2	3.7 (-5.3, 12.6)	0.414

SD=standard deviation; MVPA=moderate vigorous physical activity; cpm=counts per minute; CI=confidence interval; Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days

^Two-tailed, independent samples t-test *P* value

[#]*P*<0.05

Table 7.10 Mean daily wear time, time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks by sex for participants in Group B

	Male n=19 Mean ± SD	**Female n=22 Mean ± SD**	**Total n=41 Mean ± SD**	**Difference in means (95% CI) [male v. female]**	***P* value^**
Wear (min/day)	789.8 ± 53.6	782.7 ± 68.9	786.0 ± 61.6	7.1 (-31.7, 45.8)	0.715
Sedentary (min/day)	447.3 ± 77.9	483.8 ± 69.4	466.9 ± 74.8	-36.5 (-83.6, 10.5)	0.124
Light (min/day)	313.2 ± 70.8	273.6 ± 56.1	291.9 ± 65.6	39.7 (-1.3, 80.7)	0.057
Moderate (min/day)	26.4 ± 16.9	22.6 ± 15.4	24.3 ± 16.0	3.8 (-6.5, 14.1)	0.456
Vigorous (min/day)	2.8 ± 5.3	2.8 ± 5.5	2.8 ± 5.3	0.0 (-3.4, 3.5)	0.981
MVPA (min/day)	29.2 ± 18.7	25.3 ± 19.2	27.1 ± 18.9	3.9 (-8.1, 15.9)	0.518
cpm/day	353.0 ± 109.5	316.4 ± 137.0	333.4 ± 124.9	36.6 (-41.3, 114.6)	0.347
Steps (n/day)	6781 ± 3067	6316 ± 1861	6531± 2471	465 (-1187, 2117)	0.569
Number of breaks (n/day)	95.7 ± 11.8	94.0 ± 15.3	94.7 ± 13.6	1.7 (-6.9, 10.2)	0.696
Sedentary bouts ≥20 min	115.3 ± 72.0	139.2 ± 82.0	128.1 ± 77.5	-24.0 (-72.6, 24.7)	0.325
Sedentary bouts ≥30 min	64.2 ± 51.0	79.7 ± 63.1	72.5 ± 57.6	-15.5 (-51.6, 20.5)	0.389
Strict MVPA bouts ≥10 min	6.6 ± 8.1	7.1 ± 11.4	6.9 ± 9.9	-0.6 (-6.8, 5.7)	0.858
Modified MVPA bouts ≥10 min	13.1 ± 12.1	10.0 ± 14.4	11.4 ± 13.3	3.1 (-5.3, 11.5)	0.460

SD=standard deviation; MVPA=moderate vigorous physical activity; cpm=counts per minute; CI=confidence interval; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days

^Two-tailed, independent samples t-test *P* value

[#]$P<0.05$

Table 7.11 Mean daily percentage of total wear time spent at different activity intensities for participants in Group A

	Bouts (minutes)					
Intensity	**0 to <5**	**5 to <10**	**10 to <20**	**20 to <30**	**30 to <60**	**≥60**
Vigorous %	0.2	0.09	0.07	0.04	0.03	0.0
Moderate %	2.2	0.5	0.3	0.07	0.08	0.0
Light %	20.1	10.2	4.9	1.1	1.0	0.0
Sedentary %	15.6	12.5	14.5	7.2	7.5	1.8

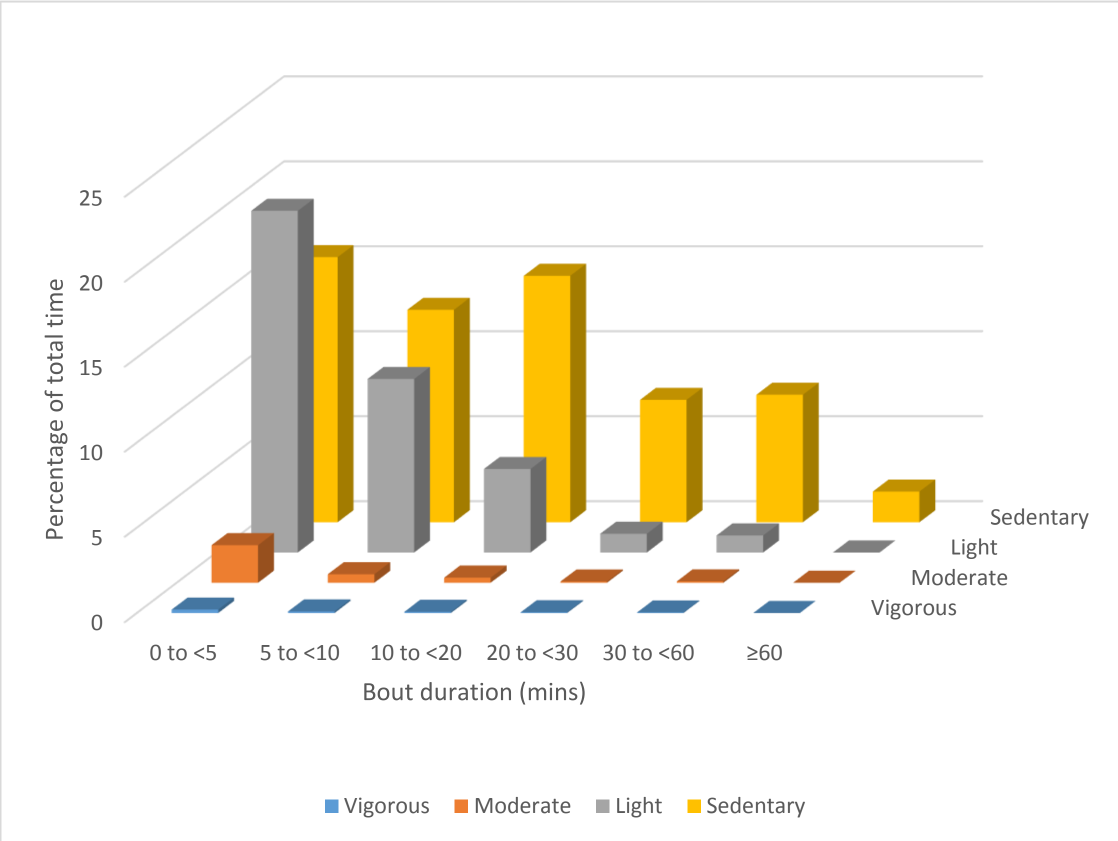


Figure 7.3 Mean daily percentage of total wear time spent at different activity intensities for participants in Group A

Table 7.12 Mean daily percentage of total wear time spent at different activity intensities for participants in Group B

	Bouts (minutes)					
Intensity	**0 to <5**	**5 to <10**	**10 to <20**	**20 to <30**	**30 to <60**	**≥60**
Vigorous %	0.13	0.09	0.08	0.03	0.03	0.0
Moderate %	2.1	0.47	0.32	0.09	0.13	0.0
Light %	20.1	10.3	4.8	1.1	0.8	0.0
Sedentary %	15.7	12.9	14.6	7.0	7.3	1.8

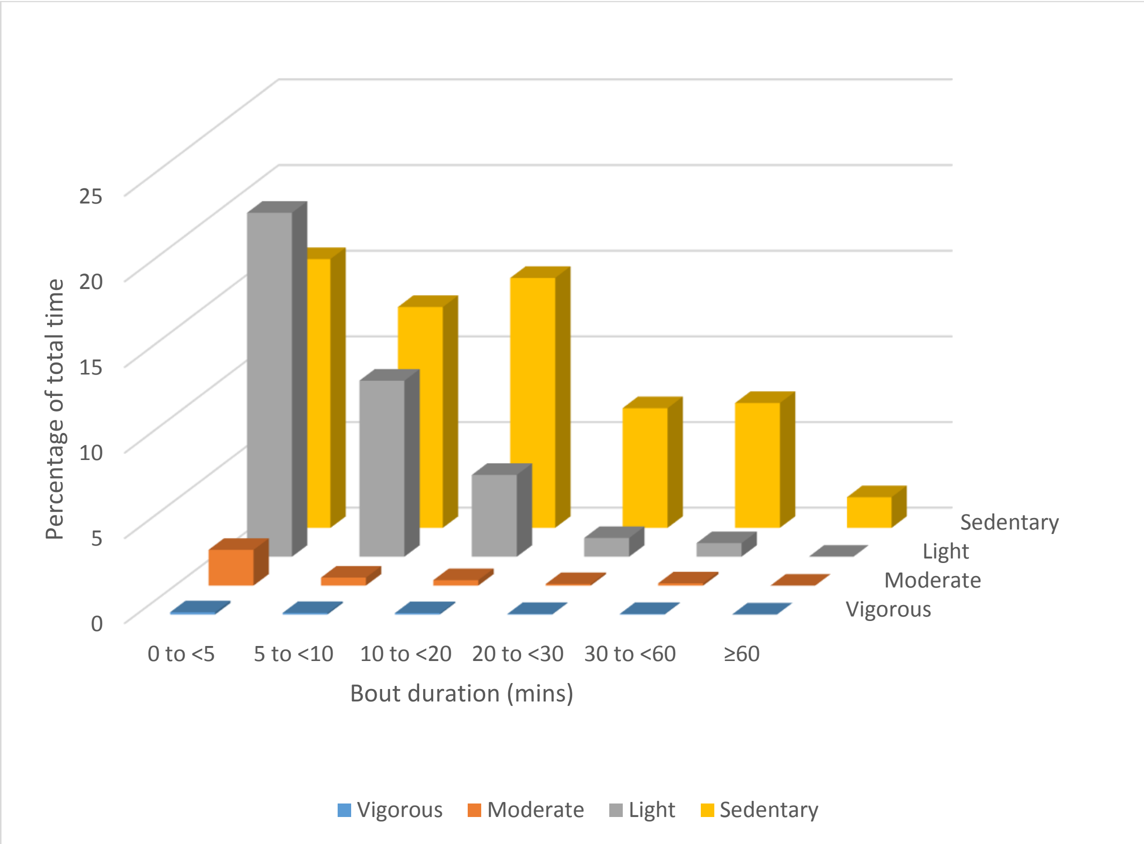


Figure 7.4 Mean daily percentage of total wear time spent at different activity intensities for participants in Group B

7.3.3 Physical activity guidelines

In Group A, 1 out of 12 (8.3%) adolescents recorded ≥60 minutes of MVPA on every day of the three valid days included. One adolescent recorded ≥60 minutes of MVPA on four out of six valid days included, and six adolescents recorded no days with ≥60 minutes of MVPA (see Table 7.13).

In Group B, zero out of 10 adolescents recorded ≥60 minutes of MVPA on every valid day. Three adolescents recorded ≥60 minutes of MVPA on three valid days (see Table 7.13); one adolescent for each of five, six and seven valid days included. Similar to Group A, half the adolescents in group B did not record ≥60 minutes of MVPA on any of the valid days. One adolescent had a mean MVPA of >60 minutes across the seven valid days included in the analysis.

Table 7.13 Adolescent participants in Group A and Group B with ≥60 minutes MVPA

Group A (n=12)		**Group B (n=10)**	
Valid days ≥60 mins MVPA (n)	**Adolescent participants (n)**	**Valid days ≥60 mins MVPA (n)**	**Adolescent participants (n)**
0	6	0	5
1	1	1	2
2	1	2	0
3	3	3	3
≥4	1	≥4	0

Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days

In Group A, 17 out of 35 (48.6%) young adults recorded a mean of 21.4 minutes or more of MVPA per day. Of these, 11 were male and 6 were female. In Group B, 17 out of 31 (54.8%) young adults recorded a mean of 21.4 minutes or more of MVPA per day. Of these, 11 were male and 6 were female (see Table 7.14).

Table 7.14 Young adult participants in Group A and Group B with ≥ 21.4 minutes MVPA per day

Group A (n=35)			Group B (n=31)		
Male n (%)	**Female n (%)**	**Total n (%)**	**Male n (%)**	**Female n (%)**	**Total n (%)**
11 (57.9%)	6 (37.5%)	17 (48.6)	11 (68.8%)	6 (40.0%)	17 (54.8)

Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days

7.3.4 Relationship between physical activity, anthropometric and DEXA variables

Tables 7.15 to 7.18 present the rank order relationships between wear time, sedentary behaviour, physical activity, anthropometric and DEXA variables for young adults in Group A and Group B. Tables 7.19 to 7.24 present the differences in wear time, sedentary behaviour and physical activity variables between anthropometric and percentage body fat categories for young adults in Group A and Group B. There were no rank order relationships between wear time and anthropometric and DEXA variables or differences in wear time between anthropometric and percentage body fat categories suggesting that any relationships observed between sedentary behaviour, physical activity, anthropometric and DEXA variables were not due to differences in wear time.

For females in Group A there was a moderate to good negative rank order relationship between time spent in sedentary behaviour and BMI (rho=-0.647, *P*=0.007), percentage body fat (rho=-0.659, *P*=0.014), waist circumference (rho=-0.571, *P*=0.021) and waist-to-height ratio (rho=-0.598, *P*=0.014). There was also a moderate to good negative rank order relationship between time spent in bouts of sedentary behaviour greater than 30 minutes duration and BMI (rho=-0.500, *P*=0.049) (see Tables 7.15 and 7.16). These rank order relationships between times spent in sedentary behaviour and BMI, waist circumference and waist-to-height ratio for female young adults were also observed in Group B. These results suggest in female young adults, an inverse relationship between BMI, percentage body fat, waist circumference and waist-to-height and time spent in sedentary behaviour. There were no rank order relationships between BMI and time spent in any of the physical activity intensities for female young adults in Group A, however in Group B there was a moderate to good positive rank order relationship between cpm and BMI (rho=0.629, *p*=0.012) and percentage body fat (rho=0.615, *p*=0.033), suggesting a direct relationship between physical activity, BMI and percentage body fat.

For young adult males in Group A there was a moderate to good negative rank order relationship between time spent in vigorous activity and percentage body fat (rho=-0.666, *p*=0.007) (see Table 7.15). This rank order relationship was also observed for young adult males in Group B (rho=-0.658, *p*=0.014). In Group B there was also a fair positive rank order relationship between BMI and moderate activity for young adult males (rho=0.498, *p*=0.050) and the group as a whole (rho=0.443, *p*=0.013), as well as a positive rank order relationship between BMI and time spent in MVPA (rho=0.373, *p*=0.039) for the group as a whole (see Table 7.17).

There were no differences in wear time, time spent in sedentary behaviour or physical activity intensities when BMI, percentage body fat or waist-to-height ratio were classified using standard cut-points, however there was a difference in the number of breaks in sedentary behaviour (see Tables 7.21 and 7.22). In both Groups A and B young adults with a percentage body fat classified as healthy weight had a greater number of breaks from sedentary behaviour than young adults with a percentage body fat classified as obese (Group A: 18.0, 95% CI 6.0, 30.0) or overweight and obese (Group B: 11.5, 95% CI 2.2, 20.8). Although this difference was not observed when using standard BMI or waist-to-height cut-points, it does suggest that young adults with lower percentage body fat moved more frequently than young adults with a higher percentage body fat.

Table 7.15 Relationship between BMI, percentage body fat and mean daily wear time, time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks for young adult participants in Group A

	rho	*P* value	rho	*P* value	rho	*P* value
BMI	**Male n=19**		**Female n=16**		**Total n=35**	
Wear (min/day)	0.326	0.173	-0.274	0.305	-0.010	0.954
Sedentary (min/day)	0.140	0.569	-0.647	0.007[#]	-0.229	0.186
Light (min/day)	0.316	0.188	0.226	0.399	0.212	0.221
Moderate (min/day)	0.241	0.319	0.179	0.506	0.213	0.220
Vigorous (min/day)	-0.258	0.286	-0.134	0.620	-0.234	0.177
MVPA (min/day)	0.169	0.488	0.099	0.716	0.133	0.446
cpm/day	0.092	0.708	0.341	0.196	0.233	0.178
Steps (n/day)	0.226	0.353	-0.085	0.753	0.061	0.730
Number of breaks (n/day)	-0.115	0.639	-0.066	0.807	-0.112	0.523
Sedentary bouts ≥20 min	0.200	0.411	-0.471	0.066	-0.053	0.763
Sedentary bouts ≥30 min	-0.095	0.700	-0.500	0.049[#]	-0.275	0.109
Strict MVPA bouts ≥10 min	0.141	0.564	-0.036	0.894	0.039	0.822
Modified MVPA bouts ≥10 min	0.126	0.608	-0.147	0.586	-0.019	0.916
Percentage body fat*	**Male n=15**		**Female n=13**		**Total n=28**	
Wear (min/day)	0.025	0.930	-0.440	0.133	-0.097	0.624
Sedentary (min/day)	0.121	0.666	-0.659	0.014[#]	-0.113	0.568
Light (min/day)	0.111	0.694	-0.159	0.603	0.050	0.799
Moderate (min/day)	-0.204	0.466	0.088	0.775	-0.098	0.619
Vigorous (min/day)	-0.666	0.007[#]	-0.053	0.864	-0.400	0.035[#]
MVPA (min/day)	-0.275	0.321	0.055	0.859	-0.192	0.327
cpm/day	-0.321	0.243	0.363	0.223	-0.083	0.676
Steps (n/day)	-0.214	0.443	-0.291	0.334	-0.235	0.229
Number of breaks (n/day)	-0.279	0.315	-0.495	0.086	-0.107	0.587
Sedentary bouts ≥20 min	0.332	0.226	-0.297	0.325	-0.014	0.943
Sedentary bouts ≥30 min	0.288	0.298	-0.297	0.325	-0.044	0.825
Strict MVPA bouts ≥10 min	-0.182	0.517	-0.006	0.985	-0.206	0.294
Modified MVPA bouts ≥10 min	-0.312	0.258	-0.113	0.713	-0.326	0.091

MVPA=moderate vigorous physical activity Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days; rho=Spearman's rank correlation coefficient
*percentage body fat available only for participants with DEXA scan results
[#]*P*<0.05

Table 7.16 Relationship between waist circumference, waist-to-height ratio and mean daily wear time, time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks for young adult participants in Group A

	rho	***P* value**	**rho**	***P* value**	**rho**	***P* value**
Waist circumference	**Male n=19**		**Female n=16**		**Total n=35**	
Wear (min/day)	0.267	0.270	-0.303	0.254	-0.175	0.316
Sedentary (min/day)	0.058	0.814	-0.571	0.021[#]	-0.401	0.017[#]
Light (min/day)	0.314	0.190	0.150	0.579	0.172	0.323
Moderate (min/day)	0.127	0.604	0.112	0.680	0.113	0.518
Vigorous (min/day)	-0.270	0.264	-0.240	0.370	-0.184	0.291
MVPA (min/day)	0.058	0.814	0.007	0.978	0.056	0.750
cpm/day	0.140	0.567	0.224	0.405	0.277	0.108
Steps (n/day)	0.107	0.663	-0.194	0.471	-0.058	0.742
Number of breaks (n/day)	0.026	0.915	-0.147	0.587	-0.113	0.517
Sedentary bouts ≥20 min	0.112	0.647	-0.429	0.097	-0.191	0.272
Sedentary bouts ≥30 min	0.088	0.721	-0.435	0.092	-0.190	0.273
Strict MVPA bouts ≥10 min	0.130	0.597	-0.113	0.677	0.039	0.825
Modified MVPA bouts ≥10 min	0.046	0.852	-0.236	0.378	-0.039	0.825
Waist-to-height ratio	**Male n=19**		**Female n=16**		**Total n=35**	
Wear (min/day)	0.331	0.167	-0.280	0.294	-0.050	0.777
Sedentary (min/day)	0.144	0.557	-0.598	0.014[#]	-0.263	0.127
Light (min/day)	0.327	0.171	0.200	0.457	0.224	0.195
Moderate (min/day)	0.157	0.522	0.100	0.712	0.118	0.498
Vigorous (min/day)	-0.289	0.231	-0.234	0.383	-0.247	0.153
MVPA (min/day)	0.082	0.738	-0.001	0.998	0.041	0.813
cpm/day	0.184	0.450	0.223	0.407	0.250	0.148
Steps (n/day)	0.129	0.599	-0.196	0.467	-0.025	0.889
Number of breaks (n/day)	0.030	0.903	-0.097	0.720	-0.024	0.892
Sedentary bouts ≥20 min	0.184	0.450	-0.455	0.076	-0.120	0.492
Sedentary bouts ≥30 min	0.179	0.464	-0.464	0.070	-0.129	0.461
Strict MVPA bouts ≥10 min	0.145	0.554	-0.133	0.623	0.006	0.973
Modified MVPA bouts ≥10 min	0.058	0.814	-0.248	0.355	-0.079	0.653

MVPA=moderate vigorous physical activity Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days; rho=Spearman's rank correlation coefficient
[#]*P*<0.05

Table 7.17 Relationship between BMI, percentage body fat and mean daily wear time, time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks for young adult participants in Group B

	rho	*P* value	rho	*P* value	rho	*P* value
BMI	**Male n=16**		**Female n=15**		**Total n=31**	
Wear (min/day)	0.455	0.077	0.455	0.077	0.031	0.867
Sedentary (min/day)	0.109	0.688	-0.611	0.016#	-0.243	0.187
Light (min/day)	0.247	0.356	0.254	0.362	0.213	0.249
Moderate (min/day)	0.498	0.050#	0.450	0.092	0.443	0.013#
Vigorous (min/day)	-0.296	0.266	0.350	0.200	-0.020	0.913
MVPA (min/day)	0.359	0.172	0.418	0.121	0.373	0.039#
cpm/day	0.091	0.737	0.629	0.012#	0.333	0.067
Steps (n/day)	0.224	0.405	0.089	0.752	0.145	0.436
Number of breaks (n/day)	-0.374	0.154	-0.107	0.704	-0.225	0.223
Sedentary bouts ≥20 min	0.319	0.228	-0.329	0.232	0.033	0.858
Sedentary bouts ≥30 min	0.281	0.292	-0.382	0.160	-0.012	0.949
Strict MVPA bouts ≥10 min	0.417	0.108	0.236	0.396	0.272	0.139
Modified MVPA bouts ≥10 min	0.300	0.259	0.128	0.649	0.140	0.454
Percentage body fat*	**Male n=13**		**Female n=12**		**Total n=25**	
Wear (min/day)	0.082	0.789	-0.413	0.183	-0.106	0.615
Sedentary (min/day)	0.110	0.721	-0.531	0.075	-0.182	0.385
Light (min/day)	0.110	0.721	-0.119	0.713	0.054	0.798
Moderate (min/day)	-0.006	0.986	0.385	0.217	0.070	0.738
Vigorous (min/day)	-0.658	0.014#	0.370	0.236	-0.333	0.104
MVPA (min/day)	-0.272	0.368	0.343	0.276	-0.056	0.790
cpm/day	-0.330	0.271	0.615	0.033#	-0.039	0.852
Steps (n/day)	-0.203	0.505	-0.098	0.762	-0.176	0.400
Number of breaks (n/day)	-0.214	0.482	-0.503	0.095	-0.122	0.561
Sedentary bouts ≥20 min	0.225	0.459	-0.154	0.633	-0.002	0.994
Sedentary bouts ≥30 min	0.264	0.384	-0.154	0.633	-0.019	0.927
Strict MVPA bouts ≥10 min	-0.033	0.914	0.235	0.462	-0.072	0.731
Modified MVPA bouts ≥10 min	-0.155	0.614	0.094	0.771	-0.286	0.165

MVPA=moderate vigorous physical activity Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days; rho=Spearman's rank correlation coefficient
*percentage body fat available only for participants with DEXA scan results
#*P*<0.05

Table 7.18 Relationship between waist circumference, waist-to-height ratio and mean daily wear time, time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks for young adult participants in Group B

	rho	***P* value**	**rho**	***P* value**	**rho**	***P* value**
Waist circumference	**Male n=16**		**Female n=15**		**Total n=31**	
Wear (min/day)	0.418	0.107	-0.350	0.201	-0.057	0.760
Sedentary (min/day)	0.088	0.745	-0.514	0.050[#]	-0.305	0.095
Light (min/day)	0.291	0.274	0.182	0.516	0.250	0.175
Moderate (min/day)	0.227	0.399	0.346	0.206	0.266	0.149
Vigorous (min/day)	-0.351	0.182	0.240	0.389	0.001	0.997
MVPA (min/day)	0.137	0.613	0.304	0.271	0.240	0.193
cpm/day	0.024	0.931	0.479	0.071	0.319	0.081
Steps (n/day)	0.026	0.922	-0.032	0.909	-0.011	0.952
Number of breaks (n/day)	-0.026	0.922	-0.189	0.499	-0.092	0.624
Sedentary bouts ≥20 min	0.206	0.444	-0.289	0.296	-0.086	0.644
Sedentary bouts ≥30 min	0.212	0.431	-0.336	0.221	-0.085	0.649
Strict MVPA bouts ≥10 min	0.261	0.328	0.153	0.586	0.206	0.265
Modified MVPA bouts ≥10 min	0.092	0.735	0.038	0.894	0.078	0.678
Waist-to-height ratio	**Male n=16**		**Female n=15**		**Total n=31**	
Wear (min/day)	0.462	0.072	-0.313	0.255	0.031	0.868
Sedentary (min/day)	0.075	0.782	-0.551	0.033[#]	-0.254	0.168
Light (min/day)	0.347	0.188	0.247	0.375	0.285	0.121
Moderate (min/day)	0.273	0.306	0.342	0.212	0.288	0.117
Vigorous (min/day)	-0.254	0.343	0.249	0.371	-0.026	0.891
MVPA (min/day)	0.193	0.473	0.297	0.282	0.256	0.164
cpm/day	0.156	0.563	0.476	0.073	0.322	0.077
Steps (n/day)	0.124	0.648	-0.036	0.899	0.030	0.871
Number of breaks (n/day)	0.052	0.849	-0.132	0.638	-0.014	0.941
Sedentary bouts ≥20 min	0.150	0.578	-0.312	0.258	-0.076	0.686
Sedentary bouts ≥30 min	0.155	0.567	-0.367	0.178	-0.096	0.606
Strict MVPA bouts ≥10 min	0.367	0.162	0.129	0.646	0.217	0.241
Modified MVPA bouts ≥10 min	0.178	0.511	0.019	0.947	0.062	0.740

MVPA=moderate vigorous physical activity Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days; rho=Spearman's rank correlation coefficient
[#]*P*<0.05

Table 7.19 Mean daily time spent in time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks by BMI category for young adults in Group A

	BMI category*					
	Healthy weight n=13 (37%)	**Overweight n=10 (29%)**	**Obese n=12 (34%)**	**Total n=35 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**	$F_{2,32}$	***P* value^**
Wear (min/day)	730.4 ± 84.9	784.6 ± 69.1	730.6 ± 93.2	745.9 ± 85.0	1.80	0.190
Sedentary (min/day)	464.7 ± 98.4	456.8 ± 47.0	412.6 ± 78.9	444.6 ± 81.1	1.52	0.242
Light (min/day)	248.0 ± 67.4	295.0 ± 50.5	295.6 ± 69.1	277.8 ± 66.1	2.15	0.142
Moderate (min/day)	15.3 ± 11.8	27.0 ± 17.6	21.0 ± 13.1	20.6 ± 14.5	1.74	0.203
Vigorous (min/day)	2.3 ± 3.4	5.8 ± 8.7	1.3 ± 3.2	3.0 ± 5.6	1.27	0.306
MVPA (min/day)	17.7 ± 13.3	32.8 ± 22.9	22.3 ± 14.7	23.6 ± 17.6	1.71	0.208
cpm/day	296.1 ± 147.4	361.3 ± 146.2	335.7 ± 118.7	328.3 ± 136.5	0.57	0.575
Steps (n/day)	5283 ± 2192	7561 ± 2862	5720 ± 2424	6084 ± 2588	2.16	0.142
Number of breaks (n/day)	88.2 ± 17.5	95.9 ± 16.4	87.8 ± 13.1	90.2 ± 15.8	0.86	0.440
Sedentary bouts ≥20 min	134.0 ± 91.4	132.1 ± 47.3	111.5 ± 67.7	125.7 ± 71.6	0.40	0.679
Sedentary bouts ≥30 min	77.2 ± 65.9	74.8 ± 39.1	59.1 ± 46.1	70.3 ± 51.9	0.47	0.629
Strict MVPA bouts ≥10 min	4.2 ± 6.4	8.6 ± 11.1	4.7 ± 6.2	5.6 ± 7.9	0.63	0.543
Modified MVPA bouts ≥10 min	7.1 ± 7.8	16.7 ± 16.2	6.7 ± 7.6	9.7 ± 11.4	1.63	0.223

SD=standard deviation; MVPA=moderate vigorous physical activity; Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days
*BMI of young adults classified using NHMRC cut-points (NHMRC, 2013b)
^Welch's ANOVA *P* value
$^{\#}P<0.05$

Table 7.20 Mean daily time spent in time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks by BMI category for young adults in Group B

	BMI category*					
	Healthy weight n=11 (35%)	Overweight n=10 (32%)	Obese n=10 (32%)	Total n=31 (100%)		
	Mean ± SD	Mean ± SD	Mean ± SD	Mean ± SD	$F_{2,28}$	*P* value^
Wear (min/day)	787.6 ± 60.9	805.2 ± 39.0	785.6 ± 83.7	792.6 ± 62.2	0.42	0.661
Sedentary (min/day)	500.6 ± 101.1	469.9 ± 48.0	442.3 ± 80.3	471.9 ± 81.4	1.05	0.371
Light (min/day)	270.9 ± 74.5	301.5 ± 40.0	317.9 ± 85.4	295.9 ± 70.1	1.00	0.389
Moderate (min/day)	14.7 ± 11.6	27.8 ± 17.2	24.1 ± 13.1	22.0 ± 14.7	2.55	0.106
Vigorous (min/day)	1.4 ± 1.9	5.9 ± 8.7	1.4 ± 2.8	2.8 ± 5.6	1.29	0.302
MVPA (min/day)	16.1 ± 12.0	33.8 ± 22.3	25.5 ± 14.5	24.8 ± 17.7	2.88	0.083
cpm/day	262.5 ± 100.5	364.5 ± 143.4	341.0 ± 89.2	320.7 ± 118.1	2.43	0.116
Steps (n/day)	5414 ± 2325	7749 ± 2716	6241 ± 2514	6434 ± 2623	2.15	0.145
Number of breaks (n/day)	97.5 ± 15.7	97.6 ± 14.1	94.7 ± 12.9	96.6 ± 13.9	0.15	0.866
Sedentary bouts ≥20 min	136.2 ± 108.1	139.8 ± 56.5	118.3 ± 78.8	131.6 ± 82.5	0.24	0.787
Sedentary bouts ≥30 min	79.0 ± 77.8	81.5 ± 49.1	62.9 ± 51.7	74.6 ± 60.1	0.36	0.704
Strict MVPA bouts ≥10 min	2.2 ± 2.9	8.7 ± 11.1	5.8 ± 6.4	5.4 ± 7.7	2.57	0.111
Modified MVPA bouts ≥10 min	5.4 ± 6.1	17.1 ± 15.9	8.0 ± 8.1	10.0 ± 11.6	2.36	0.126

SD=standard deviation; MVPA=moderate vigorous physical activity; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days
*BMI of young adults classified using NHMRC cut-points (NHMRC, 2013b)
^Welch's ANOVA *P* value
$^{\#}P<0.05$

Table 7.21 Mean daily time spent in time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks by percentage body fat category for young adults in Group A

	Percentage body fat category*					
	Healthy weight n=7 (25%)	**Overweight n=10 (36%)**	**Obese n=11 (39%)**	**Total n=28 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Mean ± SD**	$F_{2,21}$	***P* value^**
Wear (min/day)	783.5 ± 75.5	754.4 ± 85.8	724.3 ± 98.6	749.9 ± 88.8	0.99	0.393
Sedentary (min/day)	472.0 ± 68.4	443.0 ± 87.6	417.5 ± 81.3	440.2 ± 80.8	1.12	0.350
Light (min/day)	293.1 ± 46.1	278.5 ± 52.5	283.8 ± 76.9	284.2 ± 60.1	0.18	0.838
Moderate (min/day)	17.2 ± 8.0	26.0 ± 19.7	21.6 ± 13.4	22.1 ± 14.9	0.91	0.424
Vigorous (min/day)	1.2 ± 1.4	6.9 ± 8.6	1.4 ± 3.3	3.3 ± 6.0	2.02	0.167
MVPA (min/day)	18.5 ± 7.6	32.9 ± 24.3	23.0 ± 15.0	25.4 ± 18.1	1.62	0.229
cpm/day	272.1 ± 51.6	411.9 ± 171.5	335.1 ± 126.1	346.8 ± 139.1	3.42	0.059
Steps (n/day)	6415 ± 1364	7233 ± 3414	5611 ± 2529	6391 ± 2679	0.78	0.477
Number of breaks (n/day)	102.6 ± 9.0[a]	92.0 ± 13.0[a,c]	84.6 ± 15.0[b,c]	91.8 ± 14.4	5.22	0.017[#]
Sedentary bouts ≥20 min	100.0 ± 46.5	119.9 ± 58.2	125.1 ± 71.0	116.9 ± 59.9	0.48	0.627
Sedentary bouts ≥30 min	49.7 ± 30.9	67.4 ± 45.0	70.0 ± 49.6	64.0 ± 43.3	0.72	0.501
Strict MVPA bouts ≥10 min	2.6 ± 3.0	10.8 ± 11.5	4.8 ± 6.4	6.4 ± 8.6	2.40	0.124
Modified MVPA bouts ≥10 min	5.8 ± 4.6	17.9 ± 16.1	6.9 ± 7.6	10.5 ± 12.0	2.44	0.119

SD=standard deviation; MVPA=moderate vigorous physical activity; Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days
*percentage body fat classified using cut-points developed using age, sex and BMI (Pasco et al., 2014);
^Welch's ANOVA *P* value
[#]$P<0.05$

Table 7.22 Mean daily time spent in time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks by percentage body fat category for young adults in Group B

	Percentage body fat category*				
	Healthy weight n=7 (28%)	**Overweight/obese n=18 (62%)**	**Total n=25 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Difference in means (95% CI) [healthy weight v. overweight/obese]**	***P* value^**
Wear (min/day)	806.1 ± 63.5	790.0 ± 62.6	794.5 ± 61.9	16.1 (-46.0, 78.2)	0.580
Sedentary (min/day)	481.0 ± 67.3	462.4 ± 78.6	467.6 ± 74.7	18.5 (-49.5, 86.6)	0.566
Light (min/day)	305.6 ± 53.0	298.7 ± 72.2	300.6 ± 66.4	6.9 (-49.2, 62.9)	0.798
Moderate (min/day)	18.5 ± 9.0	24.8 ± 16.8	23.1 ± 15.1	-6.3 (-17.2, 4.6)	0.240
Vigorous (min/day)	1.0 ± 1.6	4.0 ± 6.9	3.2 ± 6.0	-3.0 (-6.6, 0.6)	0.096
MVPA (min/day)	19.5 ± 9.9	28.9 ± 20.3	26.2 ± 18.3	-9.3 (-21.9, 3.3)	0.139
cpm/day	277.0 ± 71.1	356.2 ± 126.2	344.1 ± 117.8	-79.2 (-163.0, 4.6)	0.063
Steps (n/day)	6763 ± 1236	6701 ± 3102	6718 ± 2683	61.7 (-1734, 1857)	0.944
Number of breaks (n/day)	106.1 ± 8.3	94.6 ± 13.1	97.8 ± 12.9	11.5 (2.2, 20.8)	0.018[#]
Sedentary bouts ≥20 min	98.2 ± 54.9	134.1 ± 73.6	124.0 ± 69.7	-35.8 (-93.5, 12.9)	0.205
Sedentary bouts ≥30 min	47.4 ± 37.0	78.1 ± 53.3	69.5 ± 50.6	-30.8 (-70.6, 9.1)	0.121
Strict MVPA bouts ≥10 min	2.4 ± 3.3	7.4 ± 9.3	6.0 ± 8.3	-5.0 (-10.2, 0.2)	0.057
Modified MVPA bouts ≥10 min	5.7 ± 5.6	12.6 ± 13.6	10.7 ± 12.2	-6.9 (-14.9, 1.1)	0.087

SD=standard deviation; MVPA=moderate vigorous physical activity; CI=confidence interval for the difference in means by percentage body fat category; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days
*percentage body fat classified using cut-points developed using age, sex and BMI (Pasco et al., 2014)
^Two-tailed, independent samples t-test *P* value
[#]$P<0.05$

Table 7.23 Mean daily time spent in time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks by waist-to-height ratio category for young adults in Group A

	Waist-to-height ratio category*				
	No increased Risk n=14 (40%)	**Increased risk n=21 (60%)**	**Total n=35 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Difference in means (95% CI) [no increased risk v. increased risk]**	***P value^***
Wear (min/day)	749.8 ± 97.8	743.4 ± 77.8	745.9 ± 85.0	6.4 (-58.0, 70.8)	0.839
Sedentary (min/day)	463.4 ± 90.3	432.1 ± 73.9	444.6 ± 81.1	31.3 (-28.6, 91.1)	0.292
Light (min/day)	260.9 ± 56.6	289.0 ± 70.7	277.8 ± 66.1	-28.1 (-72.2, 15.9)	0.203
Moderate (min/day)	22.3 ± 17.4	19.5 ± 12.5	20.6 ± 14.5	2.8 (-8.4, 14.0)	0.608
Vigorous (min/day)	3.2 ± 5.8	2.8 ± 5.6	3.0 ± 5.6	0.5 (-3.6, 4.5)	0.813
MVPA (min/day)	25.5 ± 20.5	22.3 ± 15.8	23.6 ± 17.6	3.3 (-10.1, 16.6)	0.617
cpm/day	315.4 ± 142.0	336.9 ± 135.5	328.3 ± 136.5	-21.4 (-120.1, 77.3)	0.660
Steps (n/day)	6433 ± 3052	5851 ± 2278	6084 ± 2588	582 (-1396, 2561)	0.548
Number of breaks (n/day)	88.8 ± 16.6	91.2 ± 15.5	90.2 ± 15.8	-2.4 (-13.8, 9.1)	0.672
Sedentary bouts ≥20 min	136.7 ± 78.2	118.4 ± 67.8	125.7 ± 71.6	18.3 (-34.4, 71.1)	0.480
Sedentary bouts ≥30 min	79.3 ± 60.5	64.3 ± 45.8	70.3 ± 51.9	15.0 (-24.4, 54.4)	0.438
Strict MVPA bouts ≥10 min	6.1 ± 8.7	5.3 ± 7.6	5.6 ± 7.9	0.7 (-5.2, 6.6)	0.801
Modified MVPA bouts ≥10 min	12.2 ± 13.4	8.1 ± 9.8	9.7 ± 11.4	4.2 (-4.5, 12.8)	0.331

SD=standard deviation; MVPA=moderate vigorous physical activity; CI=confidence interval for the difference in means by risk; Group A=participants who wore the accelerometer for a minimum of 8 hours for 3 days
*waist-to-height ratio of young adults classified as increased risk if ≥0.5 (Ashwell & Hsieh, 2005)
^Two-tailed, independent samples t-test *P* value
[#]*P*<0.05

Table 7.24 Mean daily time spent in time spent in sedentary behaviour and physical activity, counts per minute, number of steps and number of breaks by waist-to-height ratio category for young adults in Group B

	Waist-to-height ratio category*				
	No increased Risk n=12 (42%)	**Increased risk n=19 (58%)**	**Total n=31 (100%)**		
	Mean ± SD	**Mean ± SD**	**Mean ± SD**	**Difference in means (95% CI) [no increased risk v. increased risk]**	***P* value^**
Wear (min/day)	799.9 ± 64.7	788.0 ± 61.9	792.6 ± 62.2	11.9 (-36.7, 60.4)	0.618
Sedentary (min/day)	493.0 ± 87.8	458.6 ± 76.4	471.9 ± 81.4	34.4 (-29.7, 98.5)	0.277
Light (min/day)	281.4 ± 47.0	305.1 ± 81.3	295.9 ± 70.1	-23.7 (-70.9, 23.5)	0.314
Moderate (min/day)	22.8 ± 17.7	21.5 ± 13.1	22.0 ± 14.7	1.3 (-11.1, 13.7)	0.830
Vigorous (min/day)	2.7 ± 5.9	2.9 ± 5.5	2.8 ± 5.6	-0.2 (-4.6, 4.2)	0.929
MVPA (min/day)	25.5 ± 20.7	24.4 ± 16.2	24.8 ± 17.7	1.1 (-13.6, 15.8)	0.878
cpm/day	302.5 ± 130.6	332.2 ± 111.6	320.7 ± 118.1	-29.8 (-124.6, 65.1)	0.521
Steps (n/day)	6740 ± 3076	6241 ± 2364	6434 ± 2623	498 (-1678, 2675)	0.637
Number of breaks (n/day)	96.3 ± 12.3	96.8 ± 15.2	96.6 ± 13.9	-0.6 (-10.8, 9.7)	0.911
Sedentary bouts ≥20 min	141.3 ± 91.5	125.5 ± 78.3	131.6 ± 82.5	15.8 (-50.6, 82.3)	0.626
Sedentary bouts ≥30 min	83.9 ± 72.1	68.7 ± 52.5	74.6 ± 60.1	15.1 (-35.3, 65.5)	0.537
Strict MVPA bouts ≥10 min	4.6 ± 7.9	6.0 ± 7.8	5.4 ± 7.7	-1.3 (-7.3, 4.6)	0.646
Modified MVPA bouts ≥10 min	11.4 ± 13.8	9.2 ± 10.2	10.0 ± 11.6	2.2 (-7.5, 11.9)	0.638

SD=standard deviation; MVPA=moderate vigorous physical activity; CI=confidence interval for the difference in means by risk; Group B=participants who wore the accelerometer for a minimum of 10 hours for 4 days

*waist-to-height ratio of young adults classified as increased risk if ≥0.5 (Ashwell & Hsieh, 2005)

^Two-tailed, independent samples t-test *P* value

[#]$P<0.05$

7.4 Discussion

The aim of this study was to describe the sedentary behaviour and physical activity levels of adolescents and young adults with Down syndrome and relationships with anthropometric and DEXA variables. As judged by the Australian Physical Activity Guidelines (Australian Government Department of Health, 2014) adolescents and young adults with Down syndrome were not sufficiently active, exhibiting long bouts of sedentary behaviour. A positive rank order relationship between BMI and vigorous activity in young men and between percentage body fat and breaks from sedentary behaviour suggested that physical activity may be related to the health of young adults with Down syndrome. Unexpectedly, there was an inverse rank order relationship between BMI and sedentary behaviour in young women with Down syndrome which requires further investigation.

The Actigraph GT3X accelerometer was a feasible tool for collecting physical activity data of adolescents and young adults with Down syndrome. Of all participants in the PANDs study, 94.9% (56/59) wore the accelerometer with 87.5% of these participants wearing it for seven or more days. These results are similar to those reported in an Australian pilot study where 19 out of 23 participants wore a RT3 accelerometer for at least 6 out of 7 days (Shields et al., 2009), a recent Australian study where 14 out of 20 children wore a RT3 accelerometer for at least 4 out of 7 days (Shields et al., 2017), a Spanish study where 19 out of 20 adolescents wore an Actical accelerometer for at least 4 out of 7 days (Matute-Llorente et al., 2013), and a further Spanish study of adolescents where 100 out of 109 adolescents wore an Actigraph accelerometer for at least 3 out of 7 days (Izquierdo-Gomez et al., 2014).

Studies of physical activity in adolescents and young adults with Down syndrome have used varying minimum wear time protocols and this study analysed the results using two of the more common protocols – 8 hours wear for 3 days (Group A) and 10 hours wear for 4 days (Group B). The use of stricter minimum wear protocols can result in fewer participants and subsequent loss of data (Colley, Connor Gorber, & Tremblay, 2010; M. Smith et al., 2017; Toftager et al., 2013), and there is no consistent protocol for populations with intellectual disability (Leung, Siebert, & Yun, 2017). Due to the less strict minimum wear protocol, participation in Group A was higher (83.9%, 47/56) than participation in Group B (73.2%, 41/56). A lower participation rate with a stricter minimum wear protocol was also reported at the start of a longitudinal study of adults with intellectual disability, where 66.4% of participants met the 8 hours/3 days rule and 26.8% met the 10 hours/4 days rule (Ptomey et al., 2017).

Previous research in New Zealand has reported that in adolescents of Pacific Island heritage without Down syndrome (n=204), increased body fatness was associated with less compliance with stricter protocols (M. Smith et al., 2017). In the PANDs study there were no discernible differences in any of the anthropometric or DEXA variables between those who were and were not included in the group with the stricter protocol but this could have been due to lower numbers. There was however a lower proportion of males and a higher proportion of females in Group B with the stricter protocol compared to Group A.

Adolescents spent a mean of 37.6 minutes (Group A) and 34.3 minutes (Group B) in MVPA, whereas young adults spent a mean of 23.6 minutes (Group A) and 24.8 minutes (Group B) in MVPA. In a Spanish study of adolescents with Down syndrome (n=109) which used a similar protocol to Group A in the PANDs study, the authors reported that older adolescents (aged 18-21 years) spent less time in MVPA than younger adolescents (Izquierdo-Gomez et al., 2014). In both Groups A and B of the PANDs study no differences were evident between age groups in time spent at any physical activity intensity which may be due to the small sample size.

There is no agreement on the physical activity cut-points that should be used with the data of young people with Down syndrome (Izquierdo-Gomez et al., 2014), and syndrome specific cut-points may be more appropriate with this group due to differences in gait and metabolic rate when walking (Agiovlasitis et al., 2015). Cut-points for specific accelerometers have been proposed for adolescents with Down syndrome (Agiovlasitis et al., 2011; Peiris et al., 2017), however there is a need to validate these for different age groups and in larger cohorts (Peiris et al., 2017), as well as develop cut-points specifically for the Actigraph GT3X with 60 second epochs.

Compared to two objective studies of the physical activity levels of Australian adolescents (Ridgers, Timperio, Crawford, & Salmon, 2012) and young adults (McVeigh, Winkler, Howie, et al., 2016) without Down syndrome, adolescents in the PANDS study spent greater time and young adults spent less time in MVPA. In their study of Australian adolescents aged 15-17 years (n=203), Ridgers et al. (2012) used uniaxial Actigraph accelerometers and

Freedson's cut-points to analyse the relationship between objective and subjective levels of physical activity and compliance with the physical activity guidelines over 5 and 7 day minimum wear periods (8 hours minimum wear per day). In their study, mean time spent in MVPA was 30.0 minutes over the five day minimum wear period and 27.8 minutes over the 7 day period mean time, less than the 37.6 minutes recorded by adolescents in Group A of the PANDS study. Conversely in their study of young adults aged 22 years using Actigraph GT3X accelerometers, Freedson's cut-points and minimum time of 10 hours across 4 days, McVeigh, Winkler, Howie, et al. (2016) reported a mean time spent in MVPA of 36.2 minutes, compared with the 24.8 minutes recorded by young adults in Group B of the PANDs study. Further research is required to determine if the physical activity levels of Australian adolescents and young adults with Down syndrome differs from their peers without Down syndrome and possible explanations for these differences.

Using the standard cut-point of <100 cpm (Matthews et al., 2008), adolescents spent a mean of 7 hours 5 minutes (Group A) and 7 hours 32 minutes (Group B) in sedentary behaviour and young adults spent a mean of 7 hours 24 minutes (Group A) and 7 hours 52 minutes (Group B). In comparison, young adults without Down syndrome spent a mean of 9.2 hours in sedentary behaviour (McVeigh, Winkler, Howie, et al., 2016). In a recent USA study comparing the sedentary behaviour and physical activity of adolescents with and without Down syndrome there was no difference in sedentary behaviour time (Pitchford et al., 2018). In the current study, no difference in sedentary behaviour time was observed between age groups which is consistent with research of adolescents and young adults with intellectual disability including Down syndrome (Phillips & Holland, 2011). Previous research involving adolescents with Down syndrome have reported that more time was spent in sedentary behaviour in older adolescent age groups compared to younger adolescent age groups (Esposito et al., 2012; Izquierdo-Gomez et al., 2014), however the oldest adolescents in either study were 18-21 years old (Izquierdo-Gomez et al., 2014).

In the PANDS study male participants in Group A spent less time in sedentary behaviour than female participants. This compares with other studies where no difference in time spent in sedentary behaviour between male and female adolescents (Izquierdo-Gomez et al., 2014) and young adults with Down syndrome (Nordstrøm et al., 2013) were reported. In a recent Australian study of young adults without Down syndrome there was also no difference in time spent in sedentary behaviour by individual sex (McVeigh, Winkler, Howie, et al., 2016).

This is the first study to use EVA to describe the sedentary behaviour and physical activity patterns of adolescents and young adults with Down syndrome. Developed to show the pattern of both frequency and intensity of physical activity and sedentary behaviour (Straker et al., 2014), EVA has recently been used in a study of Western Australian young adults without Down syndrome (McVeigh, Winkler, Howie, et al., 2016). In both this and the PANDs study, for young adults a greater percentage of time was spent in bouts of sedentary behaviour with only a small percentage of time spent in short bouts of moderate and vigorous activity across all bout lengths. Of concern in the current study, 16% of total time in both groups was spent in bouts of sedentary behaviour greater than 20 minutes duration. In a study of Canadian adults without Down syndrome (n=4935) increased total time in sedentary behaviour and in bouts ≥20 minutes were associated with increased insulin levels and diastolic blood pressure, independent of time spent in MVPA (Carson et al., 2014). A meta-analysis of ten studies investigating the relationship between sedentary behaviour and health outcomes in adults without Down syndrome also found that increased time spent in sedentary behaviour increased the odds of metabolic syndrome by 73% (Edwardson et al., 2012). This meta-analysis also emphasised the risks associated with sedentary behaviour were independent of those associated with inactivity (Edwardson et al., 2012). Further research is needed with groups of adults with Down syndrome to determine if the health risks associated with prolonged sedentary behaviour are similar.

The Australian Physical Activity Guidelines recommend that adolescents should spend ≥60 minutes in MVPA daily and young adults should accumulate ≥150 minutes of MVPA per week (Australian Government Department of Health, 2014). In the PANDS study 8.3% (1/12) of adolescents in Group A spent ≥60 minutes in MVPA on each of the 3 days included in the analysis. None of the ten adolescents included in Group B met the recommendation of ≥60 minutes of MVPA daily. However these results are similar to those reported for Australian adolescents without Down syndrome (Ridgers et al., 2012). In the study by Pitchford et al. (2018), compared to adolescents without Down syndrome, those with Down syndrome (n=22) spent significantly less time in vigorous activity and MVPA, and subsequently fewer met the MVPA guideline of 60 minutes per day. There is evidence to suggest that achieving ≥60 minutes of MVPA on 3-5 days per week also has health benefits (Okely et al., 2012), however half the adolescents in both groups of the PANDs study did not meet the recommendation of ≥60 minutes on any of the days included in the analysis, indicating a need for increased physical activity.

In young adults with Down syndrome 48.6% (17/35) of participants in Group A, and 54.8% (17/31) of participants in Group B achieved a mean of 21.4 minutes of MVPA per day which, if extended over 7 days could potentially meet physical activity recommendations (Australian Government Department of Health, 2014). These results are lower than those reported for West Australian young adults without Down syndrome where, consistent with the greater amount of time spent in MVPA, 68% of participants recorded durations of MVPA that would comply with physical activity guidelines (McVeigh, Winkler, Howie, et al., 2016).

When investigating the relationship between physical activity levels, anthropometric and DEXA variables in young adults with Down syndrome there were some consistencies but also several differences. For females there was a consistent relationship between time spent in sedentary behaviour and all continuous anthropometric and DEXA variables, except for percentage body fat for participants in Group B. For females in Group A there was also a relationship between bouts of sedentary behaviour greater than 30 minutes and BMI, and in Group B, a relationship between cpm, BMI and percentage body fat, but these were not consistent with any other anthropometric or DEXA variables. For males in both groups there was a relationship between vigorous activity and percentage body fat, and for males in Group B there was a relationship between moderate activity, MVPA and BMI, but these were also not consistent with other anthropometric or DEXA variables. Only one prior study in adolescents with Down syndrome has reported an association between physical activity and body composition with Pitchford et al. (2018) reporting an association with percentage body fat but not with BMI. As both studies had small sample sizes further research into the relationships between physical activity levels and anthropometric and DEXA variables is needed.

In young men with Down syndrome there was a negative rank order relationship between time spent in vigorous activity and percentage body fat (Groups A and B) and a positive rank order relationship between time spent in moderate activity and BMI (Group B). A significant negative correlation between time spent in vigorous activity and percentage body fat was also recently reported for adolescents with Down syndrome (n=22), however there was no relationship between moderate activity and BMI (Pitchford et al., 2018). In Group B as a whole there was a positive rank order relationship between BMI and spent in MVPA whereas in their study of physical activity and body composition in adolescents with

Down syndrome (n=22), Pitchford et al. (2018) reported that time in MVPA significantly predicted percentage body fat but not BMI percentile in adolescents with Down syndrome. Studies with larger samples are needed to confirm the relationship between physical activity and overweight and obesity in adolescents and young adults with Down syndrome.

In adults without Down syndrome a greater amount of time spent in sedentary behaviour was associated with increased odds of metabolic syndrome which included central obesity (Edwardson et al., 2012). Interestingly analysis of the relationship between sedentary behaviour, anthropometric and DEXA variables in the PANDs study found an inverse relationship in young women with Down syndrome. In Groups A and B there was a negative rank order relationship between time spent in sedentary behaviour and BMI, waist circumference and waist to height ratio. There was also a negative rank order relationship between percentage body fat and time spent in sedentary behaviour, and between BMI and time spent in sedentary behaviour bouts ≥30 minutes in Group A. Other studies involving adolescents with Down syndrome have reported no significant relationship between anthropometric or DEXA variables and sedentary behaviour (Esposito et al., 2012; Pitchford et al., 2018) and further research is required.

As research into the relationship between sedentary behaviour and body composition in young adults with Down syndrome is limited, factors influencing sedentary behaviours in those with a higher BMI are unclear. Through semi-structured interviews with parents and young people with Down syndrome, it has been identified that family members and other support people are key facilitators of participation in physical activity (Alesi, 2017; Barr & Shields, 2011; Mahy, Shields, Taylor, & Dodd, 2010). It is therefore possible that family members/carers of young women with a higher BMI facilitated their young person to spend less time in sedentary behaviour as previously suggested (Jobling et al., 2006). The moderate to strong rank order relationship between BMI, percentage body fat and cpm observed for young women, and the positive rank order relationship between minutes spent in MVPA and BMI for Group B as a whole supports this suggestion. Further research with is required to confirm these findings and identify contributing factors.

In both Groups A and B there was a difference in the number of breaks from sedentary behaviour, with young adults with a BMI classified as healthy weight recording a higher number of breaks compared with young adults with a BMI classified as obese. No previous study of young adults with Down syndrome has reported the number of breaks from sedentary behaviour or association with anthropometric or DEXA variables. In adults without Down syndrome a higher number of breaks has been associated with lower BMI, waist circumference, blood glucose and triglyceride levels (Carson et al., 2014; Healy et al., 2008; Healy et al., 2011) and further research is needed to confirm these relationships in young adults with Down syndrome.

This is the first study to analyse the sedentary behaviour and physical activity levels of adolescents and young adults with Down syndrome using two data reduction protocols. The stricter protocol (Group B) excluded data from six participants who did not meet the minimum 10 hours over 4 days rule, most of whom were male. Comparing the results between groups, participants spent similar amounts of time in sedentary behaviour and physical activity, and the patterns of sedentary behaviour and physical activity as analysed using EVA were also comparable. There was a difference in the number of adolescents meeting the Australian Physical Activity Guideline with fewer participants in Group B resulting in none of the adolescent participants meeting the Guideline. Conversely for young adults a higher percentage met the Australian Physical Activity Guideline in Group B compared to Group A. There were similar findings in the relationships between sedentary behaviour, physical activity, anthropometric and DEXA variables, both as continuous and categorical variables between groups, although relationships between BMI, percentage body fat and cpm, and between BMI and moderate activity were only observed in Group B. In future studies the use of the stricter protocol is recommended along with measures to increase compliance with wearing the accelerometer for as long as possible, particularly in males.

This study had several strengths and limitations. Feasibility of the Actigraph GT3X accelerometer as a tool to measure sedentary behaviour and physical activity in adolescents and young adults with Down syndrome was high, with only three participants declining to wear it and all participants who did assent, wearing it for a minimum of 3 days. There were no differences in the characteristics of participants in Group A, Group B and non-participants from the PANDs study, although a smaller proportion of males were included in Group B. Data were collected over a two-year period across all seasons so any impact of seasonal variability in physical activity was avoided.

There were limitations however with study design, use of the accelerometer, standard cut-points and sample size. Similar to most studies of physical activity in adolescents and young adults with Down syndrome (Esposito et al., 2012; Izquierdo-Gomez, Martínez-Gómez, et al., 2015; Matute-Llorente et al., 2013; Nordstrøm et al., 2013; Shields et al., 2009; Shields et al., 2017), the PANDs study was a cross-sectional design and therefore no causal relationships between sedentary behaviour, physical activity, anthropometric and DEXA variables can be inferred. Accelerometers were unable to measure time spent in aquatic physical activity (Matute-Llorente et al., 2013) and swimming is one of the preferred types of physical activity for adolescents and young adults with Down syndrome (Oates et al., 2011). This study was also limited by the use of standard physical activity, anthropometric and percentage body fat cut-points which may not have been appropriate for adolescents and young adults with Down syndrome. Although specific cut-points have been developed for different accelerometers and epochs (Agiovlasitis et al., 2011; Peiris et al., 2017) there is a need for cut-points to be developed for the Actigraph GT3X with 60 second epochs. As discussed in 5.4, the NHMRC cut-point for overweight had lower sensitivity and a Down syndrome specific cut-point may be required. Additionally, percentage body fat and waist-to-height ratio cut-points may also not be suitable for young people with Down syndrome and this may have impacted on the relationships with sedentary behaviour and physical activity. Low sample size has been a limitation with the relationships between sedentary behaviour, physical activity, anthropometric and DEXA variables in adolescents unable to be analysed. Further studies with larger samples are recommended.

Future research should also include feedback from participants and their families about the experience of wearing an accelerometer and identify reasons for not wearing it for longer periods, especially in young males. Focus groups conducted with adolescents without Down syndrome (n=61) identified that the look and feel of the accelerometer and waist strap, and discomfort during physical activity may be a problem with compliance (Audrey, Bell, Hughes, & Campbell, 2013). Studies have started to use Fitbit devices alongside accelerometers to measure physical activity, (Ptomey, Sullivan, et al., 2015; Schneider & Chau, 2016) and further investigation is required.

In conclusion, most adolescents and almost half the young adults in the PANDs study did not meet Australian Physical Activity Guidelines and thus were insufficiently active. Females spent more time in sedentary behaviour than males, with participants as a whole spending 16% of wear-time in prolonged bouts of sedentary behaviour. Relationships between sedentary behaviour, counts-per-minute, anthropometric and DEXA variables in young women suggested that as BMI increased, time in sedentary behaviour decreased and physical activity increased, although the reasons for these findings are unknown. In males, a higher BMI was associated with less time spent in vigorous activity, and in all participants those with a percentage body fat classified as healthy weight recorded more breaks from sedentary behaviour than participants with a percentage body fat classified as obese. Further studies are required to confirm the relationships between sedentary behaviour, physical activity and body composition in adolescents and young adults with Down syndrome, along with the importance of support to facilitate participation.

Chapter 8 Discussion, conclusions and recommendations

The aim of this thesis was to describe the anthropometry and body composition of adolescents and young adults with Down syndrome and the relationships with physiological, behavioural and social factors including dietary intake, physical activity and sedentary behaviour. This aim was achieved through the cross-sectional analyses of data from the Down syndrome NOW and PANDs studies. The Down syndrome NOW study was a parent completed questionnaire-based study of the health, social, educational and functional aspects of Down syndrome completed in three waves (2004, 2009 and 2011). The PANDs study was a study of the body composition, dietary intake, physical activity and sedentary behaviour of a sample of adolescents and young adults with Down syndrome.

This thesis has added to the knowledge of the prevalence of overweight and obesity in adolescents and young adults with Down syndrome, and how reported BMI changed over time. To the candidate's knowledge this thesis was the first to use an adapted Child Feeding Questionnaire (Birch et al., 2001) with a group of family members/carers of adolescents and young adults with Down syndrome, and to have analysed the relationships between proxy-reported BMI of young adults with Down syndrome and family member/carer perception of overweight and obesity, main meal setting, food preparation skills and family income. To the candidate's knowledge this thesis was also the first to report the sensitivity and specificity of the standard adult BMI cut-points (NHMRC, 2013b), apply adult percentage body fat cut-points (Pasco et al., 2014), and use EVA (Straker et al., 2014) to describe the body composition, sedentary behaviour and physical activity patterns specifically of a sample of adolescents and young adults with Down syndrome.

8.1 Anthropometry and body composition of adolescents and young adults with Down syndrome

High proportions of overweight and obesity have been reported in several studies of adolescents and young adults with Down syndrome (Basil et al., 2016; Hatch-Stein et al., 2016; Krause et al., 2016; Real de Asua et al., 2014a; Seron et al., 2014; Soler Marin & Xandri Graupera, 2011; Xanthopoulos et al., 2017) and similar proportions were found in the analysis of data from both the Down syndrome NOW and PANDs studies. In the Down syndrome NOW study (2009 wave) 66.7% (16/24) of adolescents had a proxy-reported BMI classified as overweight or obese, similar to 70% (100/143) of young adults in the 2011 wave. In the PANDs study 61.5% (8/13) adolescents and 67.4% (31/46) young adults had a measured BMI classified as overweight or obese. These proportions were higher than those reported for the Australian population of adolescents (38.9%) and young adults (52.4%) without Down syndrome (Australian Bureau of Statistics, 2015b) and are of concern for health outcomes and quality of life (Grondhuis & Aman, 2014).

From 2004 to 2009 and from 2004 to 2011, the relative risk for adolescents and young adults with Down syndrome of having a reported BMI categorised as overweight or obese increased, with a greater risk for females than males in the 2004/2009 cohort. This finding was supported by earlier research in young people with Down syndrome (Miyazaki & Okumiya, 2004) and in young Australians without Down syndrome (Patton et al., 2011; Zalbahar et al., 2017). Analysis of data from the Mater-University of Queensland Study of Pregnancy cohort revealed that at age 14 years, 75.5% of adolescents (n=1494) had a BMI classified as healthy, and 24.5% had a BMI classified as overweight or obese (Zalbahar et al., 2017). At age 21 years, 66.3% had a BMI classified as healthy, and 33.7% had a BMI classified as overweight or obese (Zalbahar et al., 2017). Of those with a BMI classified as healthy at age 14, 15.3% had a BMI classified as overweight or obese at age 21 years (Zalbahar et al., 2017). Cohort studies into the changes in BMI over time in adolescents and young adults with Down syndrome are limited, and further research is required to confirm adolescence and young adulthood as a key times for intervention.

Adolescents and young adults with Down syndrome have been reported to have shorter height (Parra et al., 2017; Pitchford et al., 2018; Real de Asua et al., 2014a; Soler Marin & Xandri Graupera, 2011) compared to young people without Down syndrome. In Chapter 6 the mean measured height of participants aged 12-30 years in the PANDs study (n=58) was compared to that of a sample of young adults aged 18-30 without Down syndrome (n=244). Despite the PANDs cohort being younger, in males there was a difference of 20.3cm and in females, a difference of 19.2cm. These differences were similar to those reported in a Dutch study of children and adolescents with Down syndrome (n=1596) where the mean height of 21-year old males was 20.3cm shorter and females 18.9cm shorter when compared to growth charts for the Dutch population without Down syndrome (Van Gameren-Oosterom, Van Dommelen, Oudesluys-Murphy, et al., 2012).

Due to the shorter height of young people with Down syndrome, the use of standard cut-points for categorising BMI may not be suitable (Braunschweig et al., 2004; Soler Marin &

Xandri Graupera, 2011). Studies analysing the performance of standard BMI-for-age cut-points for adolescents with Down syndrome have reported high sensitivity of the 85th percentile (Bandini et al., 2013; Hatch-Stein et al., 2016) and high specificity of the 95th percentile (Bandini et al., 2013), similar to the analysis of adult BMI cut-points in adults with intellectual disability (Temple et al., 2010). In the PANDs study, the sensitivity and specificity of the standard adult obesity BMI cut-point were both high (80.0% and 89.5%, respectively), whereas the sensitivity and specificity of the overweight BMI cut-point were lower (50.0% and 77.3%, respectively), resulting in an underestimation of those with a BMI classified as overweight, particularly in males. Due to the small sample size, larger studies are required to confirm these results.

DEXA has been used in several studies of adolescents and young adults with Down syndrome (Bandini et al., 2013; Baptista et al., 2005; González-Agüero, Ara, et al., 2011; Nascimento et al., 2016; Nickerson et al., 2015), with two studies using standard cut-points to analyse body fat percentage (Loveday et al., 2012; Samur San-Matin et al., 2016). No previous study has applied standard adult body fat percentage cut-points in young adults with Down syndrome. Using the standard age and sex specific cut-points developed by Pasco et al. (2014), 89.5% (17/19) of young adult males and 66.7% (10/15) of young adult females with DEXA results in the PANDs study had a percentage body fat classified as overweight or obese. Conversely, using BMI cut-points, 68.4% (13/19) of young adult males and 80.0% (12/15) of young adult females with DEXA results had a percentage body fat classified as overweight or obese. As neither the BMI nor percentage body fat cut-points were specific for adolescents and young adults with Down syndrome and sample sizes were small, further research is needed to develop and validate specific cut-points in larger cohorts.

Due to the impact of shorter height on waist circumference measurements (Browning et al., 2010), it has been proposed that waist-to-height ratio may be a better indicator of central obesity in adolescents and young adults with Down syndrome (Real de Asua et al., 2014b). For female young adults in the PANDs study, standard waist circumference cut-points (NHMRC, 2013b) did not discriminate between the means of weight, BMI and total body fat, whereas the standard waist-to-height ratio cut-point (Ashwell & Hsieh, 2005) discriminated between the means of each of these variables for the total group. As waist-to-height ratio is easy to measure and calculate (Ashwell & Hsieh, 2005), it is recommended for inclusion in future anthropometric and body composition research and practice involving young adults with Down syndrome.

8.2 Factors associated with the body composition of adolescents and young adults with Down syndrome

As described in Chapter 2, socioecological frameworks can be used to describe the behaviours and factors influencing body composition (Must et al., 2014; Story et al., 2008). From the analysis in this thesis, the intersection of multiple individual, behavioural, social and community factors was associated with the anthropometry and body composition of adolescents and young adults with Down syndrome. These factors, along with the impact of barriers and facilitators of healthy lifestyle behaviours need to be considered for future program development.

In contrast to the PANDs study and earlier waves of the Down syndrome NOW study where there were no differences in BMI between male and female participants (possibly due to the small sample size in the PANDs study), a strong multivariate relationship between female sex and higher reported BMI was observed for young adults in the 2011 wave of the Down syndrome NOW study. Although female sex has been reported as an independent predictor of obesity in large studies of adults with intellectual disability (Begarie et al., 2013; Bhaumik et al., 2008; Hsieh et al., 2014; Stancliffe et al., 2011), studies investigating a relationship with sex, specifically in cohorts of young adults with Down syndrome are limited. Although higher BMI in females has been reported in two studies of young adults with Down syndrome (Jankowicz-Szymanska et al., 2013; Soler Marin & Xandri Graupera, 2011), Pucci et al. (2016) reported no difference in BMI between males and females however this may be due to an older sample with a mean age of 26.5 years. Further research is needed to confirm if female sex is an independent predictor of overweight and obesity in adolescents and young adults with Down syndrome.

In young adults with Down syndrome there was a direct relationship between percentage body fat and reported number of sugar sweetened beverage (SSB) serves, and in young adult females there was an inverse relationship between BMI, waist circumference, waist-to-height ratio and reported number of fruit serves. Although no previous study has reported a relationship between percentage body fat and SSB serves specifically in adults with Down syndrome, higher soda consumption has previously been associated with obesity in adults with intellectual disability (Hsieh et al., 2014). In adolescents and adults aged 16-42 years with Down syndrome, those with a BMI classified as healthy weight or overweight were more likely to be higher fruit consumers than those with a BMI classified as obese (Nordstrøm et al., 2015), but no association was reported between BMI and fruit and vegetable consumption for young adults without Down syndrome (Nour et al., 2017). Further research is required to determine if consumption of fruit, SSB or any other food group is associated with overweight and obesity in adolescents and young adults with Down syndrome.

In the 2011 Down syndrome NOW study, 20.9% (43/206) of adolescents and young adults consumed fast food at least two or three times per week, and 79.1% (163/206) consumed fast food once a week or less frequently. In common with adolescents and young adults without Down syndrome (Australian Bureau of Statistics, 2014), those with Down syndrome had a preference for fast food as identified by family members/carers in the 2004 Down syndrome NOW study "*Loves junk food - chocolate, hamburgers, chips etc.".* In females, univariate analysis revealed that higher reported BMI was associated with more frequent fast food consumption, as all females who consumed fast food more than once a week (12/12) had a reported BMI classified as overweight or obese. Previous research involving adolescents with intellectual disabilities (n=207) and their parents also reported a positive relationship between the frequency of fast food consumption and BMI (George et al., 2011), however studies are limited and further research involving adolescents and young adults with Down syndrome is needed.

In the 2011 Down syndrome NOW survey 10.1% (22/217) of family members/carers reported their adolescent or young adult with Down syndrome could prepare an adequate variety of meals without supervision, with 52.5% (114/217) able to prepare simple foods without supervision, 26.7% (58/217) able to prepare simple foods with supervision and 10.6% (23/217) required all food prepared. These figures were similar to the study of independent living skills of Dutch adolescents with Down syndrome where 6.6% were able to prepare hot food without supervision and 55.5% could prepare a simple meal (breakfast) without supervision (Van Gameren-Oosterom et al., 2013).

In a dietary survey of Irish adults with intellectual disability (n=131) including Down syndrome, only 28% of participants made their own food choices (Hoey et al., 2017), similar to a previous study of adults with intellectual disability (n=68) where 60.3% reported having little choice in the food they ate and 2.9% reported no choice (Koritsas & Iacono, 2016). As proportions of overweight and obesity in this study were high, the authors proposed that the food prepared by family members/carers were not meeting nutritional needs (Koritsas & Iacono, 2016). This is supported by the analysis of two large surveys of USA adults with and without disabilities (n=11, 811), which reported adults with disabilities were more likely to surpass recommendations for saturated fat and not meet recommendations for fibre, vitamin A, vitamin C, calcium and potassium (An, Chiu, Zhang, & Burd, 2015). These results, along with the positive relationship between higher food preparation skills and reported BMI in adolescents and young adults with Down syndrome as discussed in Chapter 3, highlights the importance of food literacy knowledge and skill development which includes both family members/carers and young people with Down syndrome themselves (Hoey et al., 2017).

As discussed in Chapter 7, most adolescents and half the young adults with Down syndrome in the Down syndrome NOW 2011 study were not meeting Australian Physical Activity Guidelines. In addition there was evidence of a negative relationship between BMI and time spent in vigorous activity, and between percentage body fat and breaks from sedentary behaviour, as well as a negative relationship between time spent in sedentary behaviour and BMI. Questionnaires, interviews and focus groups with family members, carers, sports instructors and young people with Down syndrome and intellectual disability have identified several barriers to and facilitators of physical activity (Alesi, 2017; Alesi & Pepi, 2017; Barr & Shields, 2011; S. J. Downs et al., 2013; Mahy et al., 2010; Shields & Synnot, 2016; Shields & Synnot, 2014; Taliaferro & Hammond, 2016). The potential impact of these facilitators and barriers on the physical activity and sedentary behaviour levels of adolescents and young adults with Down syndrome needs to be considered in the interpretation of these results.

Physiological factors associated with Down syndrome, including hypotonia, cognitive and motor skills, obesity, congenital heart conditions and communication difficulties have been identified as barriers to participation in physical activity (Alesi, 2017; Alesi & Pepi, 2017; Barr & Shields, 2011; Mahy et al., 2010; Pikora et al., 2014; Shields & Synnot, 2016). Short attention spans, lack of motivation and dislike of physical activity have also been acknowledged (S. J. Downs et al., 2013; Mahy et al., 2010; Pikora et al., 2014; Shields & Synnot, 2016; Taliaferro & Hammond, 2016). In the 2004 Down syndrome NOW study family members/carers of adolescents and young adults with Down syndrome also identified dislike of physical activity '*hates to walk…*' as a factor which impacted on their young person's ability to maintain a healthy weight. These along with other factors need to be considered in helping young people with Down syndrome to achieve the Physical Activity Guidelines.

Family members/carers are key facilitators of physical activity for adolescents and adults with Down syndrome, as initiators, role models, advocators and organisers (Alesi, 2017; Alesi & Pepi, 2017; Barr & Shields, 2011; S. J. Downs et al., 2013; Lin et al., 2010; Mahy et al., 2010; Shields & Synnot, 2016; Shields & Synnot, 2014; Taliaferro & Hammond, 2016). In families where parents and siblings enjoyed being physically active, children and adolescents with Down syndrome were inclined to be more active themselves (Barr & Shields, 2011). However as adolescents and adults with Down syndrome often required supervision and transport from family members/carers to participate in physical activity, lack of interest, motivation and time limited opportunities (Barr & Shields, 2011; S. J. Downs et al., 2013; Mahy et al., 2010; Shields & Synnot, 2014; Taliaferro & Hammond, 2016). As time spent in sedentary behaviour decreased and physical activity increased in young adult females with higher BMI, and time spent in vigorous activity increased in males with lower BMI, it is proposed that some family members/carers were overcoming these barriers.

8.3 Limitations

There were several limitations to this thesis which need to be considered in the interpretation and extrapolation of results. These include limitations in study design, recruitment, methodology and analysis of the Down syndrome NOW and PANDs studies.

This thesis was a cross-sectional study of the anthropometry, body composition, food and physical activity behaviours of adolescents and young adults with Down syndrome. As such, causation cannot be inferred. Data collection for the 2011 Down syndrome NOW study occurred in 2011/2012, whereas data collection for the PANDs study occurred from 2013 to 2015. This gap in time limited the design of the PANDs study, in that data collected in 2011 on food and physical activity behaviours could not be assumed to be the same in 2013/15. For this reason, data from the PANDs study (apart from questionnaire data) were analysed separately.

In all three waves of the Down syndrome NOW study, questionnaires were long with multiple sections, which may have resulted in respondent fatigue and incomplete data (Oates et al., 2011). Despite the length of these questionnaires, response fractions for all three waves were high (greater than 70%) and efforts were made to facilitate participation. These included making the questionnaire available both on paper and online, follow-up phone calls to ensure the questionnaire was received and understood, and the ability to complete the questionnaire with a member of the research team if desired.

Due to difficulties with self-reporting (Peiris et al., 2017) questionnaires were proxy-completed, usually by a parent. As food was consumed and physical activity performed outside as well as inside the home, accurate reporting of the food and physical activity behaviours of adolescents and young adults with Down syndrome may be limited (Foerste et al., 2016). Height and weight were also proxy-reported, however this was more practical for a large population-based study (Brettschneider et al., 2012). Directly measured height and weight were included in Chapter 5, with similar proportions of BMI classified as overweight and obese.

The PANDs study was limited by small sample size (n=59), specifically of adolescents (n=13) and may not have been representative of the population. Similar to the Down syndrome NOW study, follow-up phone calls were made to facilitate participation. Collection of data occurred at a venue familiar to the participant and their family member/carer (usually their home) with a visit to Curtin University required only if assent was provided for a DEXA scan. The impact of selection bias (Hammer et al., 2009) on participation in the PANDs study was not assessed, and this may have influenced results.

Throughout this thesis, standard cut-points were used in the analysis of BMI, percentage body fat, waist circumference and waist-to-height ratio. Due to the shorter height reported for adolescents and young adults with Down syndrome, standard BMI cut-points may not have been suitable for this population (Zemel et al., 2015). Although this thesis has recommended the development and use of specific cut-points for adults with Down syndrome, new cut-points were not suggested and these need to be a focus of future research.

As discussed in Chapter 6 there were limitations in the collection and interpretation of reported food and beverage data. To reduce respondent burden, food data was collected using a mFR. Although both participants and their family members/carers received training in the use of the mFR and were left with visual printed instructions, not all participants used the mFR or included the fiducial marker in all images. The development of video instructions that could be loaded on the device or available online may have supported its use. Data on who used the mFR to capture images and feedback on the usability of the app would also have been beneficial.

Food choices made either by the PANDS study participant or their family member/carer may have been affected by social desirability bias (Hébert, 2016) and this was not assessed. Additionally, measurement error may also have occurred in the recording of usual food intake (Labonté et al., 2016; Subar et al., 2015). As iPods could not be taken to school and some parents were hesitant about the iPod being taken out of the home, foods and beverages may have been consumed without an image being captured. A booklet was provided for participants and their family members/carers to record uncaptured images, however this may have not been complete. To minimise this impact follow-up discussion of usual intake was conducted with participants and their family member/carer to prompt any forgotten foods or beverages as well as clarify details not recorded in images (e.g. sugar added to beverages), however memory of these details may have been affected by the time between recording the data and the follow-up discussion. Finally as two trained analysts identified foods and beverages in the images and estimated portion size, there may have been differences in estimations, particularly in images where the fiducial marker was absent.

Limitations of the physical activity component of the PANDs study were discussed in Chapter 7. Similar to limitations associated with standard anthropometric and percentage body fat cut-points, the use of standard physical activity and sedentary behaviour cut-points was a limitation. Although new physical activity cut-points have been developed in studies involving adolescents with Down syndrome (Agiovlasitis et al., 2011; Peiris et al., 2017), these could not be applied to the accelerometer data collected in this study due to differences in the type of accelerometer and epoch chosen. The accelerometer was unable to measure time and intensity of aquatic based physical activity and details of these were not collected separately. Low sample size also impacted on statistical analysis and results.

8.4 Recommendations

From this thesis several recommendations have emerged for further research and practice. As this thesis comprised a cross-sectional analyses and causation cannot be inferred, longitudinal research on the impact of food and physical activity behaviours on health outcomes for adolescents and young adults with Down syndrome is needed including confirmation of sex as an independent predictor.

Due to differences in anthropometry and possibly body composition, development of Down syndrome specific cut-points for BMI, percentage body fat and further validation of the waist-to-height ratio cut-point for adolescents and young adults with Down syndrome are recommended. Waist circumference data should be included in future anthropometric and body composition research for the calculation of waist-to-height ratio. Further research is also needed to monitor changes in BMI, percentage body fat and waist-to-height ratio over time to identify critical periods for intervention and support.

Whilst the mFR app was feasible for adolescents and young adults with Down syndrome to use, further development of the app and training materials is recommended. Specifically, reduction in the number of steps in capturing the image and the development of video instructions are suggested. Future research using the mFR in groups with Down syndrome should include user feedback and the recording of who captured the images.

Although Down syndrome specific physical activity cut-points have been suggested for particular accelerometers and epochs, cut-points for the Actigraph GT3X accelerometer with 60 second epochs are required. Future studies should also include user feedback on the use of accelerometers with adolescents and young adults with Down syndrome. Future studies are also needed to determine if time spent in sedentary behaviour decreases with increasing BMI in young adult females with Down syndrome and possible reasons for this occurrence.

Life expectancy for people with Down syndrome is increasing (Glasson et al., 2016) and overweight and obesity can detrimentally affect quality of life (Grondhuis & Aman, 2014). High proportions of adolescents and young adults with Down syndrome had a BMI and percentage body fat classified as overweight or obese, with a waist-to-height ratio reflective of increased metabolic risk. As the relative risk of overweight and obesity increased from adolescence to young adulthood, and higher BMI was associated with skills and behaviours associated with transition, this stage of life is a prime opportunity for intervention and support. Similar to adolescents and young adults without Down syndrome, those with Down syndrome need to consume additional vegetable serves and less energy-dense nutrient-poor food and sugar sweetened beverage serves, be more physically active and be less sedentary to achieve nutritional and physical activity guidelines. As family members/carers are responsible for the food choices and physical activity opportunities for most adolescents and young people with Down syndrome, support and intervention needs to include both young people with Down syndrome and the people who care for them.

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Appendix B

Down syndrome NOW study 2011 questionnaire

The questionnaire has not been included in this thesis due to copyright. For information about the questionnaire please contact Associate Professor Helen Leonard at the Telethon Kids Institute telethonkids.org.au

Appendix C

Ethics approval to use data from the 2004 and 2009 Down syndrome NOW study waves

Curtin University

Memorandum

To	Ms Katherine Bathgate
From	Leslie Thompson
Subject	Protocol Approval – SPH – 03 - 2011
Date	February 21st, 2011
Copy	Associate Professor Jill Sherriff

School of Public Health

Telephone 9266 7819
Facsimile 9266 2958

Email: l.thompson@curtin.edu.au

Thank you for your "Form C Application for Approval of Research with Low Risk (Ethical Requirements)" for the project titled "Overweight and Obesity in Children and Young Adults with Down Syndrome". On behalf of the Human Research Ethics Committee, I am authorised to inform you that the project is approved.

Approval of this project is for a period from February 18th, 2011 to February 17th, 2012.

The approval number for your project is SPH – 03 - 2011. *Please quote this number in any future correspondence*. If at any time during the twelve months changes/amendments occur, or if a serious or unexpected adverse event occurs, please advise me immediately.

Thank you

L Thompson

Mrs Leslie Thompson
Ethics Coordinator
School of Public Health
Curtin University

Please Note: The following standard statement must be included in the information sheet to participants:
This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number «Approval_Number»). If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or hrec@curtin.edu.au

Appendix D

Ethics approval to use data from the 2011

Down syndrome NOW study wave

Curtin University

Memorandum

To	Associate Professor Jill Sherriff, School of Public Health
From	A/Professor Stephan Millett, Chair, Human Research Ethics Committee
Subject	Protocol Approval **HR 143/2011**
Date	1 October 2011
Copy	Katherine Bathgate, School of Public Health

Office of Research and Development

Human Research Ethics Committee

TELEPHONE 9266 2784
FACSIMILE 9266 3793
EMAIL hrec@curtin.edu.au

Thank you for your application submitted to the Human Research Ethics Committee (HREC) for the project titled "*Food and physical activity behaviours of young adults with Down syndrome".* The Committee notes the prior approval by Princess Margaret Hospital for Children Ethics Committee (1715/EP) and has reviewed your application consistent with Chapter 5.3 of the *National Statement on Ethical Conduct in Human Research*.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 143/2011.** *Please quote this number in any future correspondence*.
- Approval of this project is for a period of twelve months **29-09-2011** to **29-09-2012**. To renew this approval a completed Form B (attached) must be submitted before the expiry date **29-09-2012**.
- If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Faculty Graduate Studies Committee.
- The following standard statement **must be** included in the information sheet to participants: *This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 143/2011). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.*

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **FORM B** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development:
When the project has finished, or

- If at any time during the twelve months changes/amendments occur, or
- If a serious or unexpected adverse event occurs, or
- 14 days prior to the expiry date if renewal is required.
- An application for renewal may be made with a Form B three years running, after which a new application form (Form A), providing comprehensive details, must be submitted.

Regards,

A/Professor Stephan Millett
Chair Human Research Ethics Committee

Appendix E

Ethics approval for the PANDs study

Curtin University

Memorandum

To	Associate Professor Jill Sherriff, School of Public Health
From	A/Professor Stephan Millett, Chair, Human Research Ethics Committee
Subject	Protocol Approval **HR 145/2011**
Date	12 January 2012
Copy	Katherine Bathgate School of Public Health Associate Professor Deb Kerr School of Public Health Dr Helen Leonard School of Public Health

Office of Research and Development

Human Research Ethics Committee

TELEPHONE 9266 2784
FACSIMILE 9266 3793
EMAIL hrec@curtin.edu.au

Thank you for providing the additional information for the project titled "*Factors influencing the body composition of adolescents and young adults with Down syndrome - Phase 2".* The information you have provided has satisfactorily addressed the queries raised by the Committee. Your application is now **approved**.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 145/2011.** *Please quote this number in any future correspondence*.
- Approval of this project is for a period of twelve months **10-11-2011** to **10-11-2012**. To renew this approval a completed Form B (attached) must be submitted before the expiry date **10-11-2012**.
- If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Faculty Graduate Studies Committee.
- The following standard statement **must be** included in the information sheet to participants:

  This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 145/2011). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Applicants should note the following:

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- An application for renewal may be made with a Form B three years running, after which a new application form (Form A), providing comprehensive details, must be submitted.

Regards,

A/Professor Stephan Millett
Chair Human Research Ethics Committee

Appendix F

Supplemental tables from Chapter 3

Table 3.36 Mean reported BMI and the number of days physically active in the previous week for participants in the Down syndrome NOW 2011 wave

	BMI						Difference in means [physically active 0-2 days vs 3-7 days]					
	Male		Female		Total		Male		Female		Total	
Number of days physically active	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**
0-2 days	26	28.5 ± 5.9	21	33.9 ± 10.7	47	30.9 ± 8.7	1.7 (-1.1, 4.5)	0.218	2.6 (-2.7, 7.9)	0.325	1.9 (-1.0, 4.8)	0.189
3-7 days	45	26.8 ± 5.2	43	31.3 ± 7.2	88	29.0 ± 6.6						
Total	71	27.4 ± 5.5	64	32.1 ± 8.5	135	29.6 ± 7.5						

SD=standard deviation; CI=confidence interval
^Two-tailed, independent samples t-test *P* value
[#]*P*<0.05

Table 3.37 Number of days in the week prior participants in the Down syndrome NOW 2011 wave were physically active by reported BMI category

	BMI category*					
Number of days physically active	**Healthy weight**	**Overweight**	**Obese**	**Total**	**T^c**	***P* value^**
Male					-0.50	0.616
0-2 days in the week (n)	9	9	8	26		
% within frequency category	34.6	34.6	30.8	100		
% within BMI category	31.0	45.0	36.4	36.6		
3-7 days in the week (n)	20	11	14	45		
% within frequency category	44.4	24.4	31.1	100		
% within BMI category	69.0	55.0	63.6	63.4		
Total (n)	29	20	22	71		
% within frequency category	40.8	28.2	31.0	100		
% within BMI category	100	100	100	100		
Female					-0.62	0.537
0-2 days in the week (n)	2	7	12	21		
% within frequency category	9.5	33.3	57.1	100		
% within BMI category	18.2	38.9	34.3	32.8		
3-7 days in the week (n)	9	11	23	43		
% within frequency category	20.9	25.6	53.5	100		
% within BMI category	81.8	61.1	65.7	67.2		
Total (n)	11	18	35	64		
% within frequency category	17.2	28.1	54.7	100		
% within BMI category	100	100	100	100		
Total					-0.62	0.538
0-2 days in the week (n)	11	16	20	47		
% within frequency category	23.4	34.0	42.6	100		
% within BMI category	27.5	42.1	35.1	34.8		
3-7 days in the week (n)	29	22	37	88		
% within frequency category	33.0	25.0	42.0	100		
% within BMI category	72.5	57.9	64.9	65.2		
Total (n)	40	38	57	135		
% within frequency category	29.6	28.1	42.2	100		
% within BMI category	100	100	100	100		

*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Kendall's tau-c *P* value
$^{\#}P<0.05$

Table 3.39 Relationship between impact of illness score and reported BMI for participants in the Down syndrome NOW 2011 wave

	BMI					
	Male n=75		**Female n=68**		**Total n=143**	
	rho	***P* value**	**rho**	***P* value**	**rho**	***P* value**
Impact of illness score	0.123	0.291	0.047	0.704	0.102	0.226

rho=Spearman's rank correlation coefficient

#*P*<0.05

Table 3.40 Differences in the means of the impact of illness scores by reported BMI category* for young adults in the Down syndrome NOW 2011 wave

	Impact of illness scores									
	Healthy weight		Overweight		Obese		Total		$F_{2,\ 140}$	*P* value^
	n	Mean ± SD	n	Mean ± SD	n	Mean ± SD	n	Mean ± SD		
Male	31	5.6 ± 4.1	21	4.8 ± 4.3	23	8.3 ± 7.5	75	6.2 ± 5.6	1.86	0.169
Female	12	7.8 ± 9.4	18	5.7 ± 6.4	38	7.4 ± 6.1	68	7.0 ± 6.8	0.50	0.616
Total	43	6.2 ± 6.0	39	5.2 ± 5.3	61	7.7 ± 6.6	143	6.6 ± 6.2	2.29	0.108

SD=standard deviation
*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Welch's ANOVA P value
#*P*<0.05

Table 3.45 Mean reported BMI and the number of friendships experienced by participants in the Down syndrome NOW 2011 wave

	BMI						Difference in means [0-2 friendships vs 3 or more friendships]					
	Male		Female		Total		Male		Female		Total	
Number of friendships	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**
0-2 friendships	46	27.8 ± 5.3	43	32.6 ± 8.4	89	30.1 ± 7.3	1.2 (-1.4, 3.8)	0.347	0.7 (-3.9, 5.2)	0.770	1.1 (-1.5, 3.7)	0.400
3 or more friendships	29	26.6 ± 5.6	24	31.9 ± 9.1	53	29.0 ± 7.8						
Total	75	27.3 ± 5.4	67	32.3 ± 8.6	142	29.7 ± 7.5						

SD=standard deviation; CI=confidence interval

^Two-tailed, independent samples t-test *P* value

[#]$P<0.05$

Table 3.46 Number of friendships experienced by participants in the Down syndrome NOW 2011 wave by reported BMI category*

	BMI Category					
Number of friendships	**Healthy weight**	**Overweight**	**Obese**	**Total**	**T^c**	***P* value^**
Male					-1.12	0.265
0-2 friendships (n)	17	13	16	46		
% within friendship category	37.0	28.3	34.8	100		
% within BMI category	54.8	61.9	69.6	61.3		
3 or more friendships (n)	14	8	7	29		
% within friendship category	48.3	27.6	24.1	100		
% within BMI category	45.2	38.1	30.4	38.7		
Total (n)	31	21	23	75		
% within friendship category	41.3	28.0	30.7	100		
% within BMI category	100	100	100	100		
Female					-0.89	0.376
0-2 friendships (n)	6	11	26	43		
% within friendship category	14.0	25.6	60.5	100		
% within BMI category	54.5	61.1	68.4	64.2		
3 or more friendships (n)	5	7	12	24		
% within friendship category	20.8	29.2	50.0	100		
% within BMI category	45.5	38.9	31.6	35.8		
Total (n)	11	18	38	67		
% within friendship category	16.4	26.9	56.7	100		
% within BMI category	100	100	100	100		
Total					-1.47	0.142
0-2 friendships (n)	23	24	42	89		
% within friendship category	25.8	27.0	47.2	100		
% within BMI category	54.8	61.5	68.9	62.7		
3 or more friendships (n)	19	15	19	53		
% within friendship category	35.8	28.3	35.8	100		
% within BMI category	45.2	38.5	31.1	37.3		
Total (n)	42	39	61	142		
% within friendship category	29.6	27.5	43.0	100		
% within BMI category	100	100	100	100		

*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Kendall's tau-c *P* value
[#]*P*<0.05

Table 3.47 Mean reported BMI and financial stress experienced by participant's families in the Down syndrome NOW 2011 wave

	BMI						Difference in means [under financial stress vs not under financial stress]					
	Male		Female		Total		Male		Female		Total	
Financial stress	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**n**	**Mean ± SD**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**	**Difference (95% CI)**	***P* value^**
Under financial stress	22	26.5 ± 5.8	13	33.6 ± 7.7	35	29.1 ± 7.4	-1.3 (-4.3, 1.6)	0.363	1.3 (-3.8, 6.4)	0.605	-0.9 (-3.9, 2.0)	0.518
Not under financial stress	51	27.8 ± 5.2	52	32.3 ± 8.9	103	30.1 ± 7.6						
Total	73	27.4 ± 5.4	65	32.5 ± 8.7	138	29.8 ± 7.5						

SD=standard deviation; CI=confidence interval

^Two-tailed, independent samples t-test *P* value

#*P*<0.05

Table 3.48 Financial stress experienced by participant's families in the Down syndrome NOW 2011 wave by reported BMI category*

	BMI Category					
Financial stress	**Healthy weight**	**Overweight**	**Obese**	**Total**	**T[c]**	***P* value^**
Male					0.98	0.326
Under financial stress (n)	11	5	6	22		
% financial stress category	50.0	22.7	27.3	100		
% within BMI category	37.9	23.8	26.1	30.1		
Not under financial stress (n)	18	16	17	51		
% within financial stress category	35.3	31.4	33.3	100		
% within BMI category	62.1	76.2	73.9	69.9		
Total (n)	29	21	23	73		
% within financial stress category	39.7	28.8	31.5	100		
% within BMI category	100	100	100	100		
Female					-0.77	0.442
Under financial stress (n)	2	2	9	13		
% within financial stress category	15.4	15.4	69.2	100		
% within BMI category	18.2	12.5	23.7	20.0		
Not under financial stress (n)	9	14	29	52		
% within financial stress category	17.3	26.9	55.8	100		
% within BMI category	81.8	87.5	76.3	80.0		
Total (n)	11	16	38	65		
% within financial stress category	16.9	24.6	58.5	100		
% within BMI category	100	100	100	100		
Total					0.67	0.500
Under financial stress (n)	13	7	15	35		
% within financial stress category	37.1	20.0	42.9	100		
% within BMI category	32.5	18.9	24.6	25.4		
Not under financial stress (n)	27	30	46	103		
% within financial stress category	26.2	29.1	44.7	100		
% within BMI category	67.5	81.1	75.4	74.6		
Total (n)	40	37	61	138		
% within financial stress category	29.0	26.8	44.2	100		
% within BMI category	100	100	100	100		

*BMI classified using NHMRC cut-points (NHMRC, 2013b)
^Kendall's tau-c *P* value
#*P*<0.05

Appendix G

Cover letter

Title of study: Factors affecting the body composition of adolescents and young adults with Down syndrome

Investigators: Katherine Bathgate (PhD student), Associate Professor Jill Sherriff (Curtin University), Associate Professor Deb Kerr (Curtin University), Professor Helen Leonard (Telethon Kids Institute), Mr Peter Jacoby (Telethon Kids Institute)

Dear

We would like to invite you to participate in a new research study to find out the body composition (height, weight, waist circumference, optional DEXA scan), food intake and physical activity levels of adolescents and young adults with Down syndrome aged 12-30 years living in Western Australia.

Participation in the study will involve you and your son/daughter:

- attending two visits (first one in your home, second one at Curtin University or your home) for approximately 1 hour each
- taking photos of what your son/daughter eats and drinks for 4 days
- your son / daughter wearing an accelerometer (like a pedometer) to count steps for 7 days
- your son / daughter having their body composition measured once
- completing a questionnaire on health and food behaviours

For your family's time and participation you will receive a recipe book 'Healthy Food Fast' which features many healthy, delicious recipes.

If you are happy for your son or daughter to participate in the study please either:

- Post the signed consent form in the enclosed envelope or
- Contact me directly 0421 120 885 and I will arrange to collect the consent form from you at our first meeting.

Once I have received your consent form I will be in touch with you about setting up a time to meet. If you have any questions about the study please contact me on my details below, I am particularly interested in working with families of young people with Down syndrome as I am also the mother of a teenage son with Down syndrome.

Kind regards,

Katherine Bathgate
0421 120 885
Katherine.Bathgate@telethonkids.org.au

Appendix H

Information sheet

Curtin University

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Factors affecting the body composition of adolescents and young adults with Down syndrome

INFORMATION FOR PARENTS

What is the purpose of this study?
This study will investigate the body composition, food intake and physical activity levels of adolescents and young adults with Down syndrome. There is limited information about the height, weight and other physical measurements of young people with Down syndrome as well as the type and amount of foods young people are eating, and the types and amount of physical activity in which young people participate. There are many factors that influence body composition, food intake and physical activity and this study will identify and explore these factors in Down syndrome.

Who is conducting the study?
This study is being conducted by Dietitian and PhD student, Katherine Bathgate. Katherine is a student at Curtin University and is being supervised by Associate Professors Jill Sherriff and Deb Kerr. The study is being conducted in conjunction with a larger study at the Telethon Kids Institute, under the supervision of Dr Helen Leonard.

Why has my son/daughter been invited to participate?
All adolescents and young adults with Down syndrome between the ages of 12 and 30 years are invited to participate in this study. This age group has been chosen due to the physical and social changes that happen during adolescence and young adulthood which can have an impact on body composition, diet and physical activity.

What does this study involve?
This study involves 3 parts: a questionnaire, food and physical activity measurement, and body composition measurements (height, weight, waist circumference).

1. Questionnaire - We would like you to fill in a brief questionnaire with questions about food behaviours, physical activity and how you fed your son/daughter as an infant. This will take you approximately 15 minutes to complete.

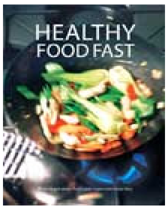
2. Diet and physical activity measurement – We would like to measure what your son/daughter eats over a period of 4 days and how much physical activity he/she does over a period of 7 days. Food measurement will be conducted by you or your son/daughter taking photos of food and drink consumed using an ipod which we will lend to you. To measure physical activity we would like your son or daughter to wear an Accelerometer (similar to a pedometer) on their clothing during waking hours for 7 days. Katherine may discuss with you the option of having your son or daughter's feet videoed while they walk for 10-15 minutes to validate the accelerometer, however this is optional. You will be provided with further information and all data collection materials when we meet to take the measurements of your son or daughter.

3. Body composition measuring - Katherine Bathgate will contact you to set up a convenient time to meet with you and your son or daughter so she can measure your son or daughter (height, weight, waist circumference). This can be done at your home or at a place convenient to you and will be conducted with your son/daughter in light clothing and with you present. As part of measuring your son or daughter's body composition you will be invited to bring your son or daughter to Curtin University for a DEXA scan. This is an optional part of the study and involves your son or daughter lying still on a bed while an X-ray arm moves

over them. The procedure takes 10 minutes and is painless. This procedure does use X-rays, however the amount of radiation is very small; the same as the amount of radiation we naturally receive in a day from background sources. We do also ask that girls and women are scanned during the first 10 days of their menstrual cycle.

Are there any risks to my son/daughter?
The only risk in this study is from the radiation of the DEXA scan. However the risk is minimal as the amount of radiation received is very low, less than the amount of radiation your son/daughter would receive in daily living.

Are there any benefits for my son/daughter?
You will be provided with information about the body composition, physical activity and dietary intake of your son/daughter which you may find useful. This information will be sent or emailed to you within 3 months of the data being collected. To thank you and your son/daughter for your time you will also receive a copy of the cookbook *Healthy Food Fast,* written by the Australian Government Department of health and Ageing, which features many quick, healthy and delicious recipes for your family to enjoy.



Does my son/daughter need to complete all parts of the study? Can he/she withdraw from the study?
It would be most beneficial to the study if you completed the questionnaire, and we were able to collect the height, weight, waist circumference, dietary intake and physical activity measurements of your son or daughter; however any level of participation is greatly appreciated. The DEXA scan is optional, and we can discuss this part in more detail when we meet to measure your son/daughter's height, weight and waist circumference. Your son/daughter is able to withdraw from the study at any time without consequence.

What happens to the information collected?
All data collected will be kept on a secure database which can only be accessed by the Research team. All identifying information (e.g. names) will be kept separately to the information provided and the identity of your son/daughter will not be linked to the data.

How will this information be used?
Once collated and analysed the information will be presented at conferences, published in journals and used to educate health professionals on the nutritional and physical activity needs of adolescents and young adults with Down syndrome. It is important that you also receive the findings of this study and these will be disseminated to you when completed.

Will confidentiality and privacy be assured throughout the study?
Yes. No names or identifying information will ever be released and all research findings that are published will be in a form that does not allow identification of any individual. We have permission from the Curtin University Human Research Ethics Committee to do this study. If you have any complaints regarding how the research is carried out please contact the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

Who can I contact for further information?

Katherine Bathgate	Assoc. Prof. Jill Sherriff	Dr Helen Leonard
PhD Student	Supervisor	Supervisor
Phone: 0421 120 885	Phone: 9266 7948	Phone: 0419 956 946
Katherine.Bathgate@telethonkids.org.au	J.Sherriff@curtin.edu.au	Helen.Leonard@telethonkids.org.au

*This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number **HR145/2011**). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.*

Appendix I

Participant information sheet

Curtin University

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What do you eat and how much do you move about?

INFORMATION FOR PARTICIPANTS

What is this study?

This study will be looking at what you eat and how much you move about. We will also be measuring how much you weigh, how tall you are and we will also measure around your waist. We would like to do this to find out more about young people with Down syndrome.

Who will I see?

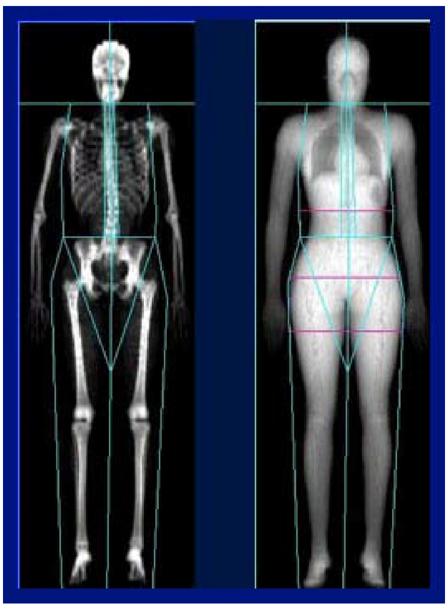
You will meet Katherine Bathgate who is the main person working in this study.

Why have I been asked to do this?

Eating good food and moving are good for health. We would like to find out what you eat and how you keep active to find out what young people need to be healthy.

What do I need to do?

Katherine would like to come and measure you at home. For 4 days Katherine would also like you to take photos of what you eat and drink and maybe write down what you eat and drink in a book. Katherine would also like you to wear a small box, like a match box on your clothes for 7 days, this will measure you moving. If you would like to Katherine can take a special photo of your body while you lie down. You will be wearing clothes and your Mum or Dad will be with you all the time. This photograph won't hurt, but you will need to lie still though as the camera takes a little while to take the photo.



http://www.zdicenter.com/bonedensity.html

Do I have to do this?

No, you do not have to do this.

Will this hurt me?

No, this will not hurt you.

Can I see the photograph?

Yes, you can see the photograph and will have a copy to take home. It will look like the one to the left.

Appendix J

Consent form

Curtin University

TELETHON KIDS INSTITUTE
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Factors affecting the body composition of adolescents and young adults with Down syndrome

CONSENT FORM FOR PARENTS/CARERS AND PARTICIPANTS

PLEASE NOTE THAT PARTICIPATION IN RESEARCH STUDIES IS VOLUNTARY AND SUBJECTS CAN WITHDRAW AT ANY TIME WITH NO IMPACT ON CURRENT OR FUTURE CARE.

I .... have read
Given Names Surname
the information explaining the study entitled: "Factors affecting the body composition of adolescents and young adults with Down syndrome" and consent for:

Name of participant.. to be included in this study.

I have read and understood the information given to me. Any questions I have asked have been answered to my satisfaction. I understand I may withdraw the participant from the study at any stage and withdrawal will not interfere with routine care. I agree that research data gathered from the results of this study may be published, provided that names are not used. I understand that any video taken for the purpose of validating the accelerometer will be of the participant's feet only.

Dated .... day of .... 201 ....

Parent/Carer Signature ....

Participant Signature ....
(If participant is 18 years or over and able to give informed consent)

Has the participant had another x-ray with contrast media (definition) in the last 7 days (some examples: barium enema, upper GI, some CAT scans) or had a nuclear scan (including bone scan and thyroid study) in the last 7 days?

No ☐ Yes ☐

Please provide your contact details so you can be contacted about participating in this study.

Address: ....

Phone: (mobile) .... Phone: (home) ....

Email..

Preferred contact method/s Mail ☐ Phone ☐ Email ☐

Preferred day/time to be contacted by phone ....

This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number ***HR145/2011****). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. Its main role is to protect participants. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.*

Appendix K

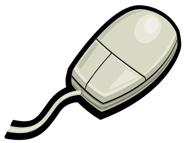
Instructions on how to complete the Down syndrome NOW questionnaire

HOW TO ACCESS THE QUESTIONNAIRE

Enter the following web address into your internet browser (ie. Internet Explorer or Firefox):

http://downsyn.ichr.uwa.edu.au

On the welcome page there is a link to further



instructions and information about the questionnaire and a Login link. Click on the Login link to begin. On the front cover of the questionnaire you should find a **username** and **password** on the left hand side. Enter these into the username and password spaces on the login page and click the Submit button to be taken to the **status page** of your online questionnaire.

COMPLETING THE QUESTIONNAIRE

The questionnaire does not have to be completed in one sitting. Each of the sections is submitted individually. On the **status page** you will see the list of sections. When you go to the **status page** for the first time all the sections will have a To be completed link. Click on the link to begin a section. At the bottom of each section there is a **Save** and a **Submit** button. If you need to exit a section before you have completed it, click on the **Save** button. When you return to the status page the section will have a **Review** link.

Click on the **Review** link to complete a partially-completed section.

When you complete a section click the **Submit** button. Once you have submitted a section you will not be able to go back and see your responses, so you may wish to print the page before submitting. If you submit a section by mistake or you need to make changes to information you have already submitted please email or phone us for assistance.

ABOUT THE QUESTIONNAIRE

Most of the questions relate to your child with Down syndrome, section 8 however relates to you. You may have completed the Down syndrome NOW questionnaire in 2004, however as the health of your young adult may have changed since then we are asking you to complete all the relevant sections.

Please answer each question unless instructed otherwise. If there are questions that you are unable to answer, please leave the question blank. Please add any additional information or comments that you wish in the spaces provided. There is no limit to the length of responses.

HELPFUL HINTS

Feel free to use the paper copy of the questionnaire as a guide for what information you will need before starting to fill your information into a particular section.

It may be more convenient for you to have some of the following information handy at the computer before you begin:

- Medical history of your child.
- The type of any general and disability services used.
- Names and doses of medications and supplements
- Therapy history of your child for last 12 months.

If you have any questions or problems with accessing the questionnaire; please contact me at Katherine.Bathgate@telethonkids.org.au or call 0421 120 885

Feedback from parents who previously completed a questionnaire online for other studies

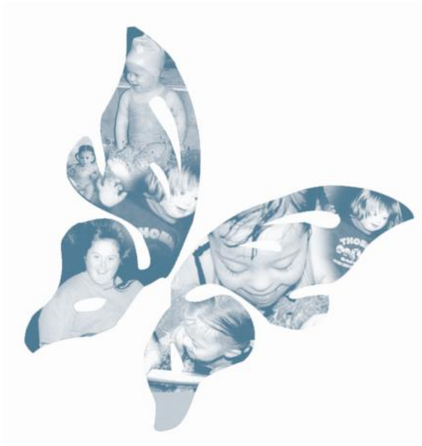
"It really is very easy, even if you are not used to using a computer"

"The questionnaire was very easy to fill out on-line. I was very impressed! WELL DONE!!! What could have been a laborious job was a pleasant one."

The
Down Syndrome Transition Team

Dr Helen Leonard
Telethon Kids Institute
PO Box 855
West Perth, WA 6008
Tel. (08) 9489 7790/
Fax. (08) 9489 7700
Mobile: 0419 956 946
Email: Helen.Leonard@telethonkids.org.au

THE DOWN SYNDROME NUTRITION & PHYSICAL ACTIVITY STUDY



Instructions for Completing the Nutrition and Physical Activity Questionnaire on the Internet

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Appendix L

Finding your way around the CHAT app

Finding your way around the CHAT app

C.H.A.T
Connecting Health and Technology

Participant ID: ______________

For more info:

Ph: Katherine on 0421 120 885
E: k.bathgate@curtin.edu.au

Welcome to CHAT

Firstly, thanks for participating in the study!

This booklet is a brief run down of how the CHAT app works in case you forget or need a quick refresher. It also includes a blank booklet at the back where you can fill out any meals or snacks you forgot to take photos of.

Have fun & call us if you have any problems!

To start..

Turn ipod on/off by holding down this button

Getting Connected

Is the wifi working? If there's no aerial, it's not connected.

Tap settings to get connected!

Find your WIFI

Go into settings and select the wifi setting you need.

Type in your password and get connected! Don't panic if you're not in wifi range you can send them later if you need!

Lets Begin!

Lets start at the begining

Tap here to get going

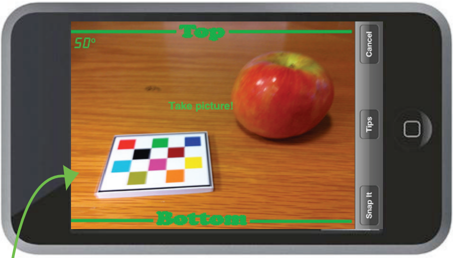
Hungry?

About to eat?
Better take a photo first!

Tap 'Before Eating'

Green is good!

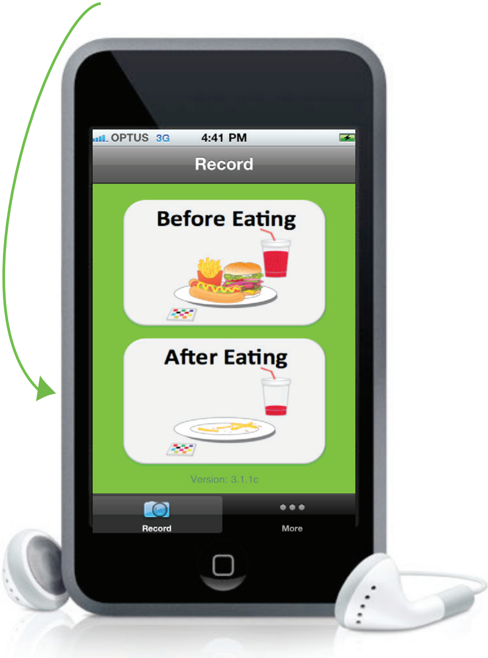
Make sure it turns green before you take the photo.
And keep the angle between 40 & 60 degrees!



Ensure everything is in the picture including the marker then press snap it!

Finished?

Hope your meal was delicious!
Just take a quick image of your plate at the end.



Even if your plates completely empty still take a photo!

Oops I forgot!

If you forget a before or after shot of your meal or both don't panic! Flip your marker over and take a photo of the Oops side instead!

Then don't forget to jot down what you had in the booklet!

That’s all folks

That is essentially all you need to know about the app.
If you have any queries contact us otherwise just enjoy the technology!

Read on to find FAQ and the booklet for missed meals!

FAQ

C.H.A.T
Connecting Health and Technology

You've got questions?

We've got answers!

FAQ

Q: What do I do if I forget to take a picture?

A: We're only human so the first step is not to panic!

The second step is to record your meal with the time, date & the closest estimation to what and how much you ate with as much detail as you can muster!

You can do this in the last few pages in the booklet!

Q: What about if I remember half way through eating my food?

A: Again don't panic!
Just take a photo as soon as you remember and one at the end and then record your meal in the booklet as well.

FAQ

Q: It keeps telling me the fiducial marker is missing when it's in the photo. What do I do?

A: Computers are never quite as clever as you and I, if the marker is definately in there then just go ahead and take it anyway.

Q: Do I even need to take photos of how much water I drink too?

A: We'd love a photo of every type of beverage (ie. water, juice, alcohol, coffee etc.) but we know this can get pretty annoying. So leave off the water if it's becoming a burden! Don't forget to put the marker in, and when possible either use a see-through cup or mark how full the glass is. Make a note in the book if you add sugar or milk to your drink as we can't see it!

FAQ

Q: Do I need to take an after photo if I've just had a drink? Isn't it obvious I would have finished it?

A: Sorry we know it's annoying but to make sure we keep up the accuracy it's imporant to record everything. Including the after shot.

Q: What happens if the app freezes or gets stuck on a screen at all?

A: Just exit the app by pressing the button at the bottom of the iPod then press the button again twice quickly, hold your finger over the CHAT app until it starts wiggling, then hit the red x and then try again!

Oops! Forgotten meals booklet!

C.H.A.T
Connecting Health and Technology

Anytime you forget to take a photo or just a before or after, jot it down in here so we can record it when you come back in!

Date: 13/8/13 Time: 8:50 AM/PM PM	Food & Drink Description	Quantities
	1 Flipside hamburger	1 Medium burger
	1 Hot chips - thick cut	Medium packet
	Aioli Dipping Sauce	3 Tablespoons
	1 Diet Coke	1 Can
	hamburger had 2 lettuce leafs, 4 slices of tomato	
	2 tbs tomato sauce, beef patty & slice of cheese	

Date:	Food & Drink Description	Quantities
Time:		
AM/PM		

Date: Time: AM/PM	Food & Drink Description	Quantities

Date: Time: AM/PM	Food & Drink Description	Quantities

Date: Time: AM/PM	Food & Drink Description	Quantities

Date: Time: AM/PM	Food & Drink Description	Quantities

Date:	Food & Drink Description	Quantities
Time:		
AM/PM		

	Food & Drink Description	Quantities
Date:		
Time:		
AM/PM		

Date:

Time:

AM/PM

Food & Drink Description	Quantities

Date: Time: AM/PM	Food & Drink Description	Quantities

Date:

Time:

AM/PM

Food & Drink Description	Quantities

Date: Time: AM/PM	Food & Drink Description	Quantities

Date: Time: AM/PM	Food & Drink Description	Quantities

Date: Time: AM/PM	Food & Drink Description	Quantities

	Food & Drink Description	Quantities
Date:		
Time:		
AM/PM		

ABOUT C.H.A.T

The CHAT (Connecting Health and Technology) project is all about testing a new research application to find out more about what young adults eat. The application for a mobile device such as an iPod or iPhone, is designed by nutritionists and engineers from Universities around the world to collect food images for analysis.

C.H.A.T
Connecting Health
and Technology

Appendix M

Instructions on how to use the Actigraph activity monitor and activity diary

How to use your Actigraph activity monitor

- Start by wearing the monitor from when you get out of bed on the first day.
- Using the belt provided secure the monitor tightly around your waist so the monitor is over your right hip and the black button is facing upwards.
- Keep the monitor on throughout the day. Please remove it for swimming and showering as the monitor should not get wet, then put it back on when you get dressed.
- You can wear the monitor during all your normal activities including sitting and walking.
- Remove the monitor each night at bed time.
- Put the monitor back on again the following morning.
- Continue wearing the monitor for a full 7 days.

Please look after the monitor and make sure it does not get wet in a pool or shower. If you have any questions about the monitor please contact Katherine Bathgate on 0421 120 885.

Please record in the table below any times that the monitor is removed and comment on the reason for its removal as this will help us to interpret the information. An example is below in the table.

Day / Date	Time Monitor On	Time Monitor Off	Reason for Removal
Thursday 31 May	7.30am	8.30pm	Bedtime